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BOOK REVIEWS

Introduction

Dear readers,
Editorial Board of the Journal of Exceptional People made several changes that should meet the expectations of our readers and contributors. First of all we insert into this issue a list of conditions to be fulfilled by each author in relation to compliance with publication ethics. The editorial staff also acquaints the readers with the process of review procedures that are performed for each sent article and you can also find the criteria by which we abide in the selection of published articles. Currently we are trying to insert each text into a centralized commercial identification system Digital Object Identifier (DOI), which should increase the chances of visibility and greater citation of published articles.

In this issue we are publishing a total of seven articles that are research scientific papers or overview essays. These articles deal with the current problems of aftercare in the Czech Republic (The current issues of Aftercare) (Růžička, Hutyrová, Wittmannová) and the problems of patients with cerebral palsy in China and the Czech Republic (Jiaojiao Wu, Shenglin Liu, Kantor, Urbanovská). There is also an article on cognitive strategies related to reading in children with SLD (Specific Learning Disabilities) (Bartoňová) and the study focused on student involvement in school management in the State of New York in the context of issues relating to students with special needs (Damiani). The last two posts are focused on the area of early intervention of children with "developmental disorder" (Xinrui Li) and the use of biofeedback in individuals with multiple disabilities in the Slovak Republic (Jančurová). The magazine is ended with usual interesting book reviews (Majerová).

I hope that by reading our magazine JEP you get a lot of new and interesting information.

Pavel Svoboda

The current issues of aftercare in the Czech Republic

(scientific paper)

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Abstract: *The following text aims to fulfil two purposes; the first purpose being to create a theoretical outline of aftercare. The second purpose comprises of presenting and comparing research regarding the explored subject. Most of the research presented in the paper was undertaken at the Institute of Special Education Studies at the Palacky University's Faculty of Education. The results of three diploma theses supervised by the author of this text are also used.*

Key words: *Aftercare, substance dependence, research, drugs, alcohol*

1 Introduction into the subject – a general outline of aftercare

1.1 A general outline of aftercare

Aftercare or aftercare programmes follow after the treatment of substance dependence in a psychiatric hospital, therapeutic community or specialised department in prison. Clients of these programmes are usually persons with impeded psychosocial development. Often they are graduates of institutional education, persons with criminal record, persons with aggression problems or persons with personality disorder in whom abstinence from the habit-forming drug uncovers therapeutic potential and the underlying cause of the initiation of dependent behaviour.

The purpose of aftercare is to retain the changes that occurred in the client throughout the treatment or, alternatively, spontaneously or after previous interventions.

In the last ten to fifteen years aftercare is the domain of aftercare centres that offer a wide range of services.

According to the conception of the Ministry of Labour and Social Affairs aftercare is one of the most essential factors for the overall efficacy of the process of treating substance dependence. The transition of the client from treatment to aftercare is in European countries considered to be the most important moment in the treatment process. This experience is in line with the practical experience of non-alcoholic drugs service providers operating in the Czech Republic. Therefore, ensuring adequate capacity in the aftercare programmes that would be commensurate to specific needs of the clients and logically complete the chain of existing services is absolutely crucial.

During the transition of the clients to the aftercare programmes the continuity of the treatment process should not be interrupted therefore it is desirable that aftercare centres communicate well with the programmes from which the clients are accepted. Ideally, contact between the client and the chosen aftercare programme should be arranged before completing the basic treatment. The team of the aftercare facility should be informed of basic principles of the treatment programme that the client has undertaken. An important element in the whole treatment process is a subsiding intensity of the support given to the client in aftercare. The client is given opportunity to take a full responsibility for his or her life. In practice the respective communities and psychiatric hospitals often collaborate long-term with aftercare centres and they inform their clients of the aftercare principles while they are still under treatment.

In aftercare programmes a multidisciplinary team is absolutely essential. The team of the program should be assembled based on the needs of the clients. Focus should be on the main purpose of aftercare which is to gradually disassemble the bonds between the client and his particular program. Each aftercare programme should aim to create a good quality network of specialists in response to the problematic areas of its clients.

The core team of the aftercare programme must comprise of a psychologist, a special pedagogue and a social worker. Special abilities include good quality training in counselling or psychotherapy and most importantly include relapse prevention. There is a vast field open in these programs for ex-users. Those work very well, under supervision and after having achieved specialised education, in the field of sociotherapy. (Kuda in Kalina, 2003).

What also appears to be helpful is contact between the given aftercare programme and external specialists such as a regional public health authority, dentists, general practitioners, free legal advisors etc.

Main elements of aftercare are:

- ***Psychotherapy*** – clients in aftercare programmes may manifest various traumatic experiences from the period of drug usage, personality disorders from time before the drug problem as well as other problems connected to the drug usage. Therefore it is essential to correctly diagnose what issues of the client are possible to deal with in real time. It is not possible to deal with all problems that arise during the period of addiction; rather, the work with client should focus on strengthening abstinence from the primary drug. For this reason support psychotherapy focused on stabilising client's emotional state is used. Current literature states that cognitive-behavioural therapy is a core therapeutic approach. According to the research among the staff of aftercare centres only few are educated in this therapeutic area. Currently, psychodynamic SUR training is prevalent.
- ***Relapse prevention*** – fear of failure is a basic motivational factor for entering an aftercare programme in newly-recovering people. For the majority of abstinent individuals it is very difficult to resist craving. The goal of relapse prevention is to equip the client with skills and knowledge and thus strengthen his self-control which lowers the risk of a relapse. Relapse prevention is therefore the theme of a substantial number of group sessions.
- ***Social work*** – a wide range of social and legal problems may be observed in clients in aftercare programmes, problems such as debts with the insurance companies and other debts, social benefits, prosecution, etc. The help offered by the social worker must be practical since most clients are not able to solve these problems on their own. A good social worker is a core member of an aftercare programme team.
- ***Work, sheltered employment and qualification*** – one of the basic elements of integration into a normal life is acquiring a job. This is one of the main tasks of an ex-user released from treatment. However, they often lack the necessary specialised qualification or the correct work manners. One possibility how these troubles may be overcome are sheltered workshops. Those enable the client to acquire basic work manners or to get a qualification. It is important to assess correctly whether the client really needs sheltered employment or is able to get a placement at the labour market. Therefore good cooperation between aftercare programmes and jobcentre offices, local firms, etc. is part of this area.
- ***Health care*** – drug-abuse is damaging to the human body. Among the most frequent problems of the clients are: hepatitis type B and C, gynaecologic and dental problems. Health care should not be forgotten in aftercare. The clients need both mental and physical stabilisation. Cooperation with doctors and help in ensuring adequate health care are elements of aftercare.
- ***Offer of leisure activities*** – to learn to "enjoy" without drugs is an essential goal of the treatment and aftercare. It is often observed that clients, in fear of relapse,

> fill their whole daily programme with tasks. It is not possible to continue this way indefinitely; energy is lost after some time. What had seemed protective before becomes the cause of stress leading to relapse. An offer of various types of leisure activities is what really prevents relapse.

During the transition of the clients to the aftercare programmes the continuity of the treatment process should not be interrupted therefore it is desirable that aftercare centres communicate well with the programmes from which the clients are accepted. Ideally, contact between the client and the chosen aftercare programme should be arranged before completing the basic treatment. The team of the aftercare facility should be informed of basic principles of the treatment programme that the client has undertaken. An important element in the whole treatment process is a subsiding intensity of the support given to the client in aftercare. The client is given opportunity to take a full responsibility for his or her life. (Kuda in Kalina, 2003)

1.2 Structure of aftercare programmes

In a narrow sense aftercare concerns post-treatment abstinence support and maintenance. In a broader sense the aim of aftercare is social integration of the client into normal life. Among the interventions necessary for the treatment of substance abuse are relapse prevention, support group therapy, individual therapy and counselling, leisure activities, social work, work counselling, sheltered housing, sheltered employment and qualification, work with family members and health care. Intensive aftercare programme usually lasts 6–12 months; it raises the treatment efficacy rates and shortens the duration of aftercare. (Kalina, 2003) It seems to be helpful to provide the clients with certain benefits when attending the programme successfully. Among these can be internet use, washing of clothes, more counselling etc.

Aftercare programmes are under the auspices of the Government Council for Drug Policy Coordination (GCDPC) and the Ministry of Labour and Social Affairs. In order to obtain funding from government subsidies, the programmes must follow certain rules and comply with the conditions set by GCDPC. One of the most important conditions for obtaining the subsidy is obtaining a certification of the services. Certificate of professional competency is issued or withdrawn by GCDPC, based on a proposal of the Committee for Granting Certification, after a certification assessment is realized by a Certification Agency that acts based on a request for such assessment and attaching the required documents.

The granting of certification may be requested by any natural or legal person providing services to the target group of narcotic drug and psychotropic substance users, the content and assessment criteria of which are defined in the approved Standards of Professional Competency, specifically in the special section of these standards. (Kalina, 2001)

As a concrete example the structure of the services provided by The Aftercare Centre in P-centre in Olomouc can be mentioned. This centre fulfils the Standards of Professional Competency. Reasons for mentioning the programme of this centre are as follows: 1. It is the workplace of the author, 2. the centre was one of the places where the research described below was undertaken, 3. the facility is very similar to other aftercare centres.

The length of the programme in P-centre is usually 6 to 8 months depending on the needs of the client, the shortest being 3 months. The client may decide to use the sheltered housing that usually lasts 4 months. The sheltered housing is not available, however, without attending the aftercare programme.

In the early days, when the client enters the programme, he is introduced to the operation and staff of the centre, attends the first morning sessions, as well as the first session with his advisor and together they develop a plan for the first several weeks and write an agreement for the provision of services. On the following days he participates at thematic groups and clubs, explores the city of Olomouc, is introduced to other clients of the programme, looks for a job and starts working with his advisor on the therapeutic contract.

The aftercare programme comprises of compulsory and optional activities. Attendance at the compulsory activities is one of the conditions for accepting the client into the programme. The compulsory activities are:

Individual therapy – individual consultation is between the advisor and the client. The client usually attends it once a week; more frequently at the beginning of the programme. The length of one session is approximately 45–60 minutes. The date of the session is agreed on by both parties beforehand and it is their responsibility to attend the consultation or excuse one's self at least one day before. At the individual sessions the client has an opportunity to talk about his or her feelings, moods, tastes, relationships and, most importantly, works on the tasks in the contract.

