University of Zurich[UZH]

UNIVERSITY CHILDREN'S HOSPITAL ZURICH
Child Development Center

Preschool Children with Development Delay

Targeted Recruiting Opportunities for Research Projects

Marion Wenger & Michael von Rhein

The Development Delay Database (DD DB)

26th May 2023

Agenda

- Origin of the DD DB
- Children in the DD DB
- Possibilities for Research Based on the DD DB
- Ongoing AdaBD Research Project

  Based on the DD DB (Brem, Raschle, Ruff, Rauch, v. Rhein)
- Upcoming AdaBD Research Project

  Based on the DD DB (Michael von Rhein)
- Improving DD DB Access &

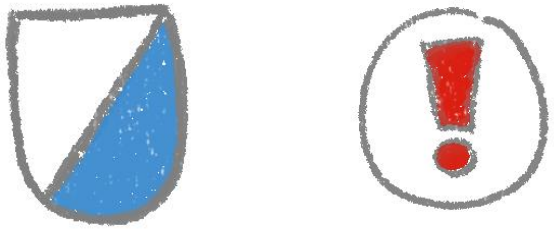
  possible DD DB Interfaces (Kathrin Grob)

Origin of the DD DB

University’s Children’s Hospital Zurich &
Cantonal Hospital Winterthur

Reasons for referral

- All types of developmental delays
- Visual and hearing impairment
- Risks for development delay



Therapies

- Early special needs education, including audio pedagogy and low vision training
- Speech therapy

NOT addressed by this process

Medical interventions covered by disability or health insurance, e.g. physiotherapy, occupational therapy, psychotherapy, but **some data is available**

Pediatrician, therapist or parents see demand or risk.
Parents agree to a referral (it is up to them).

