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Parents of children with CVI: experiences and perspectives

Preliminary findings from a survey of parents

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2024

Study and participants

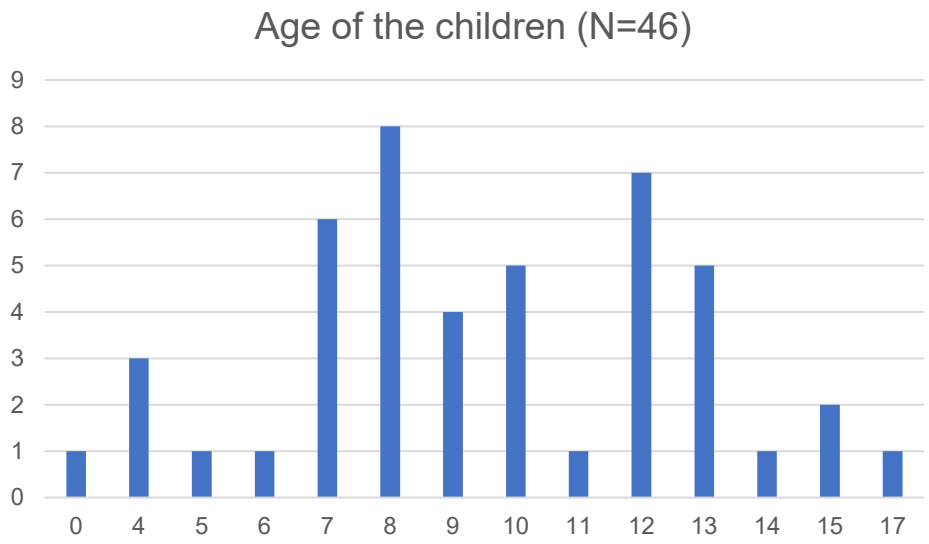
Since January 2024, parents of children with CVI have been asked about their experiences and concerns via a digital questionnaire. The survey is conducted in German. Initial preliminary evaluations were carried out for various presentations, which are summarized in this presentation.

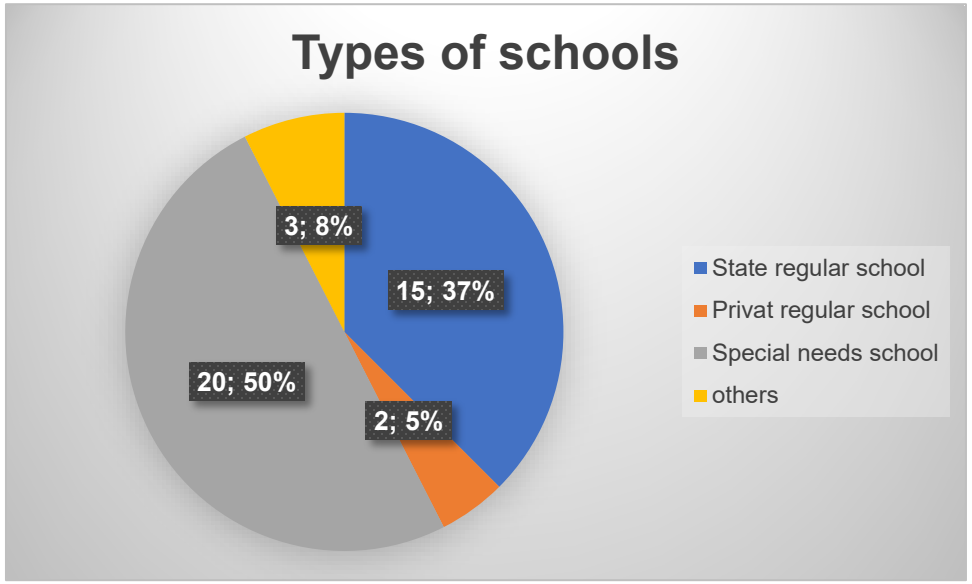
Participants: At the time of the first preliminary evaluations, 46 parents had already taken part in the survey (Germany: 41, Switzerland: 4, Austria: 1. Roles: 37 mothers (incl. one foster mother), 7 fathers, 2 unknown).

As the survey is still ongoing, further participants can be expected by the end of the survey. Individual questions could be skipped in the questionnaire. Not all parents answered every question. Both parents of a child were allowed to complete one questionnaire each.