Social work – a social worker assists the client in solving social matters. He or she sends documentation to the jobcentre office and other relevant departments at the city council about participation in the aftercare programme, changes the contact address to be in Olomouc, files requests for monthly payments in case of debts, contacts the probation and mediation services for clients with legal punishments, conditions, etc. The worker also passes contact information of general practitioners and other specialists and assists in finding a job. The worker does not solve problems for the clients, rather accompanies them so that they learn to solve these problems themselves.

Reflection groups – these are held every 14 days. The client, other members of the group and the therapists reflect on the past two weeks. They reflect on the therapeutic contract together, seal and introduce new contracts and celebrate significant events such as getting a job or housing, finishing the programme and similar. If the client is not able to attend the group for special reasons they must excuse themselves to one of the team members.

Dynamic group – is held every 14 days on Mondays just like the reflection groups but these do not have a set theme. The client is expected to bring up a topic and share it with others, to willingly accept advice, critique, opinions and suggestions, to try to express his or her feelings, moods and to show interest in other clients. Dynamic psychotherapy and cognitive-behavioural psychotherapy is used in the dynamic groups.

The goals of the group therapy are: changing the non-adaptive scheme, support maturation of personality, interpersonal communication skills, etc. (Polínek, 2013)

Thematic groups – are held once a week. The respective themes concern typical problems that the clients encounter. Programme of the thematic group consists of theoretical introduction into the theme, discussion and enacting problematic situations and possible solutions of individual problems on the given theme. In some cases the themes are brought up by clients and in others the therapists prepare a series of themes.

Housing groups – are held once a week. The group is attended only by clients using the sheltered housing and the social worker. At these sessions the running, upkeep, division of duties in care for the sheltered housing, assessment of the house manager's work and the monthly shifting of the function to another client are addressed. The housing group is chaired by managers of the two sheltered houses together.

Morning groups – are held each working day in the morning and are compulsory for the clients in the sheltered housing who do not have a stable job or are incapable of work. This group is managed by clients and the social worker. During the meeting every member makes an individual plan for the day, cleaning duties are set and practical daily problems are solved.

Clubs – are held once a week unless a different schedule is agreed on. The purpose is to spend leisure time actively and to relax. The clients and the social worker, and sometimes selected external workers take turns in its preparation.

These are among the optional activities:

Family and relationship therapy – participation of client's relatives at the therapy is very important. The parents are recommended to at least visit the P-centre to be introduced to the therapeutic programme, the team and the whole centre. If the client is not happy with the family relationships and would like to improve them he is offered a regular therapy. Clients may also be offered family or relationship therapy with specialists outside the P-centre.

Qualification – the clients receive help with choosing an accredited retraining course or distance study programme. The clients are provided with maximum support during the course. So far all clients have finished their qualification courses.
Computers and internet – altogether three computers with internet access are provided for the use of the clients. The computers should be used to acquire at least basic computer and internet skills. The clients should be careful not to become internet addicted.
Sports equipment rental – sports equipment is available for rent: mountain bikes, balls, squash rackets, rafts Palava for two with accessories, backpacks, tents and so forth. These are also available at the weekends when the clients organise their activities alone. The service is free of charge. Clients who are not accommodated at the sheltered house are required to pay an adequate deposit.
Gallery U Mloka – the gallery is open for public and various types of events are held here such as exhibitions, film-screening, drumming, poetry-reading, photographic course etc. The gallery also serves as a teahouse open for public where volunteer students help out. Clients may invite their guests here or borrow books from the gallery library. Talent for arts is not rare in ex-users. Works of art created by the clients of the aftercare programme are displayed in the gallery.

1.3 Description of the sheltered housing

The clients who are accommodated in sheltered apartments have certain responsibilities and rules connected with this service. Those are paying the rent, locking the main door, rules concerning accepting guests, washing, the internet, curfew, cleaning, phone-calling, correspondence, appointing a house manager etc. These are described in detail in the Aftercare Centre's Guide which is a manual that the client receives at the introductory consultation.

As part of the sheltered housing random testing of the clients for addictive substances in urine is carried out. The testing may be done during the day or as part of the night check. The night check is carried out usually twice a month. Not only do the clients have responsibilities but they also have their rights and one of them is for example the right for privacy. The P-centre's staff members enter the clients' rooms only when necessary and always after knocking. Clients should behave the same way to each other.

In relation to the Ministry of Labour and Social Affairs aftercare programmes must comply with the registration conditions and follow the quality standards of social services. The registration is adjudicated by the county office according to the permanent residency of a natural person or in case of a legal person the headquarters and when the provider of the organisation of social services is the Ministry itself it also issues the registration.

1.4 The client of an aftercare centre

Each aftercare centre is designed for a certain target group. Usually it is for people who were addicted to narcotic substances, underwent a treatment or had been abstinent for some time.

The Social Services Act puts the person who wants to actively use the services to the position of a contracting party. The person becomes a social services user at the time of signing the contract. The new law therefore uses the term user. A social services user can be anyone who has a contract with a social services provider as determined by law.

The types of clients in aftercare centres vary according to the requirements that the client should fulfil at entering the aftercare programme. For example The Aftercare Centre with Sheltered Housing Sananim provides its services to clients with a diagnosis of non-alcoholic drugs dependency or combined dependency on alcohol and non-alcoholic drugs. Other requirements may concern abstinence from illegal drugs and alcohol for an uninterrupted period of three months or previous fully completed treatment in an inpatient or outpatient setting. The same length of abstinence applies to persons who have not undergone previous treatment.

1.4.1 The characteristics of the client of an aftercare centre

People entering an aftercare programme come with certain previous experience and experiences, some positive and some negative. During aftercare it is necessary to bear in mind that the client possesses a unique personality and the approach must be individual. Human personality is shaped partly by genetic code, for example as in the case of the temperament, and partly by qualities gained during socialisation in which the society and family influence the values and patterns of behaviour. Some theoretical models consider temperament as crucial in the process of developing addiction to drugs and alcohol.

Supporters of psychoanalytic models consider substance dependent individuals to have severe mental conflicts, in terms of a strict superego. The use of alcohol or other substances is an escape from feelings of anger and fear. According to behavioural models substance use is learned and maintained through classical or operant conditioning. Science considers thoughts and feelings to be important determinants of behaviour in response to the environment. Given the fundamental role of the family in the learning process family factors must be noted. Majority of addicts had experienced a “polar” approach from their parents: over-protection, authoritarianism, dominance combined with inconsistency, reduced interest and hostility. In a pathogenic family there may be observed fewer activities done together and more frequent conflicts, trauma and deprivation. Individuals may also be affected by the dependence of family members on non-alcoholic drugs or alcohol.

The loss of self-esteem which is a dysfunction with a focus on the needs and behaviour of others also significantly contributes to the formation of dependency. The addicted person first binds to a person, and only later to alcohol or drugs. The use of drugs is not always associated with pathological influence of family, genetic predisposition or personality disorders. Sometimes the person is only curious about the effects of the drugs, is bored and wants to try something new. Friends and acquaintances can then be those who offer him the drug and mention its positive effects. It is well known that peer group influences the behaviour, attitudes and values of individuals.

Among the special characteristics of persons entering the aftercare programmes are a reduced resistance to stress, problems with self-esteem, an inability to maintain a lasting relationship, a fear of rejection, a low emotional response, a smaller degree of responsibility, personality disorders (disharmonious development of the personality, polymorphic psychopathy, social maladaptive disorders and asthenic disorders) and in former cannabis-based drug users also a reduced memory. (Jeřábek in Miovský, 2006)

1.4.2 The rights and responsibilities of the client in an aftercare centre

For effective functioning of an aftercare programme it is important to clearly set rules to be followed both by the client and the staff of the centre. The rights and duties of the clients are similar in all aftercare centers. The rights of the client can be adjusted by the Workers Code of Ethics which describes the procedures for the staff. The duties and rights of the clients are included in the Aftercare Centre's Guide, the knowledge of which is often a condition for the client's acceptance into the programme. Prospective service users are informed of their rights and duties before so that they know how to behave and what to expect from the staff.

Specifically, we present the rights and duties in the Aftercare Centre at P-centre in Olomouc. The staff of this centre expect from the clients willingness to work on self-improvement, an active participation in the programme, abstinence and a respect for certain basic rules such as non-violence (mental and physical) to everyone in the P-centre, a respect for the private property of the clients and the P-centre and no planning or committing crimes.

2 Research concerning aftercare

In the world a whole series of research concerning the importance of addictions treatments whether it is detoxification, inpatient or outpatient treatment or aftercare has been undertaken. Among these are for example the American research DATOS (Drug Abuse Treatment Outcomes Study) or the British NTORS (National Treatment Outcomes Research Study) (Radimecky, 2009). In the Czech Republic it is the research by the National Monitoring Centre for Drugs and Drug Addiction. The results of this research show that treating drug-users is effective, necessary and beneficial to the state. Even if the clients are not successful in staying abstinent their health and social state improves in such measure that they require less specialist care. Majority of users who undergo treatment show low-risk behaviour and a tendency to start another treatment earlier in the case of a relapse. On the website about addictology mentioned above (Radimecký, 2009) it is also stated that American and British research showed same conclusions concerning the aftercare for dependent persons. According to these, aftercare programmes raise the success rates of the treatment by 80 %, meaning that they maintain the changes, especially abstinence, that occured during treatment. It is because of what has been already mentioned above: the help with the transition from the treatment to the conditions of the normal life and the provided psychological support in overcoming the problems of everyday life.

One of note-worthy works carried out at the Palacky University is the research by Eva Maierova (2009). In her work she examined the motivation of substance users in her diploma thesis entitled: “Motivation of Female Drug Users in Compulsory and Voluntary Treatment”.

The author focused the research primarily on women. In her research she aimed to determine what motivation the female clients in compulsory treatment have compared to the clients in voluntary treatment. The answers obtained using a questionnaire and semi-structured interview showed greater motivation for treatment in women who are treated based on their own voluntary decision.

Clients recovering in voluntary treatment were most motivated by an improvement in mental health (86 %) and relationships (83 %), furthermore by improvements in the area of work (69 %), living standard (68 %), legal matters (49 %) and physical health (47 %). The respondents of compulsory treatment were most motivated by relationships (68 %), mental health (61 %), work area (52 %), living standard (51 %), legal matters (45 %) and physical health (43 %).

In both groups there is a notable match in motivation. The only difference between the groups is shown in mental health and relationships where the greatest motivating factor in voluntarily treated clients is mental health and in clients under compulsory treatment the first position is taken by an improvement in relationships.