DD DB

Registration
Special Needs Education

and / or

Registration
Speech Therapy

or

No therapy required or
the child is not entitled to
a measure by the canton

About
10%

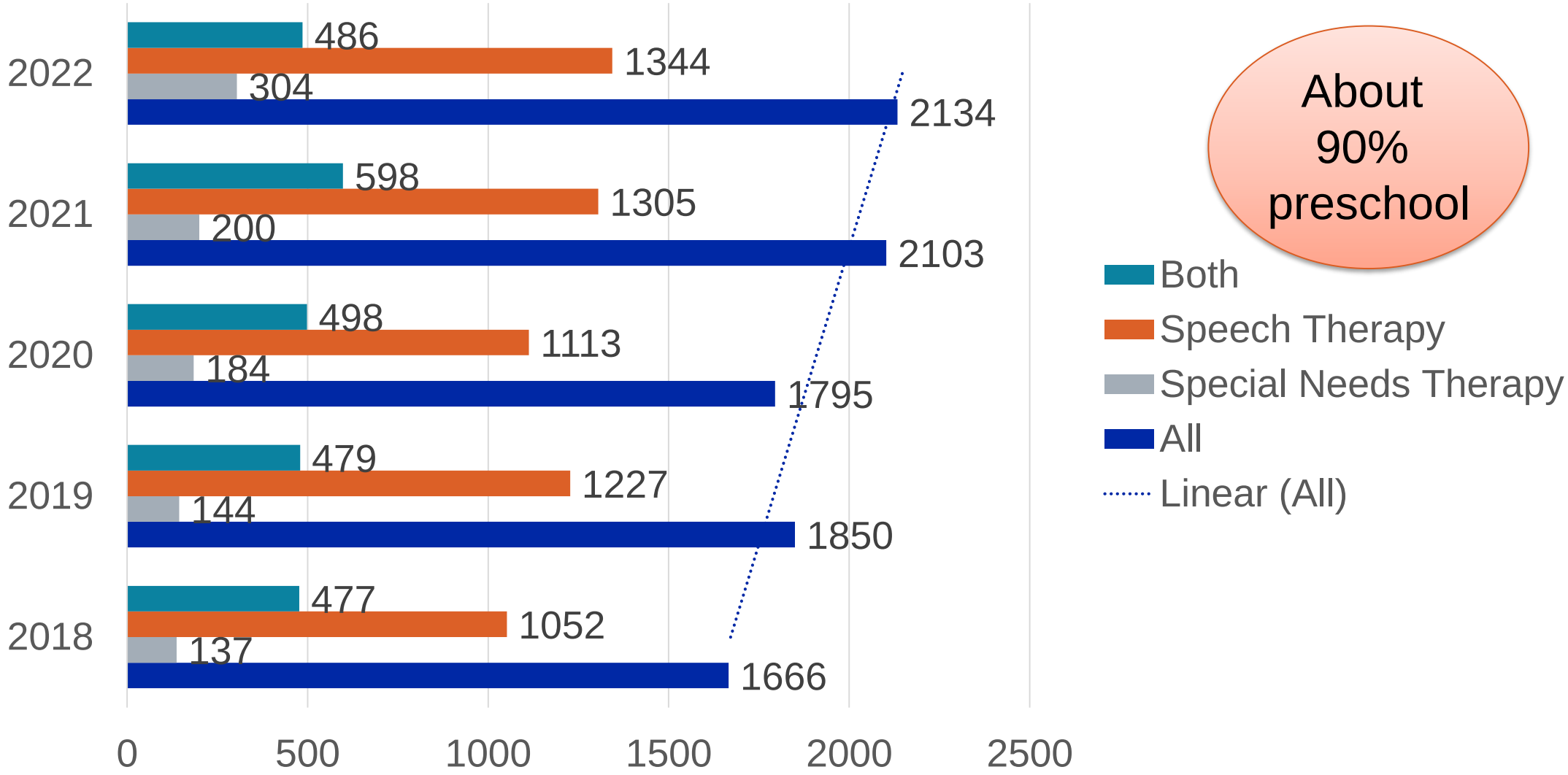
Recommendation
for a therapy

A diagnosis
is registered
as a justification
for a therapy

Canton of Zurich
pays for recommended
measure within given
time period.

