Интервью с родителями детей с диагностированным дефицитом парциальных функций

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Основу нашего мультидисциплинарного проекта «Факторы влияния на динамику обучаемости детей, нуждающихся в специальном сопровождении обучения» составляют качественно разработанные дополнительные исследования, касающиеся динамики обучаемости у детей и учеников с потребностями в специальном образовании. Задачами исследования были изучение отношения родителей к диагнозу их детей и анализ проблем семей с детьми, имеющими дефицит парциальных функций. В статье рассматриваются особенности сотрудничества родителей данной категории детей со специалистами и школьными педагогами, а также способы преодоления трудностей образования этих детей. Метод, выбранный для сбора данных – собеседование. Для выделения семантических единиц был выбран стенографический анализ, который позволил кластеризовать их в следующие категории: проявленные симптомы, диагноз, потребность в терпении, подход к ребенку/коррекционные методы, консультативное сопровождение, отношение школы/учителей к ребенку, взаимодействие со сверстниками, отношение и перспективы семьи/сиблингов.

Keywords: дети, дефицит парциальных функций, специальное образование, динамика образования, родители, интервью.

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Interviews with Parents of Children with Diagnosed Deficits of Partial Functions – Clusters

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The basis of our multidisciplinary project “Impact factors in the dynamics of educability of children in need of special education support measures” is the qualitative designed complementary research concerning the educability dynamics at children and pupils in need of special education. The aim of the investigation was to determine the attitude of parents towards the diagnosis of their children and to focus on the problems of families with children suffering from a deficit of partial functions, as well as on the cooperation with specialists and the school and the ways of tackling the education difficulties of these children. The method chosen for data collection was a participative interview. Verbatim analysis was used to isolate semantic units that could be clustered into following categories: demonstrated symptoms, diagnosis, the need of patience, approach to the child/interventions, evaluation of the counselling assistance, evaluation of the approach of the school/teachers, interaction with schoolmates, siblings/family, perspectives.

Keywords: children, deficit of partial functions, special education, educability dynamics, parents, participative interview.

Introduction

The basis of the multidisciplinary project is the research (basic; in the second phase also applied) concerning the educability dynamics at children and pupils in need of special education support measures and the factors that contribute to the matter significantly and thus influence the success/failure of the children and (especially) pupils of the target group in the school environment.

The nature of the basic research of a factual issue will be extended by the methodological issue, i.e., the verification of tools that may be used to measure educability dynamics and their determinants. The primary objective of the project is the identification, as well as the qualitative and quantitative description of the factors that fundamentally
affect educability dynamics in the context of the deficiency of primary (partial) functions in the child population of pre-school and younger school age (the first two grades of primary school attendance). The methodology will triangulate a longitudinal qualitative approach with a quantitative approach (mixed design). Such a multidisciplinary research has not yet been implemented in the Czech Republic; the current research data is insufficient and outdated for the modern Czech population representing the educational environment.

The project aims to identify, describe and compare the determinant of educability and its dynamics at children and pupils in need of special education support measures, as well as to determine the frequency, distribution and structure of deficits of partial functions in the selected population.

The main (nominal) part of the project is dedicated to the collection and analysis of the quantitative strategy data; the qualitative design constituting the merit of the submitted research report is of complementary nature.

Methodology

The objectives of the qualitative investigation: The aim of the investigation was to determine the attitude of parents towards the diagnosis of their children and to focus on the problems of families with children suffering from a deficit of partial functions, as well as on the cooperation with specialists and the school and the ways of tackling the education difficulties of these children. The method chosen for data collection was a participative interview. This led to the emergence of new topics, as mentioned in the research report, that were originally not in the focus of researchers.

The method of data collection: participative interview with focuses as research questions (a dictaphone record and a verbatim transcription without extralinguistic features):

- The diagnosis of my child;
- Problems and their development over time;
- Cooperation with the school and specialists;
- Tackling the problems (facilitators and barriers).

The sample group consisted of five anonymous mothers or children – pupils of the first and second grade in a mainstream school – with diagnosed deficits of partial functions registered at DYS-centrum Praha in the years 2016 and 2017 (their code: A-B-C-D-E). The administration work – PhD. students of the author of the research report, prof. Milan Valenta.

The method of data processing – clustering to the first level of coding in terms of the grounded theory of Corbin-Strauss, as a justified method (open coding of the grounded theory).
Results

The first stage and second stage analyses of the verbatim transcription helped isolate semantic units that have subsequently been clustered into nine categories:

I. Demonstrated symptoms (unbalanced and slower development of the child, extra sensitive child, problems with reading, writing and counting, etc.).

