

# Towards a tailored support for Williams Syndrome

Learning from individual everyday life experience

A holistic multiperspective Mixed Methods study



Those who live with Williams Syndrome (WS) every day, whether as an individual, a relative or a professional caregiver, already developed individual strategies to handle challenges and thrive from resources.

How can we learn from these experiences in order to support other families?

## Methodological approach

- Focus on individual **differences within the WS group** and **individual developmental pathways**. No control group comparison.
- **Research topics** (such as: language, social behaviour, sleep) are not defined in advance. Those topics that are deemed important by the respondents are selected and further analyzed.
- **Individuals with WS** are interviewed to include their perspectives (Prosetzky, 2014).



WBS in  
Resonanz

Forschungsgruppe zum Williams-Beuren-Syndrom

## Perspectives

3 respondent groups

1) **Williams Syndrome**

Individuals with WS of four age groups

1) children 2) adolescents 3) young adults 4) adults

2) **Relatives**

Private caregivers, e.g. parents, siblings

3) **Professional caregivers**

E.g. teacher, trainer, educators

## Research questions

1) **Challenges**

What are the most present **challenges** in everyday life?

2) **Resources**

What are helpful **resources**?

3) **Coping strategies**

How did respondents **cope** with challenges? What was helpful, what not?

4) **Personal goals**

What are individual **goals** of development for respondents?

5) **Support**

How should helpful **support** be designed?



## Methodology

### Instruments

**Semi-structured guideline interviews** (Mey & Mruck, 2010) and a **written survey**, both tailored to respondent groups, each with qualitative und quantitative components

### Analysis

**Qualitative Content Analysis** (Schreier, 2012) via MAXQDA Software, **multivariate statistical analysis**

### Sampling

Purposeful Sampling (Schreier, 2010)

### Design

**Confirmatory Sequential Mixed Methods Design** (Creswell & Plano Clark, 2011)

SEQUENCE 1	Purposeful sampling	SEQUENCE 2	SEQUENCE 3
<b>Study A</b> Interviews with <b>relatives</b> during national WS conference <i>N = 43 (May 2017, completed)</i> QUAL + quan	Selection: <b>6 typical cases + 4 atypical cases</b>	<b>Study C</b> In-depth interviews  Sets of 3 respondents per case <b>1 individual with WS</b> <b>1 relative</b> <b>1 professional caregiver</b>  <i>N = 30 interviews (spring 2018)</i> QUAL	<b>Study D</b> Written survey (online and paper-pencil)  <b>Individuals with WS</b> <b>Relatives</b> <b>Professional caregivers</b>  <i>N = 100 surveys (spring 2019)</i> qual + QUAN
<b>Study B</b> Interviews with professional caregivers in northern Germany <i>N = 32 (July - Nov. 2017, completed)</i> QUAL + quan			

## Realisation

### Funding

Project lounge was funded by the Saxon State Ministry of Research and the Arts (ending Dec. 2017)

Further funding (2018-2019) is required

### Organisation

University of Applied Sciences Zittau/Görlitz, cooperation with University Bremen, Germany

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