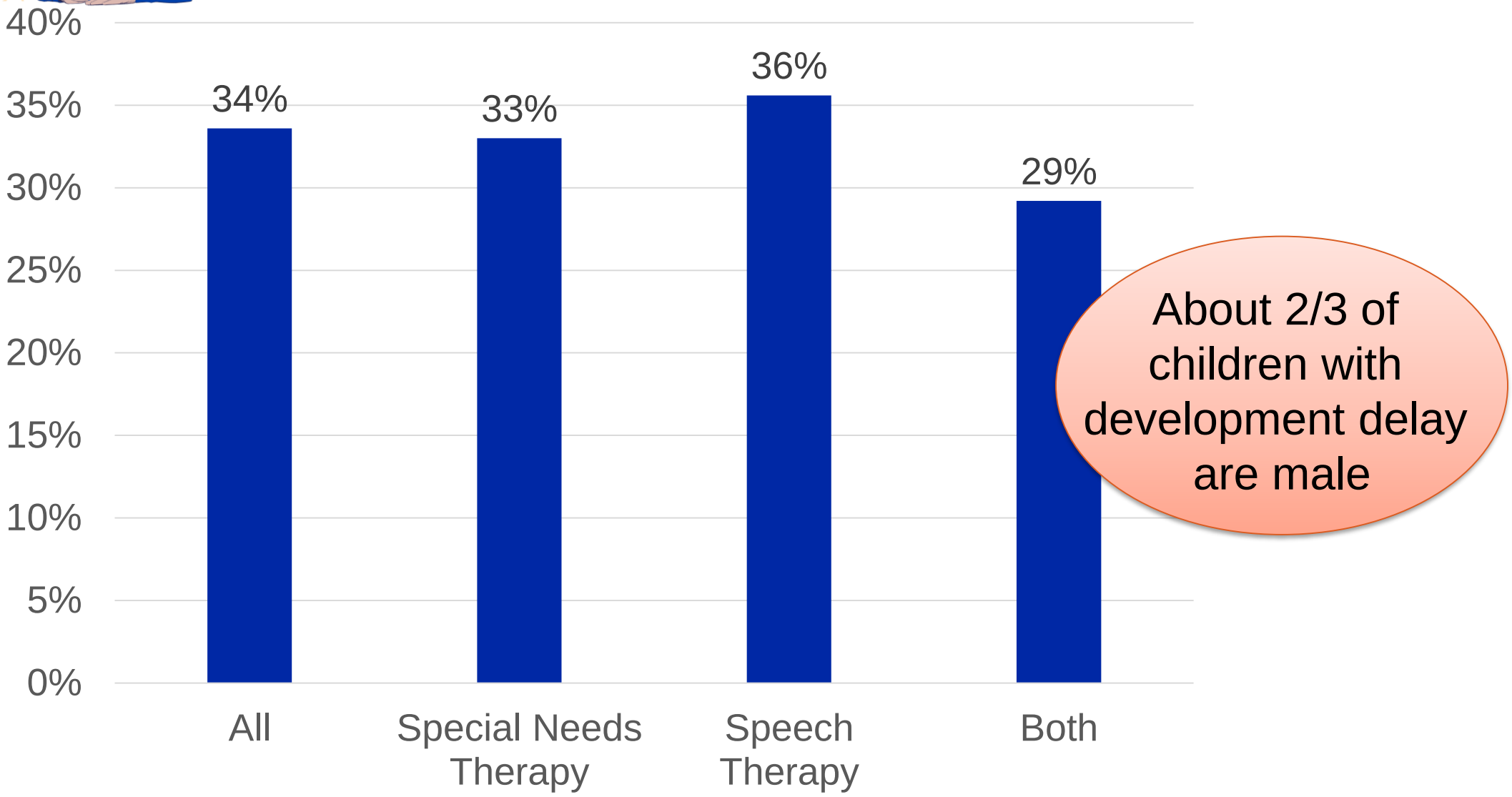
Children in the DD DB

Registered Children per Year (2018-2022)



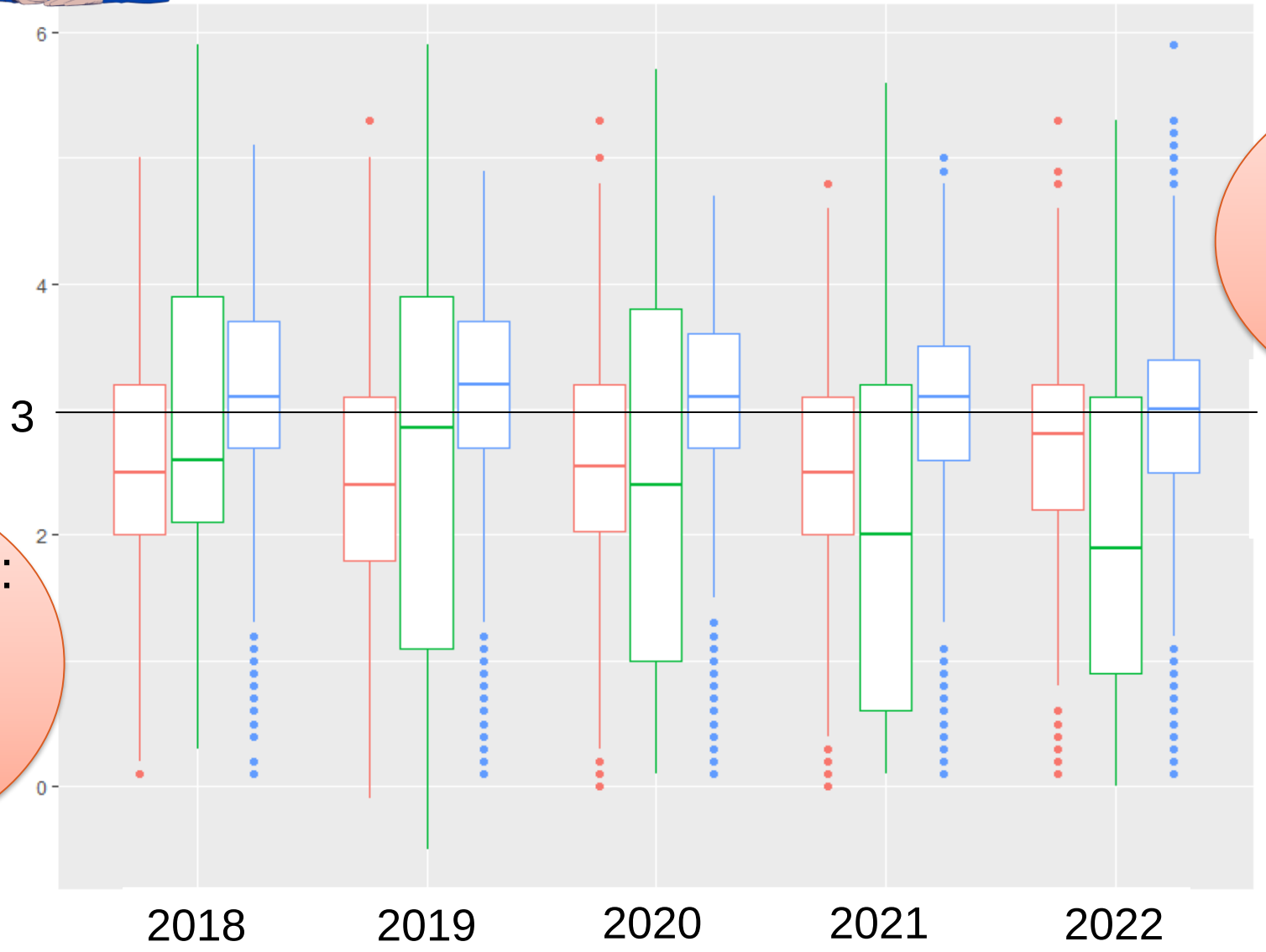
About 90% preschool

% of Girls (preschool, 2018-2022)