II. Diagnosis (when and by whom has the diagnosis been given, reactions to the diagnosis, etc.).

III. The need of patience.

IV. Approach to the child/interventions (structuring and dosing curricula, reeducation and stimulation, implementation of games, homework, extra time, etc.)

V. Evaluation of the counselling assistance.

VI. Evaluation of the approach of the school/teachers.

VII. Interaction with schoolmates.

VIII. Siblings/family.

IX. Perspectives.

The list of semantic units in the specified categories - clusters (samples) is presented below.

I. Demonstrated symptoms

A. So, it seemed to me already at the beginning of the first grade that she's sort of, a bit <...> even slower in something, she was doing better in one thing and worse in another. I was about to take a hint about it, because she was born prematurely <...> but that it can show at school, during learning, you see? <...> she’s simply slower in some stuff.

B. He (son) had his school attendance postponed because he had articulation issues… he is extremely lively… he is great at chess but doesn't like studying. Still, he does very good at school <...> at enrolment they told us to postpone his attendance for another year because he had articulation issues <...> because she tolerates his slowness (in school work).

C. He has trouble concentrating, after 10 minutes he already doesn't perceive who says what, he's already in his kind of world, he simply switches off and doesn’t perceive…

D. At the enrolment he couldn't count to five, couldn’t colour…

E. He’s so unfocused that he couldn’t integrate at all. He isn't able to write under stress.
II. Diagnosis

A. My daughter has been diagnosed with dysorthographia... I got it, because when we used to go for development examinations to a neurologist, she made us aware that difficulties could come at school <...> the teacher didn't notice anything; not at all in the first grade; only in the second grade did she come up with the fact that my daughter is slower, so we agreed that I'll take her to be diagnosed in the third grade <...> when they diagnosed her, I didn't take it as something unusual...

C. We didn't care much about it (the diagnosis). Well... we didn't experience any intense emotions...

D. I didn't take it tragically; I merely hoped that he would manage at school.

III. The Need of patience

A. Me and my husband saw at home that we need to be much more patient with her... I must be very patient. I'd advise the other parents to be extra patient...

D. It's about patience to a large extent. You can do away with many things only with the patient approach.

E. I'm not patient; we simply take turns in some way...

IV. The approach to the child/interventions

A. When she writes a dictation, for instance, it mustn't be long, we try to shorten everything. We mustn't swamp her with it... Well, she doesn't have big difficulties; it's rather that it takes her long. She's able to catch up with everything, but I need to work with her.

B. ...the postponement helped my son a lot... the older son has dysgraphia, but after he started with Comenia script, it worked out. ...of course we have some extra homework.

C. Some work has to be done every day, continuously, that's important...

D. I must work with him a lot at home; relax his wrist, do the drawing; if you practise thoroughly, the results will come; I saw that the work is not useless.

My son can perceive for 10 minutes only; he can't stay focused on some topic for the whole lesson; teachers should shorten the matter for him into those 10 minutes, follow with a different activity and then get back to the topic again. If the teacher notices that the pupils are uneasy, she does some physical exercise with them, they sing a song; this works quite well.

If you work hard, you can make it.

E. We agreed that he won't be classified, but he'll get a verbal evaluation in some subjects.
He should have had the postponement or go to some preparatory class, but the awareness is low; we didn’t know what to do.

V. Evaluation of the counselling assistance

A. I’ve already been there (DYS-centrum) with her and she was excited, that was good. She wanted to go there again. They had a really good approach there, because she was happy and she asked when we would go again...

Before they examine the child and make the report for the school, you need patience... and it’s true that, as a parent, I’m getting it (the examination report) in my hand quite late.

B. Even the name of the counselling centre – psychological, it’s a bit stressful.

D. I thought it would be paper work (in the counselling centre), but it was about lying and standing... a kind of linking the hemispheres; global, with movement; I was pleasantly surprised by that.

E. We begged the counselling centre if they would diagnose him, but at first they claimed that the school is exaggerating; that they send there every other child, and then they found out that he really has some problems.

VI. Evaluation of the approach of the school/teachers

A. They did it in a little different way at school (ad the recommendation of the counselling centre – one extra lesson); they said they wouldn’t get money on that; they put it instead of Art, that extra lesson, but Art is particularly good for her... but she’s been to that lesson twice already and she told me it was good there.