Another subject in the research were the therapists working in organisations providing voluntary treatment and therapists providing compulsory treatment. In this respect, the interest focuses on the confrontation of the therapists' opinions about the motivation in the treatment of the obtained responses from the interviewed clients.

According to therapists of the compulsory treatment group there are three types of motives. Firstly, some motives are external, concerning relationships with parents and close friends, and about 70 % of the clients are motivated by these. Other motives are children and the clients themselves. The same can be seen in clients under voluntary treatment. In both cases the clients enter the treatment at the instigation of someone else or as a result of adverse circumstances; in some it is for criminal offense and in some clients under voluntary treatment the reasons are parental pressure or unfavorable financial situation. Initially, their motivating force is external and negative and only later in the course of the treatment it starts transforming into inner and positive motivation.

We will attempt to summarise here the research realised at the Institute of Special Education Studies at the Palacky University's Faculty of Education in 2009–2013.

Research no. 1: Possibilities of social rehabilitation in aftercare programmes (Růžička, Martínková, 2009)

This research confirms the importance of aftercare programmes. It shows that aftercare programmes help the clients to find a job and friends outside the drug environment. These are two pillars of a successful social rehabilitation.

Research no. 2: The quality of life in graduates of aftercare programmes (Růžička, Klusová, 2010)

This research focused on the motivation for abstinence in graduates of The Aftercare Centre in P-center, Olomouc. The gender of the respondents was not emphasized; both women and men in an age range 24–35 years were interviewed. However, there were more men in the group.

The results obtained using a structured interview showed that respondents' motivation for abstinence lies in negative experience gained at times of the addictive behaviour. Mental and health problems associated with drug use, unsatisfactory financial situation, living on the street, poor or no relationships with family members or close persons and the subordination to the drug were among the experience. A positive motivation for abstinence was independence, self-control, achievements in treatment, plans for the future and positive relationships with close people. Some degree of similarity with the results of Eva Maierova's research may be noted here.

Research no. 3: The quality of aftercare programmes in men addicted to alcohol (Růžička, Opavová, 2013)

The results show that there is a significant difference between the clients' needs and the services the aftercare centres provide. In other words, the research revealed differences between what clients want and need and what they encountered in a particular facility. One of possible solution seems to be regular surveys on this issue by respective aftercare facilities and whenever possible and appropriate a change of the offered services or some of its aspects.

It has also been shown that the importance of aspects of offered services is comparable in clients who have used the services of an aftercare facility in the past and those who attended an aftercare facility for the first time. It seems it would be useful to pay more attention both to the newly-enrolled clients as well as the existing ones, especially in the area of aspects of the services in order to increase the credibility and thereby the support of the services. Another outcome of the research confirms that the dependency on the therapist does not change with the number of enrollment in an aftercare facility. The research results show that the therapist is a key element in an aftercare facility for the clients and this fact does not change during the aftercare treatment. Finally, the research looks at whether there is a connection between an assessment of the services of an aftercare facility and their importance and education and place of residence of the clients. No significant differences between the mentioned characteristics were noted.

Research no. 4: The quality of life in aftercare programmes clients as viewed by the staff (Růžička, Hutyrová, 2013)

This research examined the views of aftercare centres staff on four criteria of life quality in clients. These are housing, work, relationships and leisure time. The results show that the management of sheltered housing should be the responsibility of the provider with one appointed client. This is a policy frequently used in practice.

It is interesting to note that despite the impacts of economic crisis the clients have expectation of employment and many are able to find and keep a job. As regards to the relationships the clients aim to establish a long-term relationship. A new stable partner is often a motivational element for a new life without drugs.

The responses in regards to the leisure time vary significantly. This topic is very popular and it seems that clients coming from communities are more successful in planning their leisure time than clients released from psychiatric hospitals. The respondents agree that the quality of leisure time is proportional to the success of abstinence. Many aftercare programmes support this and guide the clients towards many different activities like hiking, water sports, arts etc.

The results of the research realised at our department correspond with the results of international research and clearly show the importance and impact of aftercare. For this reason we consider it beneficial to apply the principles of aftercare to the area of institutional education.

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Research on family factors and support of children with cerebral palsy

(scientific paper)

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Abstract: *Families are not only the main living area for such children with cerebral palsy but also their most reliable spiritual home. During the long-term care process, family members, especially those main caregivers are under diverse great pressure, the primary aim of this study was to examine family factors and support strategies used. Data regarding situation of children with cerebral palsy and their family factors were obtained from patient records. Results indicated that family coping styles associate with family factors and spiritual support was among the family coping strategies used most often. Not surprisingly social support was used least often, caregivers tended to seek out internal support (e. g. support from the extended family). Findings suggest the necessity to target policy makers, community supports, and attitude towards family rehabilitation. In the long run, to meet diversified needs of the child and their families, it's necessary to provide support services for the aim of enhancing children and parents' self-help ability.*

Key words: *Family factors; Family support; School adjustment; Child characteristics*

Introduction

According to the report of Chinese cerebral palsy net, the incidence rate in China was 1.8–4 ‰, an average of 3.25 ‰ among surviving infants in 2011. There are more than 6,000,000 patients with cerebral palsy (CP), the number annually increases with 4 to 5 million newborn infants. Adolescents account for more than 60 %, including at least 500,000 school-age children. Moreover, 70 % of these children lived in poverty. Families of children with CP are faced with various stressors stemming from daily care of rehabilitation and psychosocial challenges. The way families cope with these challenges can impact their physical and psychological well-being.

The field of cerebral palsy has a long history of observing and describing the medical techniques, the majority of literature on coping in families of children with cerebral palsy comes from medical rehabilitation other than family factors themselves or supports they used. The study assessing family functioning obtains information from primary caregivers in the family, which assumes that the primary caregiver brought more influence than other family members.

Methodology

This descriptive study utilized data from multiple sources to gain a picture of family factors and support of children with CP, the author designed questionnaire for families with CP, and had face to face interviews with primary caregivers. Questionnaires were completed by the primary caregiver who generally spent the most time with the child (one of them was a hired nanny). A total of 14 families were contacted as respondents for the survey in Rehabilitation Center, the Disabled Federation of Sichuan Province, China. In these cases, the separate interview responses were compared, and respondents were re-contacted to clarify any discrepancies in the questionnaire provided.

Quantitative and qualitative data analysis techniques were used to extract themes. For the quantitative analysis, respondents were asked about research process of diagnosis, degree of illness and impact on families, as well as family coping styles and support used etc.

Qualitative analytic methods were used to analyze responses to the standard interview. The research team studied the interview responses carefully, looking for emerging themes of family factors and categories of support. A coding system was developed, and sound recording data were sorted according to "families of codes" (Bogdan & Biklen, 1998). The research team, together with respondents through focus group, discussed recommendations to guide future family coping and support development work.

Findings

Children characteristics in different families

No caregivers in the fourteen families refused to participate at the time of their children's home rehabilitation. Thus, the total sample consisted of 14 families of children with CP range in age from 2 to 6 years. There are 9 in the class for younger children (mean age-3.5 years), 5 in the class for the elder (mean age-5.4 years). Just over half of the children were female (57.14%), male (42.86%). Significant relationships between parental and child coping have been found for both girls and boys (Kliewer

& Lewis, 1995), and among various illness groups (Brown et al., 1993; Kupst et al., 1995). Eleven children were born in the one-child family (78.57 %), another male and other females were not (21.43 %).

One significant question for the research was the age extent of children, family coping strategies and supports used discussing later might differ from each other because different age of definite diagnosis (see Table 1).

Table 1: Age of definite diagnosis

Age (month)	Frequency	Percentage (%)	Accumulative (%)
Several days after birth	1	7.1	7.1
1	1	7.1	14.3
3	1	7.1	21.4
7	1	7.1	28.5
8	1	7.1	35.6
12	2	14.3	49.8
13	1	7.1	56.9
14	1	7.1	64.0
15	1	7.1	71.1
16	1	7.1	78.2
18	1	7.1	85.3
26	1	7.1	92.4
Uncertain	1	7.1	99.5
Total	14	100	Mean age = 11.08

As shown in Table 1, most children with CP were diagnosed before one year old (50 %), other got diagnosis before two years old (99 %). Such children have been in the rehabilitation center for training ranging in time from 1 month to 36 months (mean time-10.6 months). From the first day of the child, parents observed the change of children day by day, they took care of them carefully and noticed changes including twisting, sitting or crawling. Parents are the main original power to take children to the hospital while they noticed children's any abnormal behavior.

Table 2: Types and pathogeny of ceberal palsy

Sample	Pathogeny									Types
	Premature delivery	Dystocia	Asphyxia	Icterus	Low body weight	Hyperpyrexia	Multiple labor	Encephalic	Other	
1			√							Convulsion
2									Unclear	Synthesis
3								√		Convulsion
4	√									Synthesis
5	√									Convulsion
6				√						Ataxia
7	√				√					Low tension
8									Unclear	Low tension
9									Unclear	Convulsion
10		√								Convulsion
11				√						Athetosis
12			√							Convulsion
13	√		√				√			Convulsion
14	√									Synthesis

Table 2 summarizes the main pathogeny and types of the children with CP. Just 35.71 % children's illness were caused by premature delivery, followed by 21.43 % were caused by asphyxia, 14.29 % were caused by icterus. Cerebral palsy may results from many reasons like deprival of oxygen, cerebral hemorrhage, toxicosis or traumatic brain injury. According to intelligence test, the average intelligence quotient of children with CP is lower than that of common people.

Family characteristics

To understand the family situation and supports used, it is necessary to examine the nature of family as a system. Some evidence suggests that family factors associate with patterns of family coping. Take Brazil & Krueger as an example, they did research on one-versus two-parent homes (2002). So does to the relationship of the caregiver, the biological versus alternative caregivers with the child (Rose & Clark-Alexander, 1998).

Table 3: Primary caregivers of children

Frequence	People	Percentage (%)
6	Parents	42.86
2	Parents and father's mother	14.29
1	Parents and father's parents	7.14
1	Parents and four grandparents	7.14
2	Mother	14.29
2	Father and father's parents	14.29

Background data were obtained through questionnaire at the on-study evaluation. Caregivers provided information on family environment factors including composition of the family (see Table 4), relationship of the child with the primary caregiver (biological, adoptive, foster, extended family). Since no family fell into the categories of foster parent family, we discussed two groups: biological versus extended family. Researchers have examined the primary caregiver the children lived with, as shown in Table 3, about 71.4 % children live with parents. About 28.5 % children live with grandparents. The percentage of children who live in the core family is 42.8 %, and the percentage of children who live in the reorganized or separated family is 7.1 %. Twelve of the main caregivers are female, seven of them are mothers, four of them are grandparents, and a nanny living in. Four of the main caregivers are male, two of them are fathers, and another two are fathers' fathers. Primary caregivers' mean year of education (8.3 years) is lower than that of parents (12.8 years).