Note on the number of children to whom the feedback relates: As both parents were able to participate, a simple summative presentation of the findings does not clearly show to how many children the feedback relates. The number of children to whom the parents' feedback relates will only be analyzed in the final evaluation of the data. The current age of the children, the age of the children at the time of diagnosis, their specific CVI-related vision problems and other information about the child can be used to filter out "duplicates" in the feedback and indicate exactly how many children the parents' feedback relates to. However, the gender distribution of the responding parents, the spread in the current age of the children and the age of diagnosis, the information on the specific disorders of the children and the surnames of the parents already suggest that the number of parents for whom both parents participated is rather low.

Details of the children

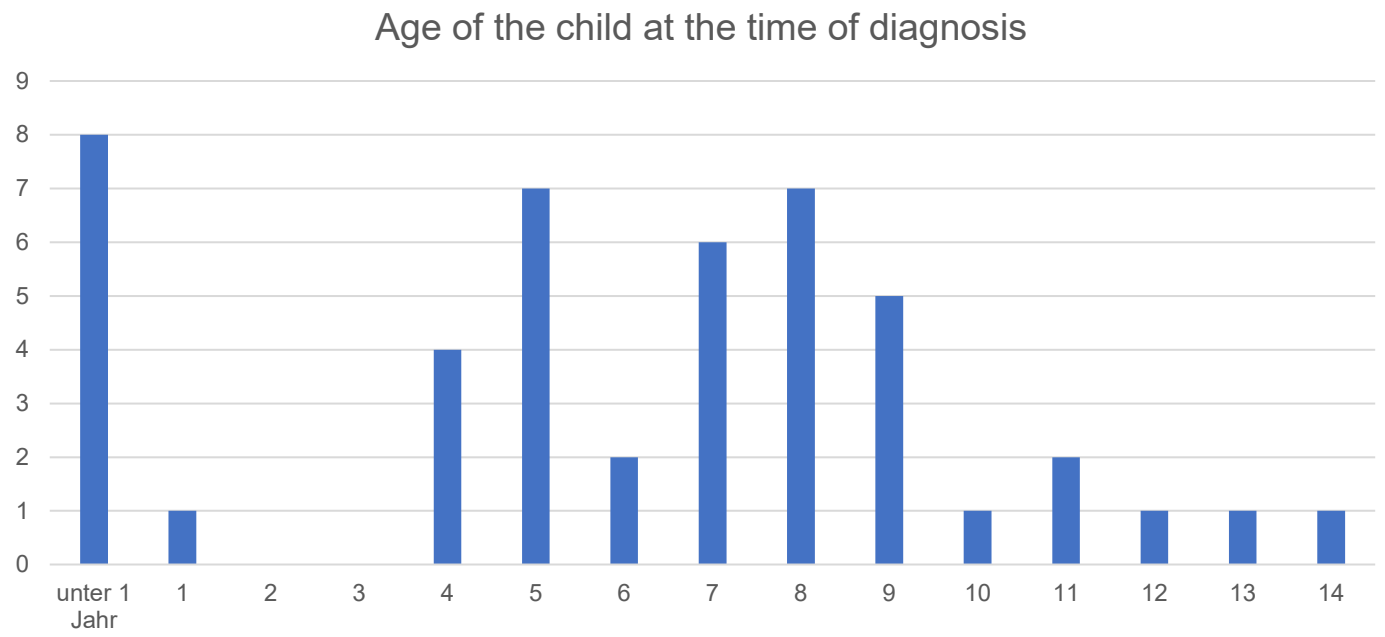




Facilities that the children attend
School: 40
Kindergarten: 4
none: 1
other: 1

Focus of the special schools
Special school with a focus on vision: 17
Focus on learning: 1
Focus on motor, physical and mental development: 1