About 2/3 of children with development delay are male

Age at Registration (preschool, 2018-2022)



Mandatory start in kindergarten if 4 years old on 31th July

Average age: 2.85 years (= 2 yrs, 10 mths)

Both
Special Needs Therapy
Speech Therapy

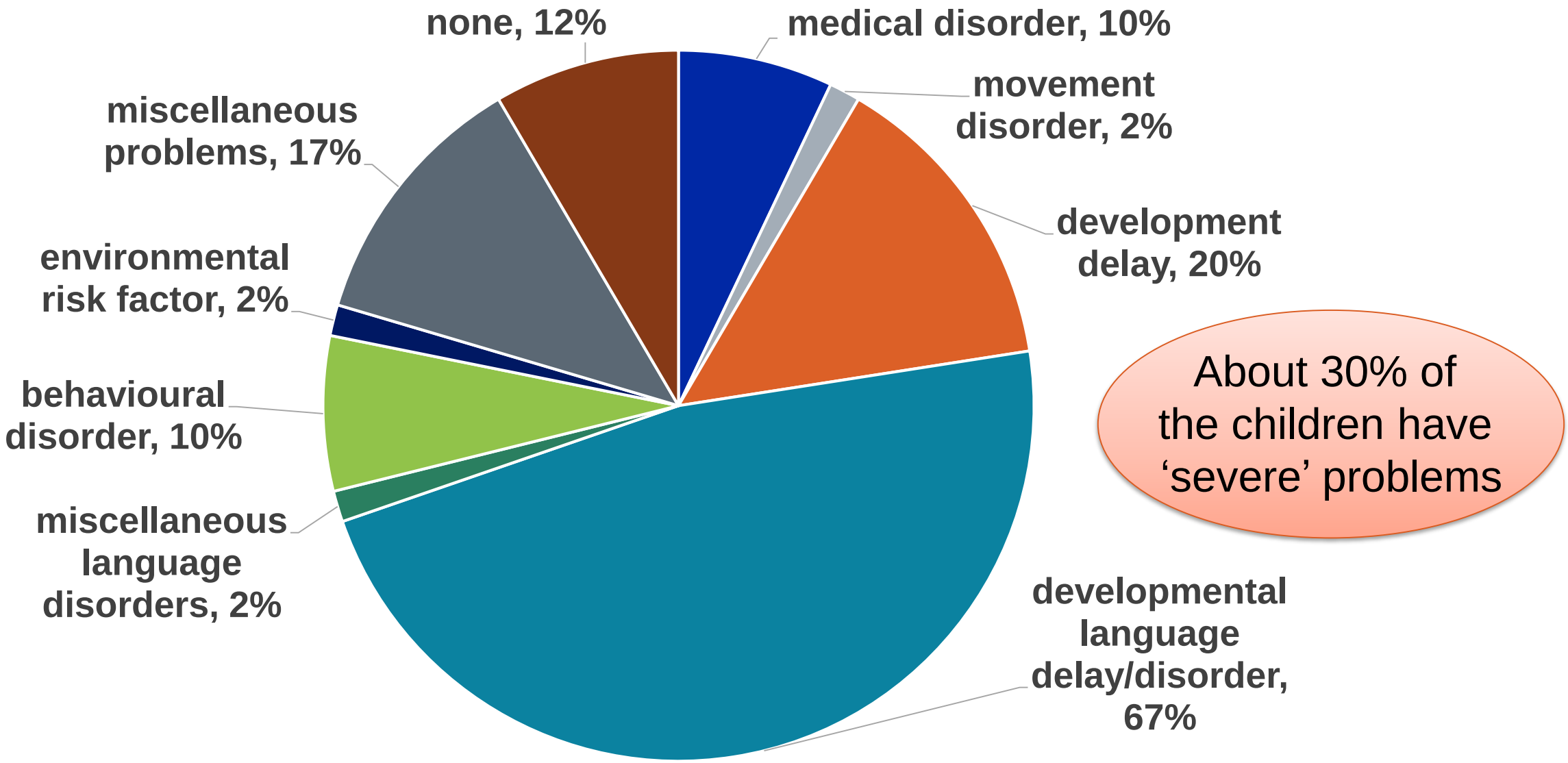
Diagnoses (preschool, 2017-2022)