More data indicates parents' characteristics of age as well as occupation. The youngest mother is twenty-eight years old, the oldest is thirty-four (mean age – 30.5). Nine of them have no career, another two mothers are farmers and three are workers. As to the father, the youngest is thirty years old, the oldest one is thirty-six (mean age – 32.4). Ten of them are workers, three are farmers, and one father carries on inoccupation. All parents are educated, however only 14.2 % graduated from university. Others are high school graduates (43 %) and primary school graduates (42.8 %).

The disease of CP influenced a small number of parents' marital status and most primary caregivers' personal relationship. In reverse, certain family environment factors have been found to influence child coping styles, such as parental supportiveness and the level of structure and organization within the home (Hardy et al., 1993).

Table 4: Marital status of parents

Marriage	Frequency	Percentage (%)	Accumulative (%)
Harmonious	2	14.30	14.30
Normal	9	64.30	78.60
Unharmonious	2	14.30	92.90
Separate	1	7.10	100.00
Divorced	0	0.00	100.00
Total	14	100.00	100.00

The primary caregivers gave response to relativity between children with CP and marital status in interviews actively. They assessed whether there was correlation between sample parents' marital status and children's CP illness by five-point scale (1 – strongly disagree, 5 – strongly agree). Good reliability and validity have been received. Two-parent homes are common, there isn't single-parent home, but one couple may agree to divorce each other after a long separation.

Family coping and support

Since a limited amount of research has suggested associations between coping and family factors, exploratory analyses will be conducted to assess relationships among these variables.

Conceptualizing coping strategies refers to passive and active techniques. When a person relinquishes control of a problem to others, passive coping techniques occur, while active coping involves an attempt to take a more active role in dealing with a problem (Brown & Nicassio, 1987). Research has demonstrated that use of denial is associated with more negative emotional impact at children with traumatic brain injury (Wade et al., 2001), suggesting that families' use of various coping strategies may influence the emotional burden of paediatric injuries.

To understand the effects that specific strategies can have on one's ability to cope with illness related stressors, past several studies have compared the effectiveness of passive versus active styles of coping. Most found little support for passive techniques with respect to physical and psychological outcomes.

Researchers did a survey of caregivers' friendly intercourse. Six caregivers usually asked help from extended family, three caregivers had good relationship with neighbors, two caregivers kept contact with friends. Table 5 illustrates primary caregivers' contact with family, specialists, friends and others, differentiating the emotion-focused support versus time-focused support.

Table 5: Primary caregivers' intercourse status

Types	Examples	Frequency	Percentage (%)
Kinfolks	Siblings	12	86
Specialists	Teachers in rehabilitation center	9	64
Others	Neighbors	5	36
Friends	Colleagues	4	29

Emotion-focused (Lazarus & Folkman, 1984) support occurs when an individual believes that nothing can be done to change the situation at the beginning of diagnosis and depresses under higher levels of distress during the long time of caring. Time-focused support is used when an individual views a stressful situation as amenable to take care of children.

To our knowledge, most support for family is associated with decreased emotional distress. Our study has specifically examined various rehabilitation or medical techniques among children with CP, and findings indicated that more serious degree of CP experienced more psychological distress than others. Combined emotion- and time-focused support, the primary caregiver have received assistance from different number of people (see Table 6).

Table 6: Number of people offering help

Number of people	Frequency	Percentage (%)	Accumulative (%)
0	2	14.30	14.30
1	1	7.10	21.40
2	3	21.40	42.80
3	3	21.40	64.20
4	1	7.10	71.30
5	2	14.30	85.60
8	1	7.10	92.70
Invalidation	1	7.10	92.70
Total	14	100.00	92.70

Checking the list of offering help, caregivers' parents are the most helpful ones (35.7 %), spouses' parents rank number two (22.3 %). Nurturing a child with CP is a great challenge including stress from psychology, spirit, and economy etc.

School-age children with CP in these cases did not go to school, thus, their expenses relate to daily expense, medical and rehabilitation fee. Three families (25 %) come from counties, and nine (75 %) are from countries. The lowest monthly family income is 1,500 RMB (215 US dollar), the highest is 8000 RMB (1143 US dollar). The family income averages 4278 RMB (611 US dollar) a month. With the rocketing up of consumer price index in China, more than 80 % respondents strongly agree with the heaviest burden for the family resulting from economy.

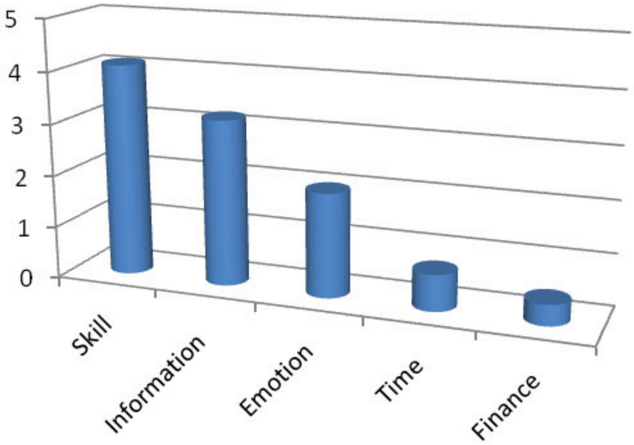

Figure 1: Types of social support

Among families of children with CP, it's obviously that social support as a means of coping is much less than the family self-support. (e. g. spiritual support from extended family). The lack of social support among illness populations is not a new finding, nor is it unique to individuals with CP. The research has demonstrated that children with chronic conditions report lower perceptions of support and smaller support networks than healthy children, and perceptions of social support may vary between illness groups (Ellerton et al., 1996). Classifying social support is apparent as shown in Figure 1, caregivers rated scores for some kinds of actual support like skills for rehabilitation from members of the medical team and information from mental health counselors or governmental offices etc. received. Study suggested that a considerable portion of caregivers spending little or no time socializing with friends and that lower perceptions of social support are associated with feeling. The child or the family's economy needs are far beyond the welfare financial support.

Respondents recalled the days when they knew the illness of children and described their feeling by many negative words such as "worry, fear, rage, self-accusation, sin" and hence. A feeling of utter helplessness washed over every family member. Comparing with emotional burden among them in the early days of diagnosis, caregivers felt more peaceful at present (see Figure 2).

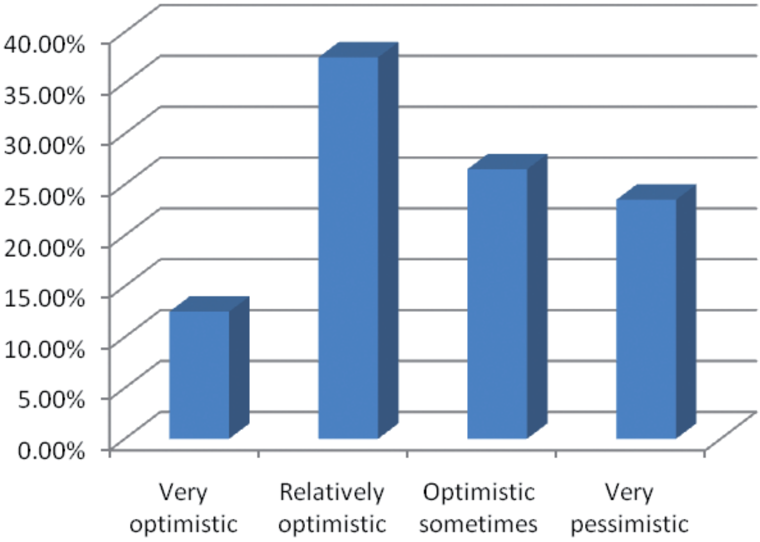

Figure 2: Primary caregivers' mentation

During the time of parenting the child with CP, some families at present are characterized by close relationship and mutual support, but without any self-help organization for caregivers or parents. The research demonstrated that both the degree of altruism and tolerance toward difference increased, they tend to offer more help than before. For the very pessimistic caregiver, a sense of fatigue for a long time and deteriorating economic status washed them over because of the child's illness.

Discussion

This finding did not reach specific statistical significance in regional difference of family. This may be partly due to the fact of the limitation of a small sample. While previous studies have examined family variables as they relate to coping in the individual with the illness, whereas this study assesses coping in the family. It's necessary because economic status here may differ from there, one hypothesis of which is associated with social support from local governments. Another possibility is that the physical and emotional impact of their own disease makes it difficult for caregivers to obtain appropriate support services for their child. Follow-up research is needed to compare economic status of families from different districts. Further studies should also be needed for the impact of parents' unemployment and economic stress on social support.

Families who use passive coping may feel helpless regarding to their ability. Those families may relinquish control of decisions about the child's disease to others, such as the medical team, rather than worry about these problems themselves. This may be helpful in some situations, but could potentially lead to problems if caregivers are not independent.

Active coping strategies positively impact the child's medical status and the family. Items about passive coping styles in questionnaire reflect an avoidance of problem situations or the tendency to relinquish control of one's problems to others.

We failed to find significant relationships between characteristics of the maternal caregiver and family coping styles. However, many studies have put forth evidence that family composition (two-parent families versus single-parent families) is related to coping styles. Moreover, past research with healthy families has found that single mothers use more strategies related to accepting responsibility compared with mothers in two-parent families (Compas & Williams, 1990).

The external support most frequently endorsed by families in our study included actual and spiritual support. Means of actual support mainly relates to medical skill, information and financial way, spiritual support is associated with time and emotion. The spiritual dimension is important for families' quality of life and its implications for caring practice. The data indicated that caregivers tended to seek out help from the extended family or friends for spiritual support. Comparing with developed countries, social welfare policy needs to be advanced for servicing children with special needs and their families in parts of China. The finding demonstrated that families of children with CP or primary caregivers tended to seek out less support from community resources than extended families. The support resources should be enlarged including community support. To make full use of community resource, promoting community involvement aimed at respecting and supporting the family of children with CP. Moreover, exploratory analyses revealed the necessity to advocate lifelong family rehabilitation for children with CP.