Details of the children



Parents as a source of knowledge

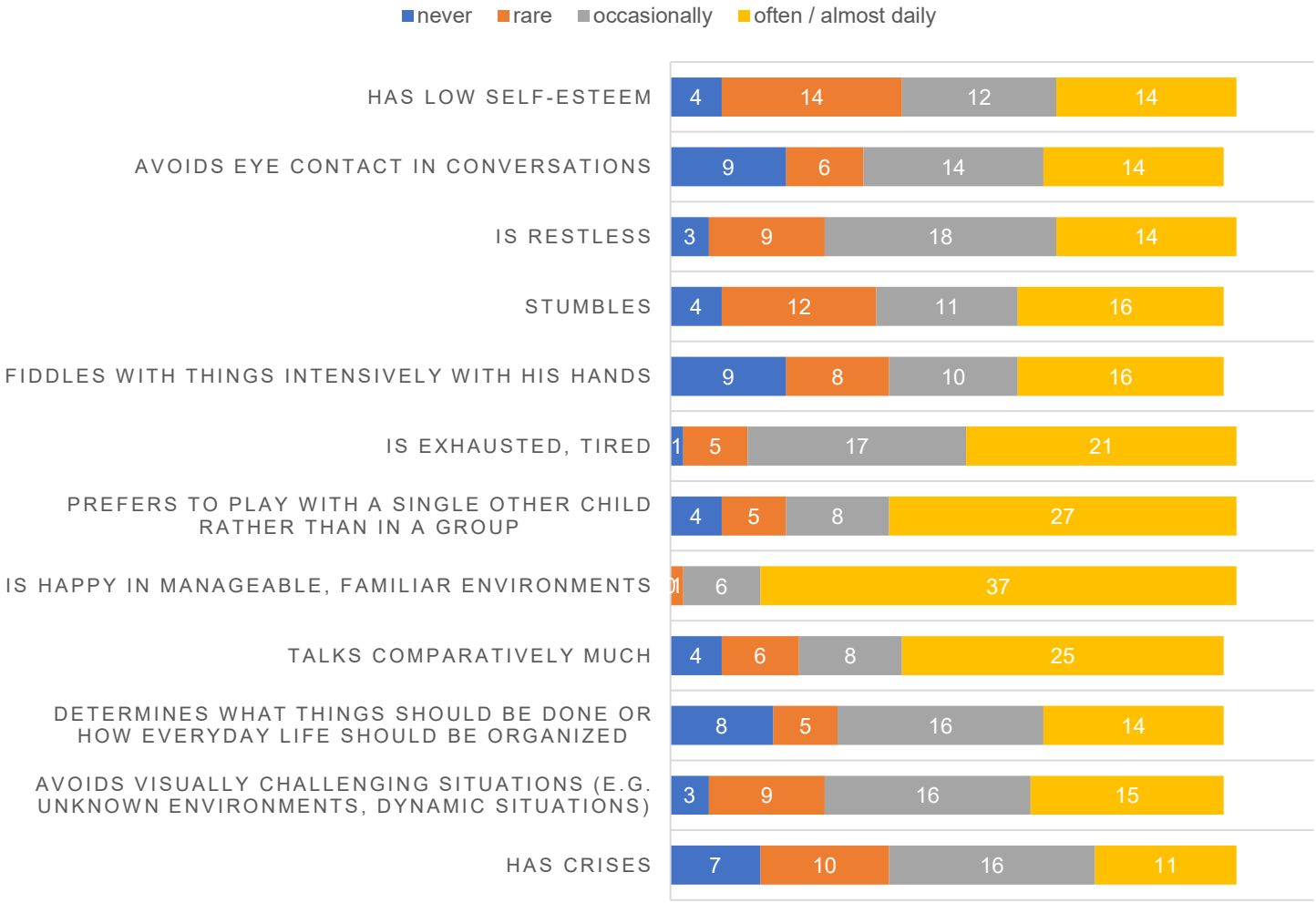
Answers to the question "*Who suspected first that your child might have a cerebral visual impairment (CVI) and that this needed to be clarified?*"

we parents ourselves	22
Paediatrician	2
Optician	0
Ophthalmologist	1
Orthoptist	4
Teacher, school management	2
Social work in early intervention, school	1
School psychologist	0
Curative educator	1
Educator/social pedagogue in a pre-school institution/kindergarten or all-day school	2
Occupational therapist	2
Assessment centre for special educational needs	7
Low Vision Specialist	2
Person from private environment	3

Other persons/institutions/situations mentioned:

- Early visual support: 4
- SPZ (there: psychology/ergotherapy): 3
- Support/counselling for a special school with a focus on vision: 2
- Motopaedist: 1
- Medical staff at school examination: 1
- Specialist Paediatrician: 1
- Risk from brain surgery: 1
- Was clear before birth: 1