56% with 1 diagnosis,
32% with >1

medical disorder	e.g. congenital heart disease, epilepsy
movement disorder	e.g. diminished fine motor skills
development delay	global or cognitive
developmental language delay/disorder	expressively and/or receptively
miscellaneous language disorders	e.g. problems caused by a head trauma
behavioural disorder	e.g. regulatory disorder
environmental risk factor	e.g. parents are unemployed
miscellaneous problems	something else than the above
no diagnosis	no therapy needed or no entitlement

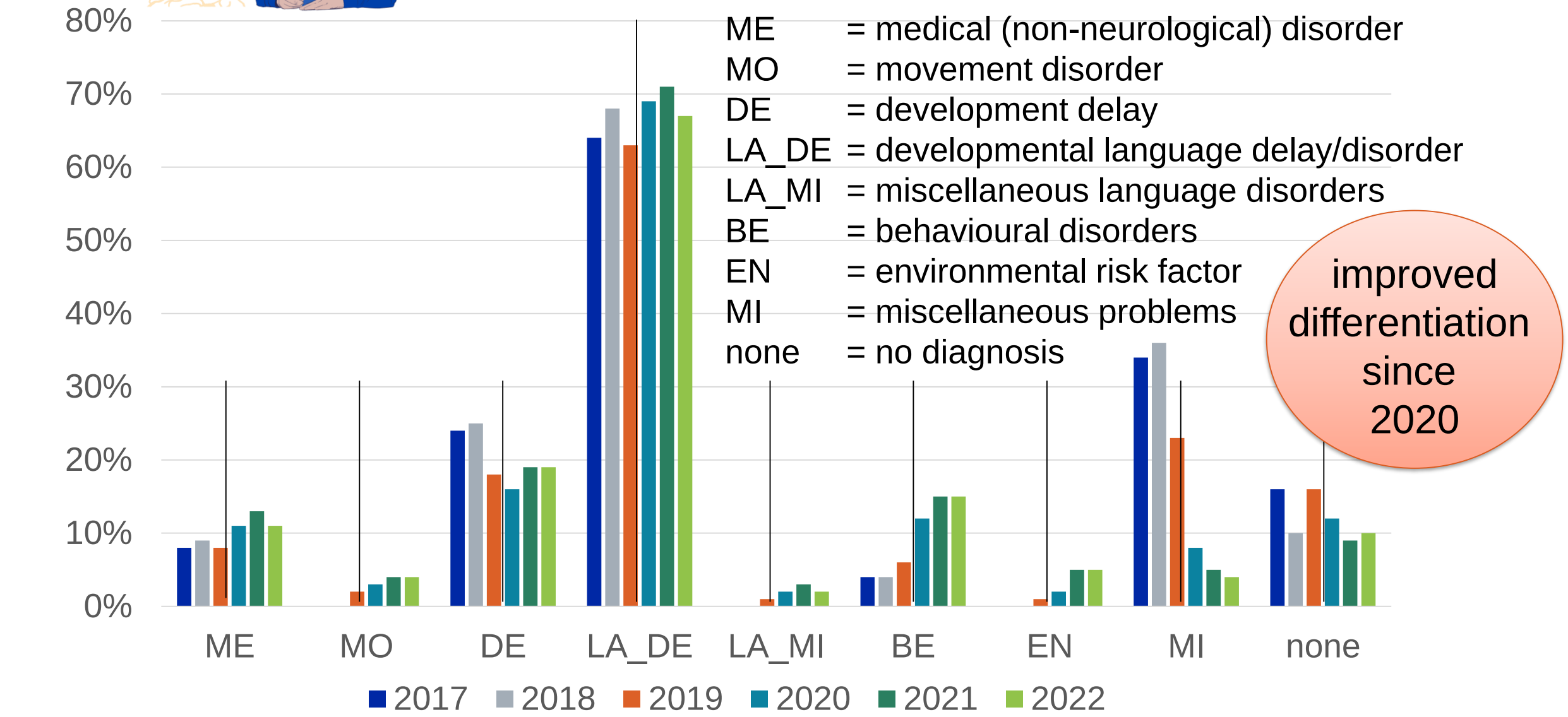
This is a generalization,
the DD DB contains more details