Given that social support can be a valuable resource in maintaining the emotional health of families dealing with chronic illness (Neville, 1998), it is concerning that families of children with CP are not relying on social resources more often. While this is certainly a valid concern, the absence of external support could negatively affect psychological and physical well-being. Thus, there is a need for interventions aimed at helping caregivers effectively seek out and utilize supportive social relationships. In addition, it's important in the long run to improve the ability for the family taking an active role in overseeing their child's development.

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Communication in students with severe cerebral palsy

(scientific paper)

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Abstract: *This paper deals with the communication process in students with severe cerebral palsy in whom there is a combination of severe mental, communicational and physical disability. It defines the basic terminology, some core concepts and describes selected findings of a qualitative study based on open, axial and selective coding. This paper describes the main categories and subcategories of the study regarding communication reactions of students, communicational topics and some of the factors that enhance good interpretation of the communication process. It also incorporates a visual diagram of a model for communication processes between teacher and student and discusses various aspects of this model, suggestions for special education practice and for further research.*

Key words: *cerebral palsy, communication, open-axis coding, axial coding, teacher's authenticity*

1 Introduction to the Issue

Cerebral palsy (CP) is a complex functional disorder that impacts many important daily activities. In the field of rehabilitation the aspects of functional health are increasingly being emphasised in defining CP while clinical characteristics of the disorder move to the background. For example Ashwal defines CP as "a group of non-progressive non-communicable neurologic conditions causing physical and cognitive disabilities during the development of an individual and disrupting functional performance, participation, mobility, muscle strength, postural functions, muscle tonus, feelings, visual functions, perception, communication and behaviour" (Ashwal, in Phipps, Roberts, 2012, pp. 422).

In this study we will address the communication process in students with severe cerebral palsy. Some conclusions of a research undertaken in students with severe limitations of movement, mental functions and communication will be presented. These students are not able to use verbal speech to communicate. According to empirical findings from pedagogic practice there is also a very little possibility to use standardised systems of alternative and augmentative communication (AAC) in these cases. Therefore a question arises: “How do teachers communicate with these students in the course of an educational process?” Communication processes in these students are still insufficiently explored. We will attempt in this study to provide at least a partial answer to the above stated question.

In research of communication between the teacher and the student with severe CP focus must be directed at communication as a complex social activity that has multiple purposes for social interaction. It must be remembered that, because of their congenital disorder, these students never experience natural communication with others and therefore cannot build on normal developmental experiences. A wholesome view of the communication process does not focus solely on the form of verbal speech substitute but also on the context of communication, communication needs of the individual, the process of interaction itself as well as its course, cognitive processes of both parties in communication or the possibility of interdisciplinary cooperation in creation of appropriate means of AAC. Because of the broadness of the problem, in this paper, we can only touch upon the themes. Some of the themes are mentioned in discussion as suggestions for further research in the field.

2 Basic terminology

Various scholarly sources use different terminology in the context of communication. We will offer definitions of the terminology used in the paper for analysing the communication process.

Communication partners

By communication partners are meant the teacher and the student with severe CP. Each one is characteristic for having previous experiences that are being brought into the interaction, as well as personality traits, needs, interests, motivation, beliefs, current emotional state, social roles and status, age, gender or a position of superiority that may be used in the interaction, to name just a few characteristics.

The issue of communication needs of a student with severe CP needs to be addressed in more detail. It is because assumptions about communication content in these students cannot be made from the communication subjects of healthy peers. Some contributions on functional communication of students introduce useful techniques stimulating thoughts on the identification of relevant communication content (Bigge, Best, Heller, 2010). These techniques are especially useful in students with higher functional level of mental abilities or in students with disability that occurred in a later age. Thorova (2006) mentions communication content in relation to the communication of students with autism spectrum disorders. She considers as relevant subjects for example the expression of agreement and disagreement, request for food, drink, favourite object, using the toilet or getting help, expression of "more" and "enough", calling for attention, signalising an object or activity, commenting an activity, expression of feelings, acquiring information or polite phrases in social communication (Thorova, 2006). The specificity of the functional state in early brain lesions, however, does not allow for drawing comparisons between communication needs in students with CP and students with autism spectrum disorders although there may be certain similarities.

Communication Environment

Communication environment is the physical surroundings in which the interaction takes place and includes for example lighting, the order of objects in the room, the presence of other people, odours, sounds, etc. Communication environment co-creates a particular atmosphere that influences the communication partners. In analyses about communication **the psychosocial element of educational setting** needs to be examined. Scholarly sources differentiate between the school climate, classroom climate and classroom atmosphere. We may also find the term social climate (Allodi, 2008). The classroom atmosphere especially influences existing communication. In practice we may observe situations when teacher's lack of concentration causes a rising anxiety in the student. As a result the student may become close and lose motivation to enter into communication.

The influence of the school environment on the specifics of communication needs must also be considered. Some teachers say that given the regular and sufficient food intake during the day it is of little functional use for the students to be able to ask for food or drink. This need, however, is in the specific training methodologies of AAC classified as the most frequently used antecedents for increasing the student's motivation to communicate (Knapcová, 2009, Richman, 1999). It is evident that the communication needs of students in the school environment may differ from the needs in the home or other environment. It is necessary to examine them separately, in close relation to educational and social situations during the class. In this area we also lack relevant data.

Context of Interaction

The context of interaction is the overall framework in which the interaction takes place. It includes connection to previous and following events to the interaction time, the way of achieving mutual understanding, the social roles of communication partners, etc. The context is very important to the communication partners of the students in terms of understanding communication intentions because teachers interpret a large section of non-verbal signals of students on the basis of the context in which these signals happens. Majority of publications and research about the communication processes in students with CP have until present focused on one of the specific issues. Context is very difficult to study because it involves a great variety of different contextual situations. Its analysis, however, is crucial for a comprehensive understanding of the communication process.

Communication Channel

The communication channel is a means for transmitting information between the subjects, a means of mutual communication. In-person communication includes verbal and non-verbal means of communication. In this connection there exist many standardised as well as non-standardised **systems of alternative communication**. International Society for Augmentative and Alternative Communication (ISAAC) defines AAC as: “A set of tools and strategies that an individual uses to solve everyday communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message.” (Burkhart, cit. 20. 3. 2013)

The conclusions of some research projects (Jelinkova, 2013) that analysed communication means in students with severe multiple disabilities show that the most frequently used means do not correlate with information about the usability of the AAC systems in domestic and foreign scholarly literature. To state one example the communication system Bliss or the Dosa method is frequently cited in scholarly literature. Neither of these systems is being used in practice although both are interesting contributions to the AAC issue. Other communication systems on the other hand are not adequately described yet because they emerged from modern innovations in electronics (for example the possibilities of using tablets).

Students with the most severe functional limitations in all of these three areas—communication, movement and mental functions—pose the biggest problem for the creation of an adequate communication system. In research to be presented below, we have divided this group of students into two groups:

- Students that are able to communicate at the level of expressing the communication intent (at least in the form of expressing yes and no) – in these students the common system AAC is more likely to be successful (ETRAN, referential objects, pictures etc).
- Students that spontaneously express likes and dislikes which is the base for teacher's understanding – here the spontaneous non-verbal reactions of the student are the basic communication means.

Non-verbal communication may be divided according to the usage of body, time and space means. Commonly, these types are recognised in healthy persons: facial expression, gestures, haptics, proxemics and communication by action (Vybiral, Roubal et al., 2010). In students with severe CP we lack the description of relevant non-verbal signals that the teachers use for interpreting the communication intents of the students.

Feedback

Feedback is the response of the communication partner or feedback to what we communicate through what we say, hear, see, feel, etc. When interpreting feedback many errors may occur since a variety of communication noises interferes in communication between a teacher and a student with severe multiple disabilities and these noises disrupt the interaction process. De Vito (2008) distinguishes noise physical, physiological, psychological and semantic. Examples from teaching experience show that new teachers often tend to underestimate the ability of the student to perceive stimuli and activity around. Because of lack of communication responses these teachers conclude a lower level of sensory-cognitive processes which can have serious consequences for the student manifested for example as the elimination of teacher's attempts for interaction.

In the following chapters we will offer a description of the research undertaken as part of dissertation work called "Educational outputs in the area of social abilities in children with cerebral palsy" and which was further elaborated on in a specialised research of IGA. We will summarise the most important findings concerning communication and offer conclusions that can be used for further examination of the described problematic areas.

3 Research Aims and Research Sample

The research aims concerned these areas:

- An examination of communication channels in students with severe CP who communicate on the level of spontaneous expression of likes and dislikes.
- An understanding of communication needs of these students.
- Understanding factors that help teachers interpret the communication signals of students.
- Relation between communication and other categories of the education process.

A qualitative methodology was used to answer these aims. Extensive data was collected about various aspects of the education process in students with severe CP from 45 semi-structured interviews with teachers, an analysis of pedagogic documentation (30 verbal assessments and 30 individual educational plans) and observations of the educational process of four students. Teachers were included in the research sample based on these criteria:

- The teacher has got a minimum of Bachelor Degree in Special Pedagogy.
- The teacher has got experience with education of students with severe CP for minimum of 2 years (2 years is, in our opinion, considered as an adequate time to create a firm relationship between teacher and the student and to get a deeper knowledge of the personality of the student).
- The teacher is willing to offer the interview or to give the student's documentation for viewing.
- The teacher is able to reflect on his work.

The following criteria were used to include students to the research sample: the student is diagnosed with CP, and has got a severe physical disability (inability of independent movement, severe limitation in self-care) and severe impairment of communication abilities (verbal communication only at the level of sounds or few words) and severe or profound intellectual disability and the student does not suffer from deaf-blindness. The data was categorised by various sources, converted into text and prepared for qualitative analysis.

4 Conclusions Based on Open-Axis Coding

Data analysis was done using open axial and selective coding based on the procedure described by Straus and Corbin (1999). Using open coding basic categories and subcategories relating to the educational process were created and divided into several groups:

- The purpose of education and educational needs of the student.
- The facilitators of interaction between teacher and student.
- The tools supporting understanding of the student.
- The specifics of communication between teacher and student.
- The statements about the student's personality.
- Procedural and methodological aspects of the educational process.
- The benefits and difficulties of teachers.
- Within the group concerning the specifics of communication between the teacher and the student the following categories were distinguished:
- Communication reactions of students.
- Interpretation of communication reactions of students.
- Communication subjects of the students.