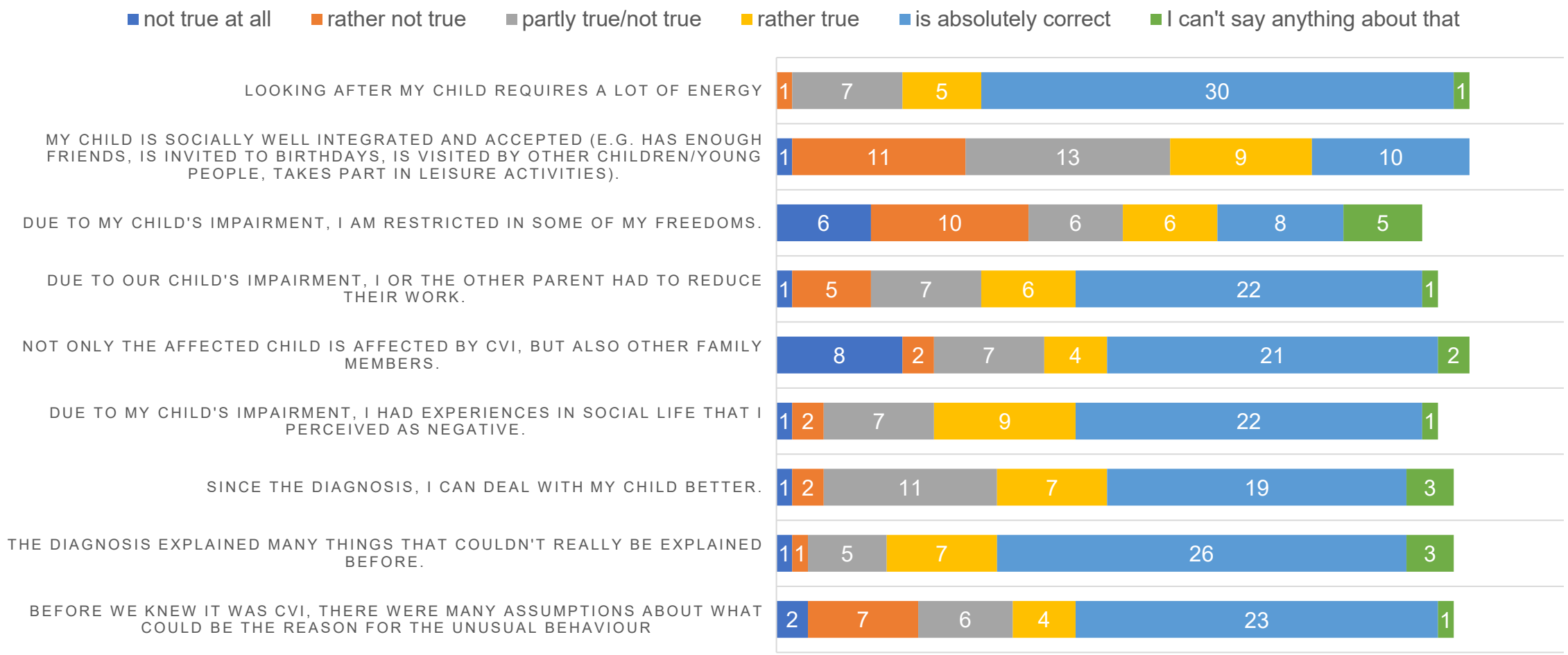
CHILDREN'S BEHAVIOUR OBSERVED BY THE PARENTS