Diagnoses (preschool, 2017-2022)



About 30% of the children have 'severe' problems

Diagnoses (preschool , 2017-2022)



Possibilities for Research Based on the DD DB

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DD DB children registered…	screen in DD DB	get relevant existing data	contact for study	send questionnaire	DNA specimen	Study-specific assessment
some time ago (since 2013)	x	x	x	x		
recently, already evaluated	x	x	x	x	(x)	(x)
recently, soon to be evaluated in person	x	x	x	x	x	x

Diagnostic work-ups for speech therapy are in-house!

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Longitudinal studies: The earliest data is from **2013!**

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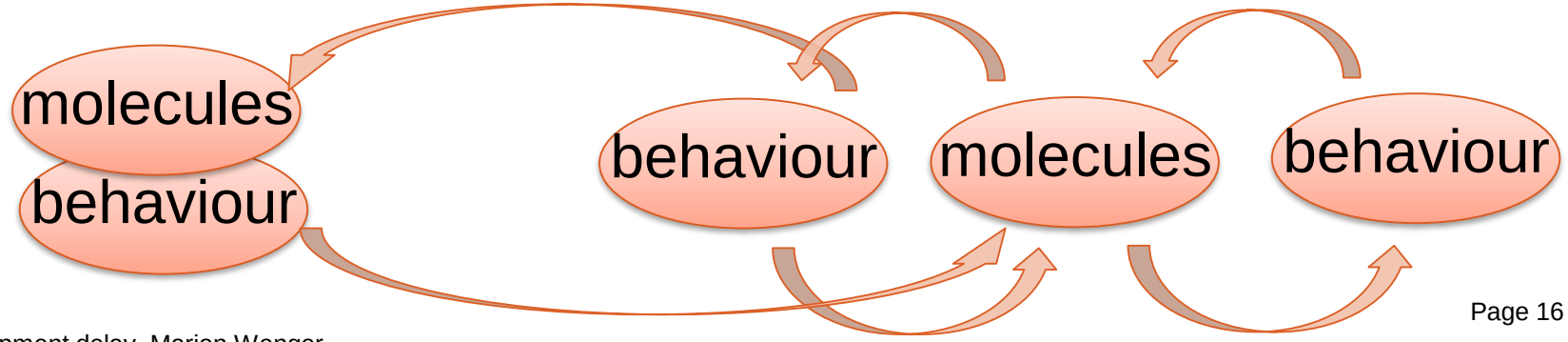
some time ago (since 2013)	x	x	x	x		
recently, already evaluated	x	x	x	x	(x)	(x)
recently, soon to be evaluated in person	x	x	x	x	x	x

Potential for PATH 1, 2 and 3!



Ongoing AdaBD Research Project
Based on the DD DB

Child Brain Circuits (Brem, Raschle, Ruff, Rauch, v. Rhein)

Child Brain Circuits (CBC) (I/III)

(Brem, Raschle, Ruff, Rauch, v. Rhein)

Goals

To gain insights into how **brain regions**

- adapt in terms of **activation** and **connectivity**
- during **multi-sensory learning**
- across early and middle childhood
- both in healthy children and patients with **developmental language disorders**

Child Brain Circuits (CBC) (II/III)

Recruting based on DD DB → **600** DD DB families will be contacted this summer

Inclusion criteria

- child started kindergarten in 2021
- child speaks Swiss German (among others)
- at least one phone number or mail address available

Criteria-based targeted recruitment

Child Brain Circuits (CBC) (III/III)

- Problems at birth
  - extreme preterm (< 31 wks)
  - lack of oxygen
  - intensive care
- hearing aid or cochlear implant
- medical or movement disorder
- development delay
- miscellaneous language disorders
- miscellaneous problems
- deferral of kindergarten (one year later than normally)
- parents with little or no knowledge of German

