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).

Registration Special Needs Education and / or Registration Speech Therapy

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

About 10%

A diagnosis is registered as a justification for a therapy

Recommendation 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)

- 2022: 2134
- 2021: 2103
- 2020: 1795
- 2019: 1850
- 2018: 1666

About 90% preschool
About 2/3 of children with development delay are male.
Age at Registration (preschool, 2018-2022)

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

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

Both Special Needs Therapy Speech Therapy
Diagnoses (preschool, 2017-2022)

56% with 1 diagnosis, 32% with >1

- medical disorder
- movement disorder
- developmental delay
- developmental language delay/disorder
- miscellaneous language disorders
- behavioural disorder
- environmental risk factor
- miscellaneous problems
- no diagnosis

- e.g. congenital heart disease, epilepsy
- e.g. diminished fine motor skills
- global or cognitive
- expressively and/or receptively
- e.g. problems caused by a head trauma
- e.g. regulatory disorder
- e.g. parents are unemployed
- something else than the above
- no therapy needed or no entitlement

This is a generalization, the DD DB contains more details.
Diagnoses (preschool, 2017-2022)

- Development delay/delay, 67%
- Developmental language delay/disorder, 20%
- Medical disorder, 10%
- Miscellaneous problems, 17%
- Environmental risk factor, 2%
- Behavioural disorder, 10%
- Miscellaneous language disorders, 2%
- Movement disorder, 2%
- None, 12%

About 30% of the children have ‘severe’ problems
Diagnoses (preschool, 2017-2022)

ME = medical (non-neurological) disorder
MO = movement disorder
DE = development delay
LA_DE = developmental language delay/disorder
LA_MI = miscellaneous language disorders
BE = behavioural disorders
EN = environmental risk factor
MI = miscellaneous problems
none = no diagnosis

Improved differentiation since 2020
Possibilities for Research
Based on the DD DB
Possibilities for Research Based on the DD DB

<table>
<thead>
<tr>
<th>DD DB children registered…</th>
<th>screen in DD DB</th>
<th>get relevant existing data</th>
<th>contact for study</th>
<th>send questionnaire</th>
<th>DNA specimen</th>
<th>Study-specific assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>some time ago (since 2013)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>recently, already evaluated</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>(X)</td>
<td>(X)</td>
</tr>
<tr>
<td>recently, soon to be evaluated in person</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

Diagnostic work-ups for speech therapy are in-house!
### Possibilities for Research Based on the DD DB

<table>
<thead>
<tr>
<th>DD DB children registered...</th>
<th>screen in DD DB</th>
<th>get relevant existing data</th>
<th>contact for study</th>
<th>send questionnaire</th>
<th>DNA specimen</th>
<th>Study-specific assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>some time ago (since 2013)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>recently, already evaluated</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>(x)</td>
<td>(x)</td>
</tr>
<tr>
<td>recently, soon to be evaluated in person</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

**Longitudinal studies:** The earliest data is from **2013**!
# Possibilities for Research Based on the DD DB

<table>
<thead>
<tr>
<th>DD DB children registered...</th>
<th>screen in DD DB</th>
<th>get relevant existing data</th>
<th>contact for study</th>
<th>send questionnaire</th>
<th>DNA specimen</th>
<th>Study-specific assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>some time ago (since 2013)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>recently, already evaluated</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>(x)</td>
<td>(x)</td>
</tr>
<tr>
<td>recently, soon to be evaluated in person</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

**Potential for PATH 1, 2 and 3!**

- molecules
- behaviour

- molecules
- behaviour

- molecules
- behaviour
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)

Recruiting 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

Exclusion Criteria

- deferral of kindergarten (one year later than normally)
- parents with little or no knowledge of German
- miscellaneous problems
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!

044 266 39 48

marion.wenger@uzh.ch
Contact us!

044 266 39 48

marion.wenger@uzh.ch
Contact us!

044 266 39 48

marion.wenger@uzh.ch