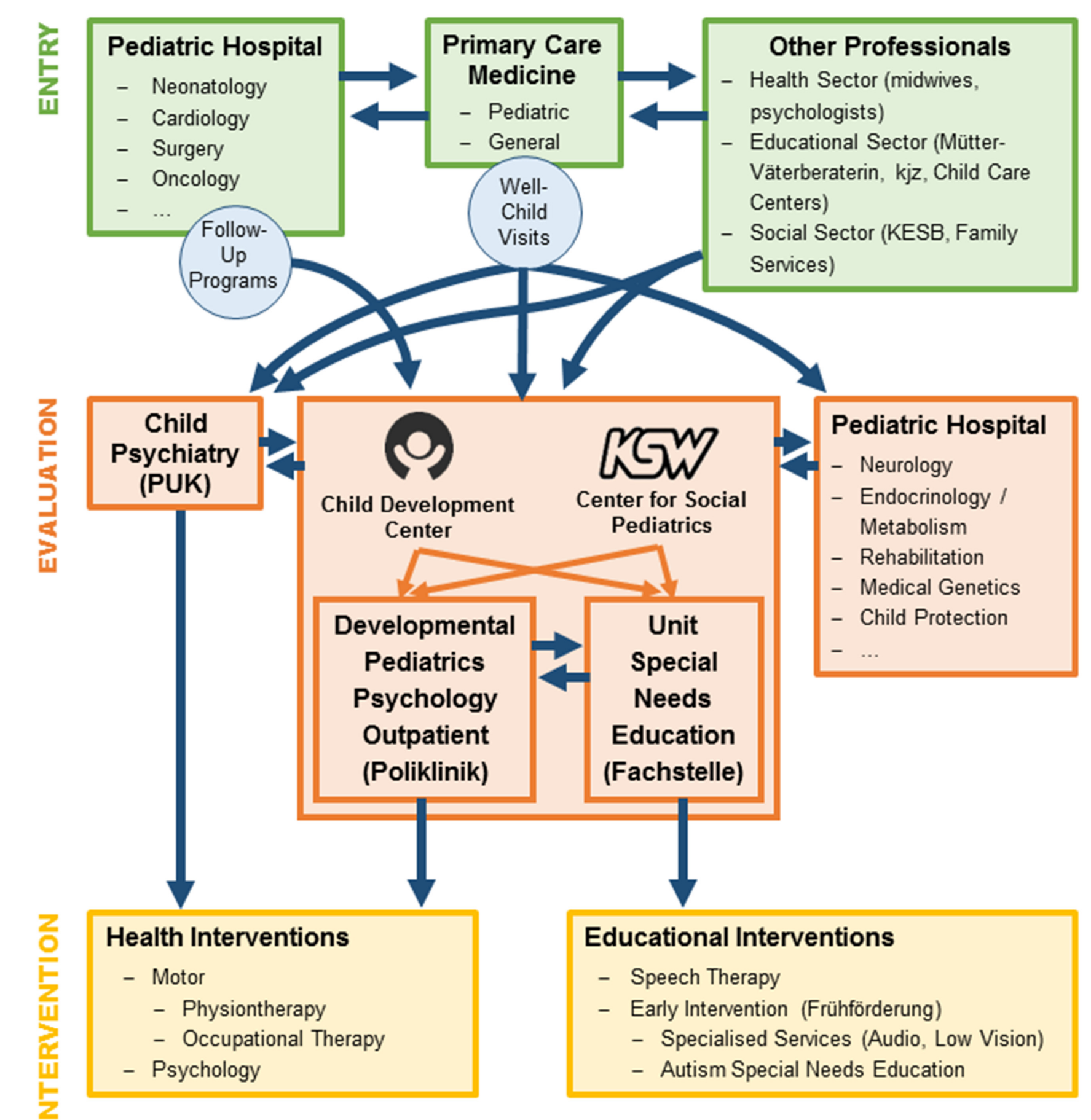


# Preschool Children with Developmental Delay The Standard of Care evaluated

## Background

- Developmental delay (DD) is one of the most common disorders in early childhood (affecting ~ 15% of all preschoolers).
- Children with DD suffer from intellectual disability (e.g., mental retardation), speech problems, social-communicative deficits (e.g., autism), sensory impairments (e.g., deafness), behavioural disorders etc.
- All preschool children with suspected DD are referred to the 2 centralized Units of Special Needs Education (USNE, Fachstellen) at the Child Development Center of the University Children's Hospital Zurich and the Center for Social Pediatrics of the Kantonsspital Winterthur.
- These 2 interdisciplinary units decide about (educational and/or health) interventions in children with DD. Detailed information about the children is entered into a centralized database.
- The **Figure (right)** illustrates the complex health, educational and social service system for children with DD in the Canton Zurich.



## Research Team

- Principal Investigator: Oskar G. Jenni, MD <sup>1</sup>
- Project Leader: Michael von Rhein, MD <sup>1, 2</sup>
- Senior Scientist: Christina Schäfer, MD <sup>1</sup>
- Database Manager: Michael Helfer, MSc <sup>1</sup>
- Special Needs Educator: Raphaela Iffländer, MA <sup>1</sup>, PhD student of the project
- Speech Therapists: Miriam Schnyder <sup>1</sup>, MSc & Ruth Rieser <sup>1, 2</sup>
- MD Student: NN
- Statisticians/Epidemiologists: Aziz Chaouch, MSc <sup>3</sup> & Valentin Rousson, PhD <sup>3</sup>

## Institutions

- 1 Child Development Center, University Children's Hospital Zurich
- 2 Center for Social Pediatrics, Kantonsspital Winterthur
- 3 Division of Biostatistics, Institute of Social and Preventive Medicine, University Hospital CHUV, Lausanne

## Funding



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Our Promise to Youth



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## Research Targets and Methods

### Target 1

The current database of DD children registered at the centralized USNE will be analyzed in regard to demographic and clinical features of the children, their activities and participation, the characteristics of their environment and the pathways of access to services.

### Target 2

The allocation processes of interventions, the use of specific therapies (e.g., nature, setting, intensity, duration of special needs education, speech therapy etc.), the possible over- or underuse of services and the developmental trajectories of the children will be assessed.

### Target 3

The needs of families and their families, stressors and resources as well as experiences and satisfaction with the system will be evaluated.

The study includes a retrospective data analysis of the entire USNE data base including diagnoses and clinical features, nature, setting, intensity and duration of early interventions between 2014-2016 (N = 6578 children, ~ 2500 new cases per year), and a prospective assessment of environmental characteristics, activities and participation (according to ICF), as well as stressors of families, their needs, expectations and satisfaction with the system.

## Expected Results and Impact

This research project will

- provide detailed **description of children with DD** in terms of their clinical, environmental and long-term features in a representative sample of the largest canton in Switzerland.
- provide detailed **insights into the structures and the utilization of health and educational care** of children with DD in the Canton Zurich.
- will establish a **sustainable registry** of services for DD children that can support policy-makers in their decisions.
- **inform professionals about evidence-based decisions for interventions** and prioritize care services for these children.
- help to **understand the mechanisms involved in parental stress** and to better promote family-centred care processes of children with special needs.