Upcoming AdaBD Research Project Based on the DD DB

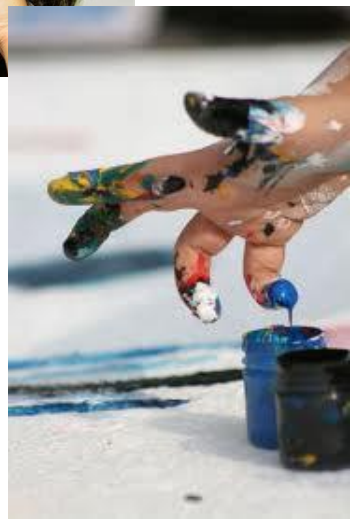
Sensory Perception Abnormalities

Michael von Rhein

Sensory Perception Abnormalities

Goals

- to assess **abnormalities** in **sensory processing** in preschool children with **developmental delay** and
- to recruit them for a **cerebral imaging** study



Methods

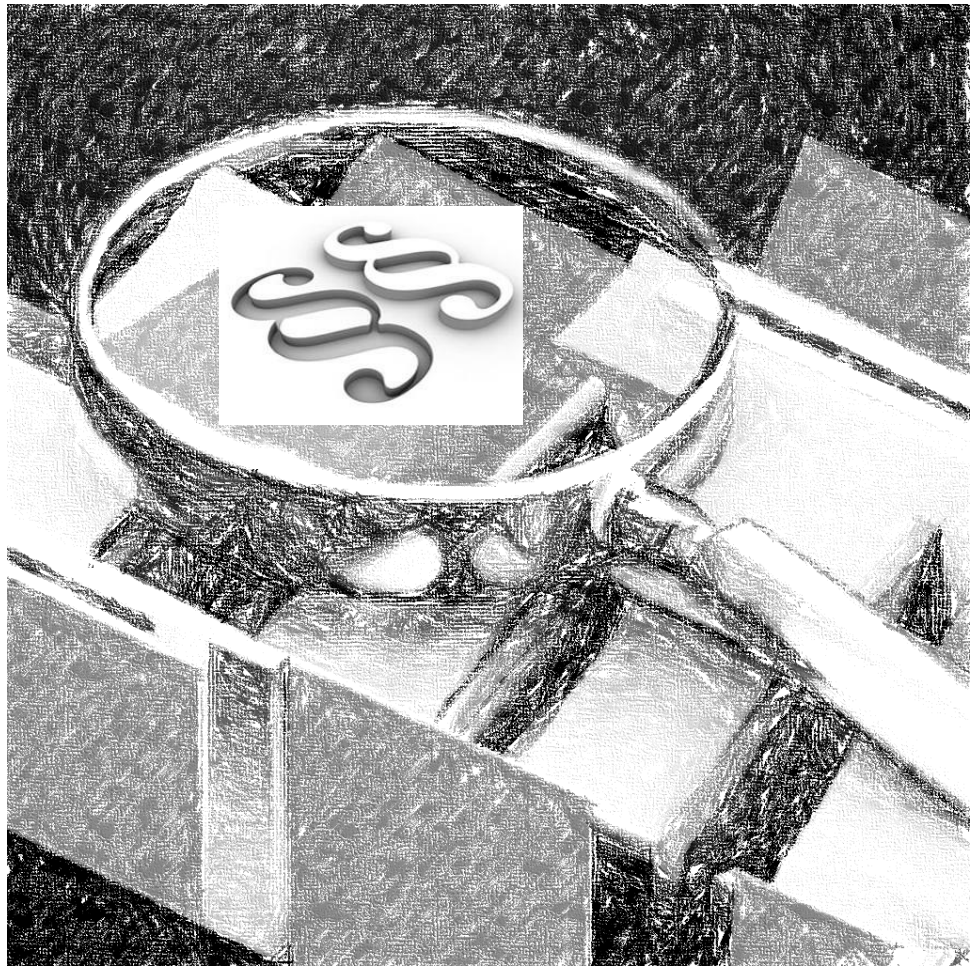
- **screen the DD DB** for children with sensory abnormalities
- target based on specific **keywords**, profiles, or diagnoses
- recruit a cohort for a **clinical work-up** and assessment including **questionnaires** for (hyper) **sensitivity** to **environmental** stimuli

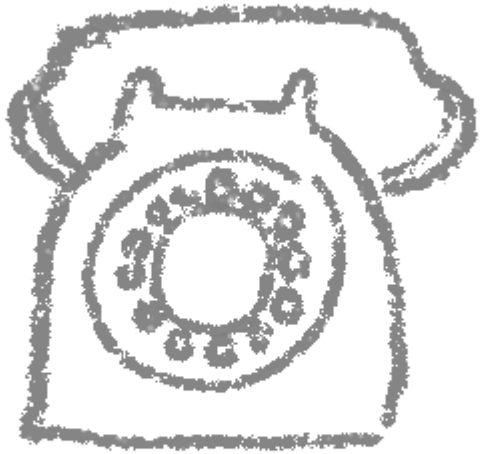
Improving DD DB Access & Possible DD DB Interfaces