Communication Reactions of Students

Communication reactions of students derived from the likes were designated as positive communication reactions and those derived from the dislikes as negative communication reactions. Furthermore, we divided the communication reactions according to the means of expression that was used into locomotive, facial, vocal, vegetative, other, unspecified reactions and reactions with a concrete communication intent (only in the last category it is possible to accurately interpret specific communication intent of the student). These reactions are described in Fig. 1.

Some communication reactions such as agitation or vegetative symptoms may have its source in both likes and dislikes which can usually only be recognised based on the context of the situation and other non-verbal signals of the student, such as facial expressions. Further examination is necessary in these cases based on the context of the situation.

When describing specific vocal expressions we realised an adequate terminology has not been created, a terminology that would enable a description of subtle differences between various vocal expressions of the students. To state just one example, Krejčířová and Langmeier (1998) describe the different types of cry in newborns. There is evidence that mothers very quickly learn to recognise the different types of cry – the cry expressing pain, hunger, the cry that aims to call the attention of an adult, etc. However, specific terms for these different types of cry have not yet been created. The situation is even more difficult in students with severe CP. We think that the range of vocal expressions could be even wider because the personality of students is more complex and they are older than in the case of newborns or infants.

Communication Reactions:	Examples:
Negative Locomotive Reactions:	Motor agitation, touching the abdomen, forward bending, fidgeting, attempting to beat the teacher, banging one's head, turning away, pushing something away, unusual movements, slouching, etc.
Positive Locomotive Reactions:	Rocking, tilting the body, waving arms, clapping, fidgeting, turning around, flapping arms, etc.
Negative Facial Reactions:	Frowning, grimacing and stiffening of the face.
Negative Vocal Reactions:	Snarling, growling, whooping, whining, or braying.
Positive Vocal Reacions:	Humming, munching, repeating a word, for example "hello", and crowing.
Vegetative Symptoms:	Changes of sweating, changes of breathing, of temperature, of salivation, narrowing or widening of pupils, etc.
Other Communication Reactions:	The pupil becomes more alert, pupil is silent and calm expressing agreement or does not react which expresses disagreement.
Unspecified Communication Reactions:	All reactions to which teachers are not able to ascribe any particular communication meaning at that moment.
Reacions with a Concrete Communication Intent:	Pointing at a desired object, making a choice by a look and "ear rubbing" to express the desire to sleep.

Fig. 1: Communication Reactions of Students

When analysing the data in this category we encountered a new way of communication which was independently reported by several teachers. We called this type of communication the Sight Communication. It must be distinguished from the methods of making choices based on the look or blink of students which is commonly described in scholarly literature (Bigge, Best, Heller 2010, Jedlička, Škodová, 2003). During the sight communication teachers visually recognise emotions currently experienced by students from the look in their eyes. One of the teachers stated that she could see glimpses of fear or joy in the look of the student. We are convinced that this form of communication requires a high level of sensitivity, intuition and an ability to connect on the part of the teachers. It remains unclear whether this is only a one-way communication (from student to teacher), or the student reacts in some way (even if only subconsciously) to the connection established with the teacher during their interaction.

Interpretation of Communication Reactions of Students

Another category explores the possibilities of interpretation of communication reactions of students. The data collected in this category is rather scarce. According to the experience of the teachers the ability to interpret non-verbal signals is enhanced through:

- intuition and sensitivity of the teacher;
- good observation skills;
- focus on para-verbal components of student's voice (intonation, emotional tone of voice, etc.);
- ability to differentiate between muscle spasm and deliberate resistance of movement;
- conversations with parents and using their experience; and
- observations of communication between the student and his or her parents.

The teachers emphasised that it is only possible to interpret communication expressions, especially the locomotive and facial expressions, based on good knowledge of the student.

Communication Subjects of the Students

In the third category we explored the communication subjects of the students. These are the most frequent subjects:
- expressing likes and dislikes and statements like "I want" or "I don't want" or "Yes" and "No";
- sharing experiences;
- choosing a meal;
- expressing physiologic needs like changing one's position;
- describing what is happening or what will be happening;
- communication about family, shopping, sports, travel or a pet of the student;
- expressing a desire for interaction or a desire to say something;
- expressing that the person should leave or that the presence of the person is welcome;
- student insists on something;
- expressing a desire to share feelings or that something is troubling him or her;
- expressing a desire to go out, play or listen to music; and
- a female student expressing that she likes a boy.

Ideas from Other Groups of Data and Categories

From among other groups of data that concerned various aspects of the educational process these categories and subcategories were stimulating in regards to communication:
- In the group the **Purpose of education and educational needs of the student** the teachers considered communication to be very important (22 statements were about communication). Respective subcategories included expression of communicational needs, training for using the AAC system, training eye contact and

other communicational skills, initiation of communication, motivation for communication and so forth.

- In the group **Facilitators of interaction between teacher and student** we obtained data regarding favourite stimuli of students. A separate category was identified, called 'Speech and stimuli connected with verbal communication created a separate category' (30 statements were in this category). In the subcategories there were speech and talking between teacher and student, voice and its paraverbal expressions, appreciation and praise, nursery rhymes and word rhythmisation, reading and story-telling.
- In the group **Procedural and methodological aspects of the educational process** subcategory called 'commenting as specific educational strategy' was created. We will address the issue of commenting in regards to the communication process later in the paper.

5 Conclusions Based on Axial and Selective Coding

In the next phase of qualitative analysis, we categorized the set categories and subcategories into four groups – input determinants, the process itself, outputs and the context of the educational process. 12 lines of special educational intervention were identified by observing the relationship between these categories across the inputs, the process and the outputs of education and by searching for hypothetical links between them, while one of the lines concerned communication. In further analysis of the collected data we selected, for each line, the main categories and created models of the respective lines. These models were then subjected to a critical view of colleagues in the workplace and several teachers from practice. There is a visual diagram of the final model concerning communication (Fig. 2).

This model shows communication in relation to important categories of the educational process. It attempts to portray the communication process between a teacher and a student as various social activities that are influenced by a variety of factors. We shall address some of the aspects and connections in this model in the following text.

6 Interpretation and Discussion

When interpreting the findings relating to the communication process we focused primarily on factors that help facilitate communication between teacher and student. We believe these factors offer inspiring conclusions for special educational theory and practice. When looking at the communication process diagram it must be remembered that it is a hypothetical model. We expect that its further study and critical reflection by practicing teachers will enable its further elaboration. At this

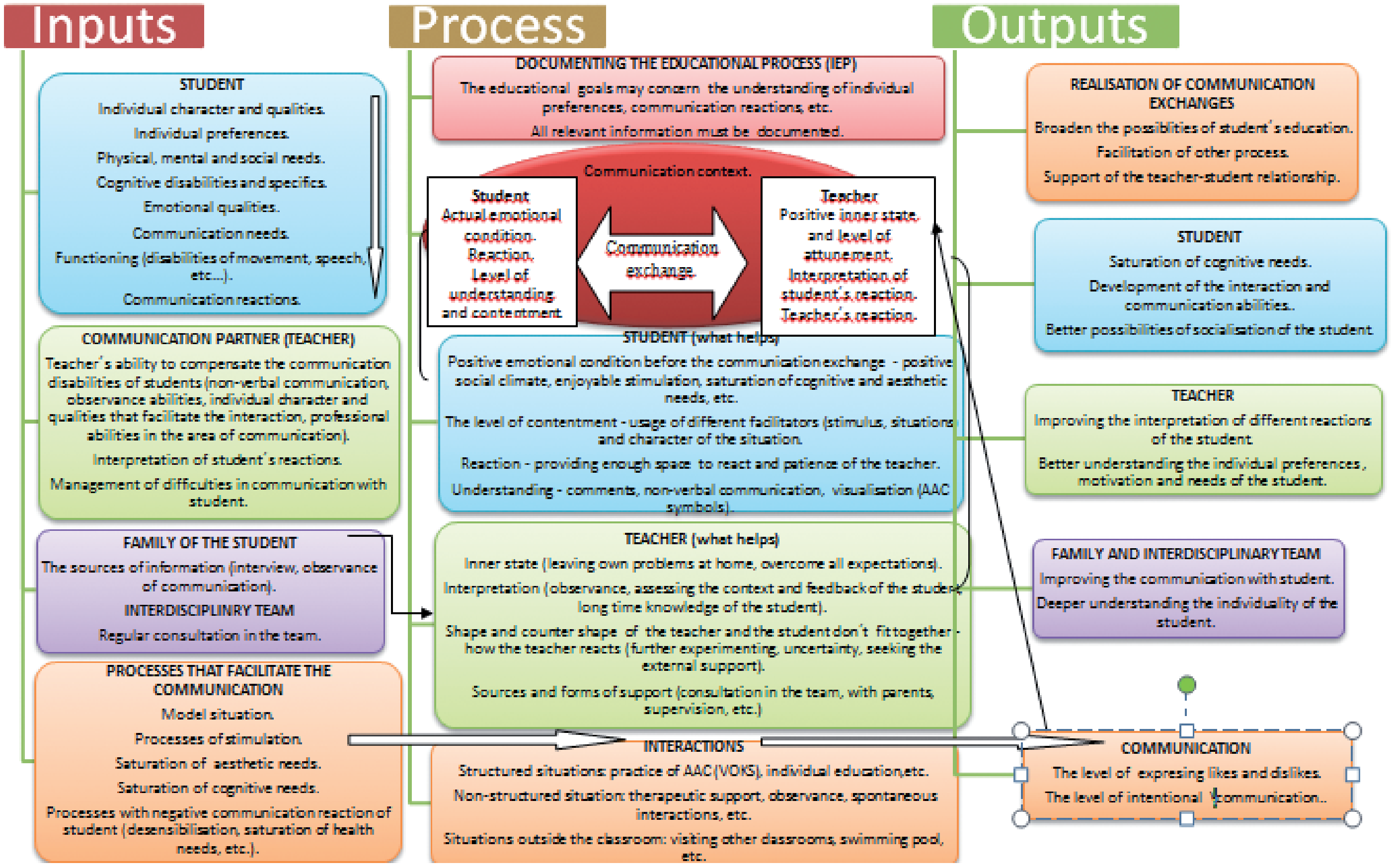

Fig. 2: Communication process

time when this model has no other alternative we offer it as a temporary theoretical construct with possible applications in the educational process. Below we will discuss some elements in the categories.