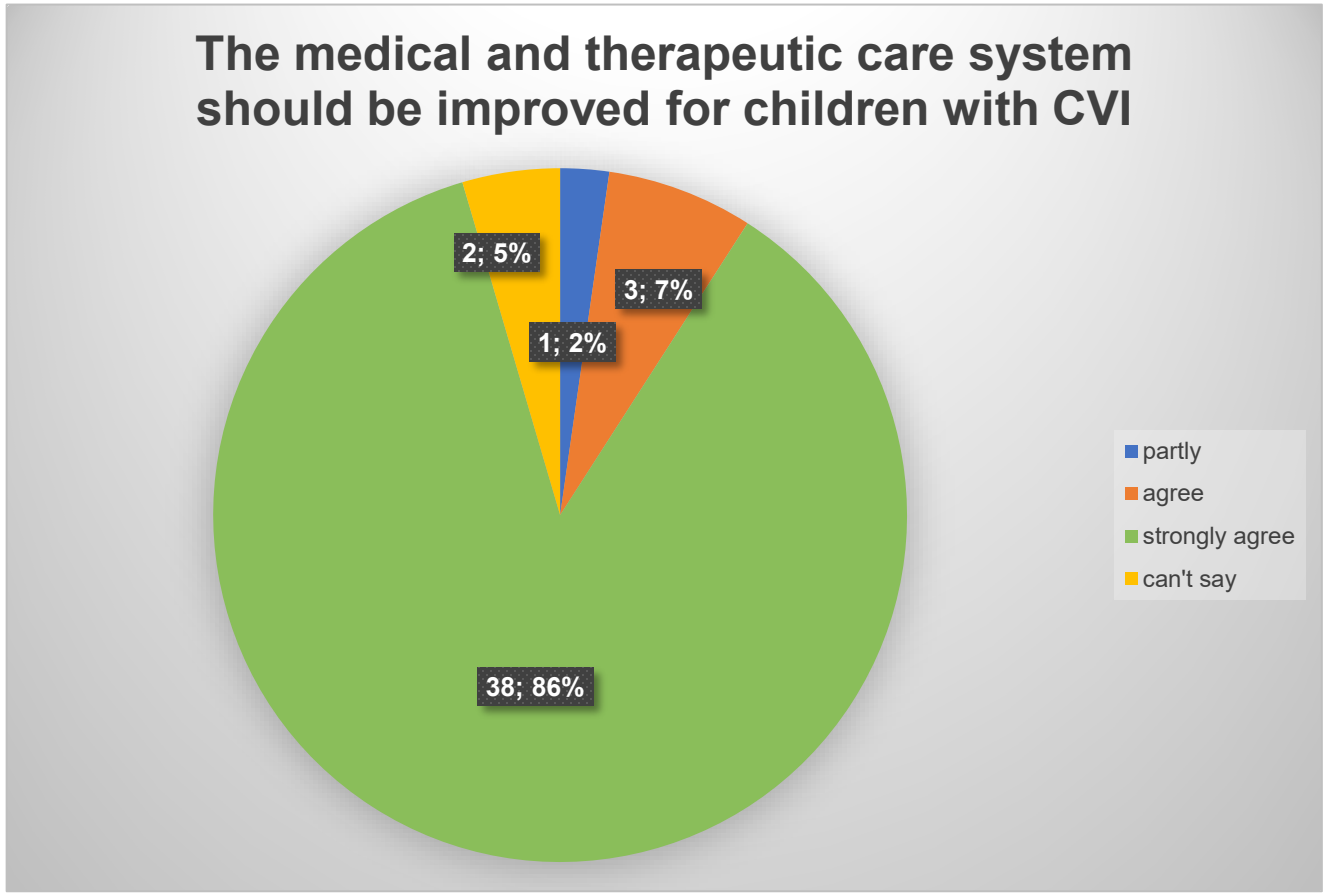
OTHER BEHAVIOURS MENTIONED

- Eye contact is not actively avoided, but makes no sense for the child due to facial recognition problems
- Automating cognitive and motorised actions
- Problems falling asleep and sleeping through the night, hyperactive, problems with body awareness (has to constantly feel his way through banging (himself and others), stamping, jumping, swinging, tightening backpacks and shoes very tightly)
- prefers to go by hand
- Has had a dissociative visual disorder (= psychogenic blindness) for 4 years due to the lack of diagnosis
- Is introverted as if he is coping with something mentally
- Difficulties in social interaction
- Sensitive to moods in the social environment, mood swings
- Avoids cutting with scissors
- Many "blindisms" outgrown, intrinsic motivation low, motivation not controllable
- Repeats the same questions over and over again, shows great anticipation or apprehension before events, slow pace in everyday life, plucks at the lip,
- Withdraws completely and sits in a box