Legal Advisor, Kathrin Grob

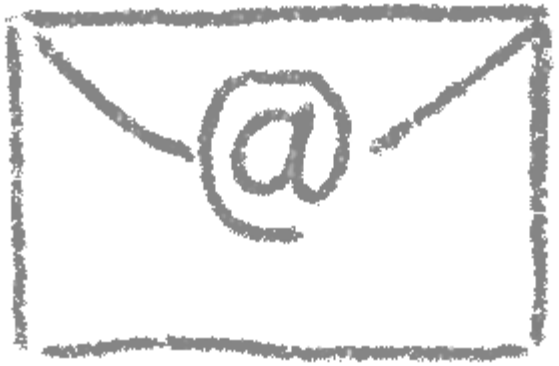
Improving DD DB Access & Possible DD DB Interfaces

- Kathrin Grob (Master of Law, UZH):
  Legal advisor since April 2023
- **Goals**
  - to clarify the **legal constraints**
  - to define a suitable **data access procedures**
  - to determine **conditions** for **data interfaces / links** to and from the DD DB
- **In Progress**
  discussion with the cantonal Data Protection Officer (kantonale/r Datenschutzbeauftragte/r)





Contact us!



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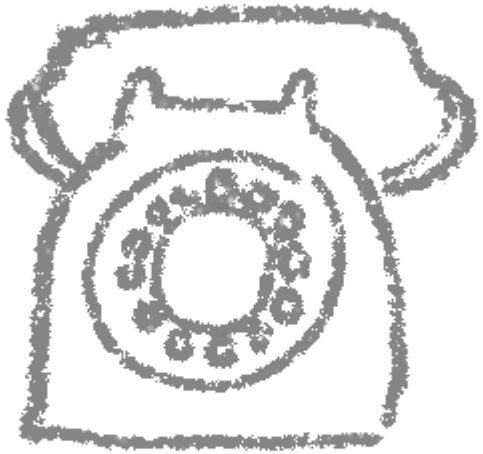

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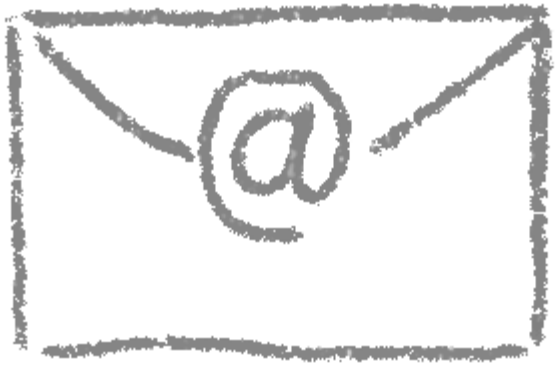

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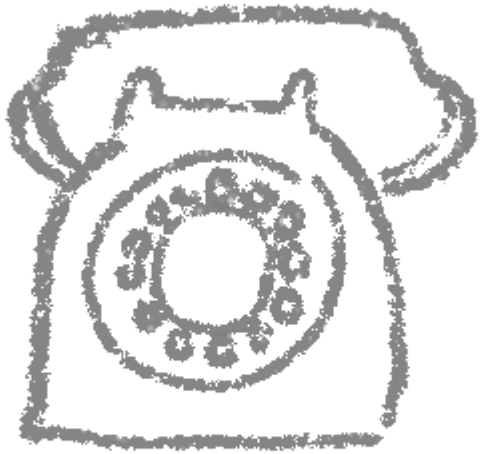

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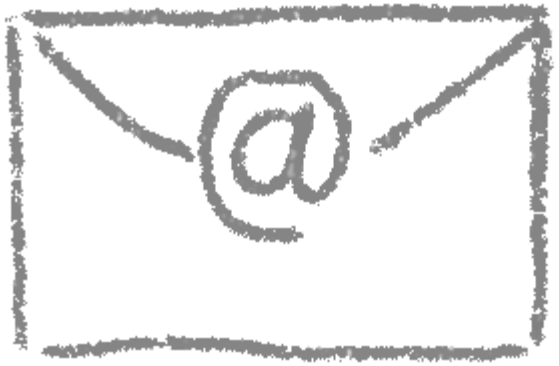

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