Communication Reactions in Students

When interpreting the findings in Fig. 1 we encountered several fundamental problems: a more extensive set of data would be required to describe and classify communication reactions of students as well as more intensive work on video recordings, while these would need to capture more concrete communication reactions. As already stated, for the description of subtle differences between vocal reactions of the students it would be useful to create specific terminology. In the previous chapter we described also some specific ways of communication between teacher and student, such as sight communication. This type of communication leads to a number of other questions regarding many specific aspects of the process of synchrony in interaction between teacher and student, the process of creating a connection with the student and the question of physiologic and mental parameters based on which teachers interpret the inner mental state of the student. Further studies will no doubt offer more extensive data than the current few case studies. If these collected data find confirmation within a larger sample it would be beneficial to design a neuropsychological research using imaging techniques in this area.

Observation of Interactions between Student and Primary Care-Giver

Based on the statements of teachers it seems that each student enters the educational process with pre-formed skills for at least some form of basic communication. Several teachers stated that in the beginning it is important to observe the interaction between the primary care-giver—most often the mother—and her child, since every mother is able to interpret certain communication signals of her child and respond adequately, although on a subconscious level. The possibility of observing the interactions between the student and his or her primary care-giver is, from our experience, not given sufficient attention in special education practice. We believe that observation of these interactions could be a common part of the first special education diagnostics because of its value in students with severe CP.

Synchrony in Interactions between Teacher and Student

Research concerning the synchrony between communication partners during their interaction uses terms such as ‘rhythmic’ or ‘interactive dance’ to describe such interactions (Condon, in Moreno, 2005). It is apparent that aspects of rhythm and tempo play an important role in communication. Communication of students with severe CP often has a very slow tempo and a specific rhythm. The teacher must also leave enough space for the reaction of the student. The reactive time of students is extremely long compared to common tempo in interactions and this requires great patience on the part of the teacher.

It seems that it is the teacher's adjustment to the slow tempo and the synchronisation with non-verbal reactions of the student is a very important ability for the realisation of effective communication. There is no doubt that the synchrony occurs on multiple levels simultaneously: physiological, energy level, motor, emotional, etc. Further research in this area could focus on determining whether the conscious focus of teachers and intentional synchronisation with the tempo and rhythm of motor manifestations of the student can improve synchrony in interaction, increase the level of mutual harmony and make the communication process more efficient.

Communication Subjects and the Students' Psychosocial Needs

The conclusions regarding the communicational needs of students will also have to be supported by further research. Analysis of communication subjects of the students and observations of the communication process shows that communication needs of the students are often closely related to the saturation of their physical, mental and social needs. Also, analysis of the facilitators of social interaction between teacher and student supports that the presence of the teacher is a sufficient motivation for students to make attempts for initiation of communication or respond to the stimuli coming from the teacher, especially when the teacher appreciates the student or show positive attitude towards him or her. The teachers' statements suggest that students with severe CP are highly likely to develop mental or social deprivation. On the other hand, however, the frustration of these students caused by insufficient saturation of psychosocial needs may be used in a positive way. In the educational process these may become a significant motivating factor for the realisation of communication and interaction. The students' achievements in the field of communication were highest in those educational situations in this research that were based on a long-term, safe and emotionally warm relationship between the teacher and the student.

Using Enjoyable Stimuli

For initiation of communication teachers mostly use those stimuli and situations that the student considers enjoyable. These stimuli are often applied within aesthetic and stimulating processes for example as part of music education, basal stimulation, in Multi-Sensory Room, etc. However, the analysis of other communication processes shows that many activities that the student considers extremely unpleasant also initiate communicational reactions as is the case in desensitisation to unpleasant stimuli (noise, unknown persons). These stimuli may initiate communication reactions very fast. They are connected with stress, though, and frequent occurrence contains the risk of negatively influencing the development of relationship between teacher and student.

Inner State of Communication Partners and Teacher's Authenticity

Several important recommendations for effective communication emerged from the analysis of an inner state of both teacher and student. Both communication partners are significantly affected by classroom climate. Teachers who work with students with severe multiple disabilities often report that their basic strategy in education is to create a positive climate in the group (Kantor, 2013). Positive emotional climate is continuously maintained and intentionally encouraged whenever difficulties occur. According to Allodi (2008) positive emotional experience is the most important requirement for teaching students with severe multiple disabilities. Some teachers in our study reported that they seek those situations for interaction with students in which the teachers feel comfortable. Those are for example situations during music therapy, basal stimulation, Snoezelen and other therapeutic and stimulating activities.

An important role of communication between teacher and student is sharing positive emotional content. This can only occur on a non-verbal level, without the need for verbal expression of the content. Teachers often expressed in interviews that in this type of communication with students they feel comfortable. However, there are certain obstacles for the teacher for achieving the necessary inner state for this type of interaction. Teachers believe that when they let themselves be stressed by their own problems they are not able to fully participate in the communication process and their emotional state has a negative influence. A similar situation occurs when the teacher is unable to accept the student, finds him or her repulsive or is not interested in him or her.

During the course of the research, however, a different perspective on the subject of inner state of communication partners started to emerge from the experience of the teachers. One respondent mentioned a situation where a female student exhibited self-inflicting behaviour whenever the teacher tried to mask her own depressed, anxious or troubled emotional state by smiling. The conflict between the non-verbal communication of the teacher and his or her emotional state can cause anxiety in students caused by the ambiguity of non-verbal signals of the communication partner and the inability to interpret the partner's emotions. Although this is an isolated experience, in the course of the research many teachers mentioned great emotional sensitivity of the students to the emotions of their communication partners. Therefore, we believe that in communication with students with severe CP the authenticity of the teacher is of great importance. The cognitive deficits of the students do not justify the assumption that it is ethical to lie to students. On the contrary, empirical experience has shown that authentic behaviour is a good start for building a relationship based on trust and mutual respect. Explanation of one's emotional state, including situations where the teacher does not feel good, may help many students to create clear and meaningful communication situations.

Communication and Shape – Counter Shape Theory

We tried to apply shape – counter shape theory by an American psychotherapist A. Pesso to the communication situations (in Pesso, Boyden-Pesso, Vrtbovská, 2009). Pesso likens communicational intents and reactions to **the interaction of shape and counter shape**. Shape and counter shape in social interaction may fit together to a certain degree just as the is shown on the diagram below (A and B).

Fig. 3: Shape and counter shape in interactive situations

For analysis of the interaction it is important whether it is possible to interpret the social interaction as a whole in terms of respective communication partners. Type A situation represents a situation when the shape and counter shape meet during the interaction and type B is a situation when these shapes do not meet. The student and the teacher may interpret the social interaction the same way, either as A or as B type. Paradoxical situations may occur when teacher considers the interaction to be of type A while the student as type B or vice versa. In extreme cases the teacher may be certain that the interaction had a positive effect on the student while the student may find it unpleasant or even traumatic. On the other hand we may also talk about situations when the interaction is beneficial to the student but the teacher interprets it in the opposite way for example because of his or her own insecurity. From this point of view, there are many ethically questionable themes in communication between teacher and student with severe CP.

In the beginning of this article we mentioned the considerable difficulty in interpreting communication situations in students with severe CP. In health care due to the risk that these situations can have on the relationship between communication partners we often meet with requirements for supervision of the entire process. In the Czech educational system supervision is rather rare but in many cases there is a need for external support of the teachers. We consider it essential to gradually increase teachers' awareness of the potential risks of interaction situations and encourage them to seek available forms of professional support. It is necessary to promote this topic within an undergraduate training of special education pedagogues within programs of higher education. It is also possible to seek alternative forms of support especially for beginning teachers. There is the possibility for example of support from more experienced colleagues, counselling centres, support groups, etc.

Teacher as a Compensating Element

During the course of the research we have repeatedly encountered the importance of communication partner of the student, in this case the teacher, for the communication as such. We have observed on the video recordings that the teacher compensates for the communicational deficits on the part of the student, by his or her behaviour, especially by continuous commenting of the ongoing activity. In those situations teachers often expressed what they thought the student may be experiencing, what he wants and what he doesn't want.

Based on an analysis of interviews and observations of the educational process we found that commenting can perform these functions: commenting helps student be oriented and promotes his or her sense of security, helps put situations into context of time, replace verbal activity of the student (teacher comments from the position of the student), stimulate cognitive processes (by naming objects, activities, events, etc.), has preventive function (e. g. prepares the student for an upcoming stimulus), maintains attention of the student and the connection established in interaction.

In analysing the communication process it is of most importance to observe the specific behaviour of the teacher who is trying to create such communication counter shapes that the student can react to despite his or her limitations in functional abilities. The whole effect of the communication process is dependent on the ability to create these counter shapes. It is also worth noting that in the absence of communication reactions of the student the teacher creates those interactive shapes that fit into the already created counter shapes. Each communication situation leads to a meaningful ending. If the student is not able to respond to communication offers at the time the teacher verbally or non-verbally communicates for the student and completes the interactive shape.

Evaluation of the Outcomes of the Communication Process

In the field of special educational theory we do not as yet have a sufficient number of relevant conclusions for the creation of methodology that would enable a comprehensive evaluation of outcomes of communication processes between teacher and student with severe CP. We can give only partial experience that was gained in this field.

The processes of interaction and communication were during the synthesis of the obtained data placed in the context of other processes of intervention. Establishing interaction with the student is a basic process from which all the processes of intervention derive. During the analysis of the case studies we found that the development of interactive situations has led to an increase in opportunities for communication in several students, namely from the level of spontaneous expression of likes and dislikes to the level of expressing concrete communication intentions, for example in the form of 'yes' and 'no'. This constitutes a significant change in the educational process especially since communication with a concrete intention may enhance some cognitive processes of the students. The student may then achieve higher functional level in the area of many other relevant activities. We may, therefore, emphasise a direct line of processes that facilitate communication, interactive situations, various levels of communication and that a widening range of opportunities for education by facilitation of other processes of intervention.

The models offered here regarding communication cannot, of course, take into account the unlimited range of various communication situations that may occur between teacher and student. We have pointed out the difference between situations in which teachers enter into the communication process with a concrete aim and situations where they let themselves be led by the student and in which the teachers' behaviour is much less controlling. Each of these types of communication situations may assume many different forms.

The risk in studying communication in students with severe CP is the reduction of the communication process to several observed facts that are emphasised at the expense of other. Communication is a complex social activity that requires establishment of a good quality relationship with the teacher on the part of the student with severe CP. Other processes of intervention constitute an important extension the possibilities of which unfold with time and in connection with the quality of communication.