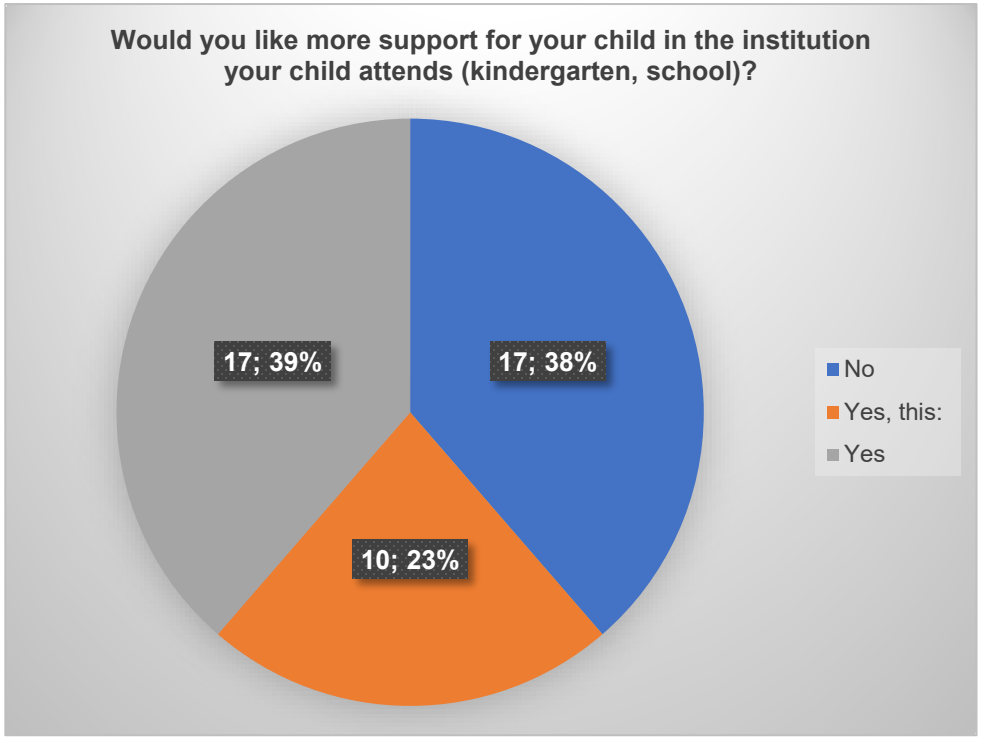
INDIVIDUAL AND SOCIAL DIMENSIONS



Expectations towards the medical and therapeutic system



Need for support in kindergarten and school



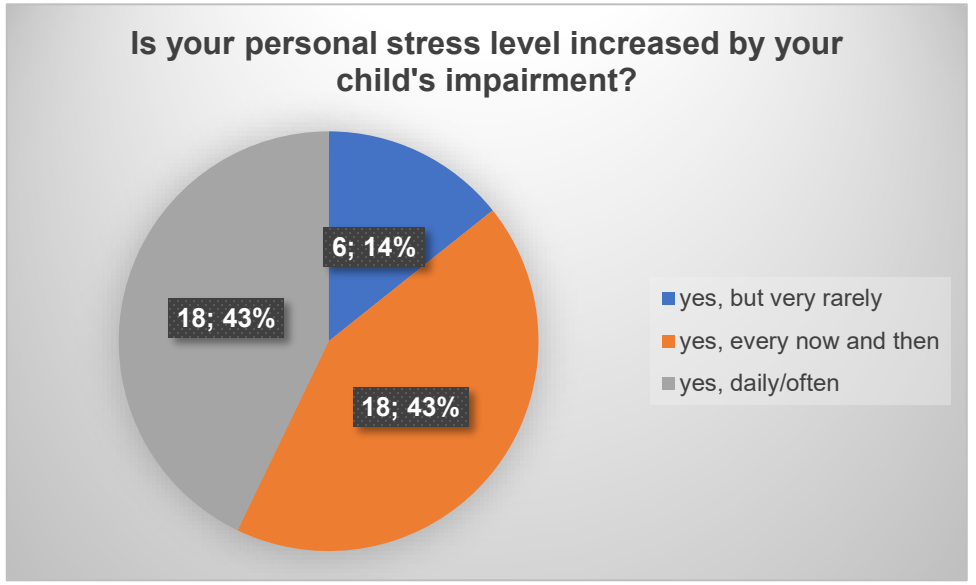
Specific wishes (selection, multiple answers were possible)

- *Teachers in special schools also need training because a child with CVI often has good visual acuity, but cannot do many things that other children with poorer visual acuity can do. Therapy should also be able to take place directly at school.*
- *Better copies of the worksheets*
- *Teachers' knowledge of CVI is often very rudimentary.*
- *Vision training at school is desirable.*
- *Inclusion is still in its infancy after compulsory schooling.*
- *The school does not support the child because of CVI. They completely ignore CVI and give him various suspected diagnoses.*
- *The actual application of the formally closed compensation for disadvantages. Currently only lip service for the most part.*
- *Understanding the impact of CVI on social behaviour.*
- *Easier access to an integrator (assistance)*
- *Learning therapy*
- *More expertise in the area of technical possibilities, didactic-methodical teaching tailored to needs!*
- *More media and digital support in the classroom.*
- *Improved sensitivity of the teachers to our son's needs.*
- *Our son is hardly given the opportunity to show or use his great resources at school*

Stress of parents and CVI

How high would you rate your current stress level? (0 = completely relaxed - 10 = very stressed)

CVI of a child and the parents' stress level



Possible answers on a 4-point scale:
no / yes, but very rarely / yes, every now and then / yes, daily/often

Quality of life of parents of children with CVI

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Final results will be published in summer 2024