I told the teacher and she merely shrugged it off... she (the teacher) said she hadn’t noticed (the problems), so I got to searching for a solution myself. Because, you know, sometimes...eee... I have this personal experience, the teacher of my older son, well, she decided, when he was in eighth grade, that he had a learning disability... well, I was truly shocked. I mean... he didn’t have any and so I brought these results from the counselling centre and she still didn’t believe me, was convinced that he had some deficit. What I’m trying to say here is that her stance is irrelevant...

B. When the teacher was told about it (the diagnosis), she started to work with it; I don’t mean any extra lessons, but she works with him during the whole second grade. Even before he got to the counselling centre, she had given him some extra lessons; she taught him some syllables and stuff. She had worked with him even before he went through the centre. Well you know, his second grade teacher has this speech disorder so, You know, she teaches at elementary and doesn’t know to articulate properly, you tell me if this is all right, I don’t think so.

As we have this very skilled teacher who realised very fast what was going on, she doesn’t give him worse grades because she is aware of his condition. Given that, I don’t
mind grades as such. She tolerates his slowness and respects his specific needs and none of
that has been reflected in his reports.

C. I miss that personal approach of the teacher; I don’t feel that the teachers care
about the children... even though I tried to talk to the teacher, I don’t feel that she’d pay
attention to it. I’d like to explain to her how he (my son) feels, but there’s no time for that
and the teachers don’t want it anyway.

She’d need an individual approach towards my son so that she’d get to know him...

E. In the kindergarten they told me that I observe him too much, but after a month the
teacher called me that she has trouble with him.

He was assigned a teacher assistant who was meant to work with him but that made
it even worse because then he got used to ignoring the teacher. He knew the assistant
would explain everything to him individually. Also, the teacher was sort of in a clash with
the assistant.

The school wanted him to do the first grade again but that would be an immense
failure for him, given that this is not an issue related to intellectual capacity...

The teacher told us he would not get grades then but the way she said it, you know,
like all the children will get their reports except for our kid. That was hell, for us and I bet
for him too. In the end he got his report except for it only had verbal evaluation which was
a good solution. Still we decided to change for a different school.

VII. Interaction with schoolmates

A. I think that somehow the children don’t perceive such things at each other.

...I didn’t notice that she’d come that someone makes fun of her that she’s slower or
stuff, not at all. We didn’t notice that ... But so far it hasn’t happened that she’d come from
school and cry that someone makes fun of her.

B. There aren’t any barriers among the classmates... he’s popular in the class; he’s
one year older (postponement for one year), so he helps the teacher and he’s regarded as
an exemplary pupil...

C. With his personality, my son’s able to communicate everything with the classmates;
it isn’t necessary that the teacher explains anything to them... especially in the school club.

D. When my son has no activity, he runs around the classroom, or when he feels some
emotion, he lives it through with his whole body; the teachers have to explain to the
classmates that it’s normal, that there’s nothing wrong about it...

E. Adults should explain to the children that they shouldn’t make fun of him because
he can’t read yet; that he has some handicap.
VIII. Siblings/family

A. Well we had to keep explaining this to our son (brother)... We made him aware that she was slower in some stuff and that he, as a senior brother, should take care of her. We simply had to explain that she was slow... Say she’s counting on her fingers and he keeps scolding her for being to slow so we had to intervene and explain that she can’t do faster. Our comments and explanations were vital, I don’t think we would do without it.

B. ...that parents are afraid to accept the truth about their child <...> whatever deficit or disability it is, it has no impact on their relation (between siblings). Both live chess, they tend to spend a lot of time together... Parents find it hard to come to terms with the disability. They keep hours and hours over textbooks, forcing their child to study and make the disability go away.

C. ... it was a change for us, but nothing essential; we just had to organise our time.

D. ...I had the support around and in my family; my partner does some of my duties...

IX. Perspectives

C. I don’t see any future trouble, he (my son) is quite smart... he’s good at numbers, at Math; he’s going to be a technical type...

D. ... he’s quite a skilful boy and I think he won’t have any trouble in the future.

E. He’s terribly unfocused; he has to learn to work with it himself, but they say that maybe in his teens... so we’ll see... we don’t know how he’ll be able to make the entrance examination for the high school.

Summary and conclusion

The investigation aimed at identifying parents’ attitudes towards the diagnosis of children, focusing on the problems of families with children with partial function deficits. Because the chosen method of data collection was an interview, more topics in the research report, which originally did not contain the focal point of interest of the researchers, emerged in the data collection process.

Verbatim analysis was used to isolate semantic units that could be clustered into following categories: demonstrated symptoms, diagnosis, the need of patience, approach to the child/interventions, evaluation of the counselling assistance, evaluation of the approach of the school/teachers, interaction with schoolmates, siblings/family, perspectives.