7 Summary

In this paper, we examined the communication processes in students with severe CP. We introduced basic terminology and conclusions of a qualitative study based on open-axis, axial and selective coding. At the level of open-axis coding basic categories were set that led to an overview of communication reactions of the students, the communication subjects and some factors that enhance interpretation of the communication processes. At the level of axial coding we searched for hypothetical connections for a better description of the communication processes and we have chosen the most essential to visualise in a diagram. In the following discussion we offered some thoughts on various aspects of the created communication model and gave suggestions for special education practice and further research.

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Basic cognitive strategies and the reading process in pupils with specific learning disabilities

(overview essay)

Miroslava Bartoňová

Abstract: *The chapter presents information on learning strategies in pupils at primary and secondary schools. It specifies some of the approaches to reading acquisition in pupils with dyslexia. This issue is perceived from the cognitive and metacognitive strategies acquisition perspective. We also focus on the definition of basic skills such as process of reading comprehension, phonological information processing, and a flair for language acquisition. The chapter contains analysis of some foreign approaches and programs in the acquisition of basic strategies during learning process as well as specific examples of good practice.*

Key words: *specific learning disabilities (difficulties), pupils with dyslexia, the process of reading, comprehension, phonology, a flair for language, education, metacognition, strategies*

1 Theoretical Basis

Specific learning disabilities (also specific learning difficulties, learning disabilities) affect a significant number of children and adults. It is a heterogeneous group of individuals. Specific learning disabilities distinct from global intellectual deficiency and children have significantly worse results in learning and writing as their classmates of the same age and level of education (Häfele, H., Häfele, H. 2009).

Experts indicate that learning disabilities affect 4–8 % of children population, whereas international comparison present incidence of specific learning disabilities (SLD) around 6 %, while the percentage of the population decreases with increasing age. Manifestations of the disorder can affect quality of life of an individual, extent depends on his/her personality, but also the environment in which he/she lives (Hallowell, E. M., Ratey J. J. 2007; ICD-10: F81.3, cf. Hollenweger, J. In Lichtsteiner Müller, M. 2011, p. 41 et seq.).

1.1 Factors affecting approaches to teaching pupils with dyslexia

At the beginning, I was looking forward to going to school, but later, when I moved to another city, I felt unaccepted by other children. It was quite difficult for me and I felt threatened at times. I was diagnosed with dyslexia in the second grade of primary school. I was taken into consideration in the lessons during the first grade. It was my father who noticed that I did not read accurately – he noticed that when he accidentally turned two pages in the reader, I continued reading what I thought might be on the page. I was reading in the context, but I did not realize that two pages were accidentally turned at once. I often hesitated to engage in discussion not to embarrass myself. School is difficult for me, it is challenging to take notes and follow a lecture, I often have to read the materials several times. I intensively prepare for the lectures and read too much, but I do not feel good if I am not prepared well. I think my experience and maturity help me in classes, and I feel that I can present a good point of view at some issues.

Pupils with dyslexia can be very vulnerable when they have to accept change, such as the start of compulsory education. If the school is informed of possible difficulties and keeps trying to offer support, this change may not negatively affect personality. Several factors must be considered in determining the most appropriate approach for pupils with dyslexia, which include:

- Context – includes the following: type of school, class size, teacher (employees) training programs, pupil's age and a current development phase
- Assessment – provides information on the seriousness of pupil's difficulties. This profile type is important to obtain initial information in order to develop a suitable intervention procedure
- Curriculum – What requirements and expectations concerning the pupil do we have? To what extent is the curriculum accessible and differentiated?
- The pupil – What is his/her motivation? What do we know about his/her learning style? How can we use this information to create a program?

Educational strategies must be individualized for each pupil. Early intervention allows pupil to achieve optimal level of development in educational, personal, social and professional areas.

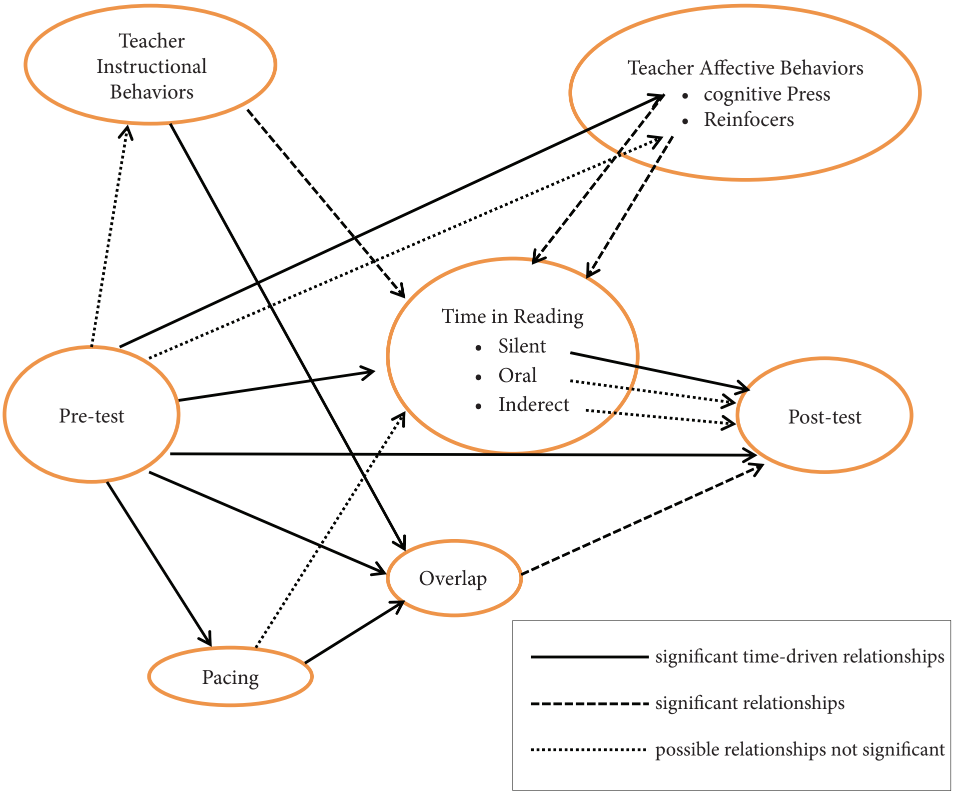

Fig. 1: A model for explaining reading achievement. (Leinzhardta, Zigmonda, a Cooley 1981, p. 352). Copyright 1981 American Educatinal Research Association.

The figure represents the structure of model based on research on classroom activities that affect pupils' attitudes toward learning. These are activities that simultaneously significantly affect development of reading skills. English researchers focused on research on classroom activities in special classes for pupils with SLD; they investigated relative effectiveness of different activities on improving reading performance of pupils. They assumed that learning is based on activities that pupils perform in the classroom, on the curriculum, but also on the teacher's behaviour that directly affects pupils' activities and only indirectly pupils' learning. They neither defined instructions for reading, nor reading methods. However, reading activities were divided into three groups. Those that are directly associated with reading (for example those that bring the pupil to writing), those that indirectly support some aspects of reading, but it is not reading itself (e. g. listening to teacher or storytelling), those that affect the acquisition of reading, but belong into a category where focus is not directly on reading itself (for example working on math skills, drawing, cutting and gluing). In this way they have created a study that offers accurate descriptive information about the instructions for reading in special classes.

Further they investigated whether it is possible to adopt specific causal relationships between the specific process and outcome variables (Fig. 1). They assumed that the way teachers structure learning environment could make a difference in the way pupils work in the educational environment (the class) and affect their level of proficiency in reading, which they reach at the end of the academic year. Fig. 1 shows the causal model of assumptions about the way the classroom variables interact. Solid black lines indicate a significant relationship, in which they assumed causal link, dotted lines indicate relationship which was expected to be significant but it was not. The main goal of Fig. 1 is to show that the final test depends on the pupil's behaviour and content of instruction. It was assumed that pupils' behaviour will be influenced by the teacher's behaviour. The research was conducted for two years in 11 special classes for pupils with specific learning disabilities with more than 100 pupils and their teachers. Data confirmed expectations and specified what happens in the classroom and how each pupil has experienced and responded to the learning environment. Pupils in special classes spent an average of only 26 minutes from the 362 minute school day by reading aloud or silently, and on average showed little progress in the process of reading skills acquisition. However, time spent on each task by pupils with dyslexia in the direct or indirect form was highly predictive for their reading skills development (Swanson, H. L., Harris K. R., Graham, S. 2003).

1.2 Reading skills development in pupils with dyslexia

The ability to read and write is one of the most demanding performances that human brain has to process. Well-established education systems for pupils with dyslexia favor phonological skills in their intervention programmes for teaching reading and writing skills; they are considered the essence of effective teaching. The next step is then the regular application of intervention programmes that are designed to ensure pupil's progress and to consolidate learning. The issue of metacognitive strategies is still being examined in the Czech education system. Recently, there has been a tendency to grip education methodologically and to improve the process of teaching reading with comprehension. The number of papers addressing early intervention for pupils with dyslexia is increasing. These efforts are to a significant extent influenced by the results of international measurements PIRLS and PISA (2011). Specialized publications present a number of views on what constitutes an essential skill for accurate and fluent reading. The basic factors include:

- verbal readiness (such as recognition of letters, spelling, syllabification, phonemic awareness, analogous strategies and linking grapheme and phoneme),
- words recognition (such as a word class recognition and visual memory usage).

The experts present five processes that are important for the development of reading skills. These processes include **phonology, syntax, working memory, semantics and spelling**. Studies focused on the process of reading agree that the deficit in reading comprehension is used as a benchmark for problems in reading; they are not addressed towards the cognitive deficiencies that highlight the difficulties in reading associated phonology.

Phonological processing of speech is considered to be one of the most common causes of dyslexic difficulties in American literature (cf. Bartoňová, M. 2012, Pokorná, V. 2010). Phonological processes affect different skills, but in the context of the development of reading skills it is most significant association of sound with a letter (for example, understanding the rules of the transition between grapheme). This skill is the basis for decoding written texts and although other ways can be used to find out the meaning of the written texts, phonological way is clearly the most important and crucial of them in early development of reading skills.

M. Mikulajová (2009) as well as many other experts emphasizes the speech sound of the child's speech – phonological awareness is perceived as an important factor for further language development. For example, it helps the child to orientate in language grammar that is necessary for the understanding of written and spoken language; and it is a prerequisite for mastering the mechanism of reading and writing. Phonological awareness is superior to concepts that include awareness and use of language, but is also crucial for understanding the script. Capabilities such as analysis, synthesis or phoneme-grapheme linking are necessary for reading and are very low in many pupils with dyslexia. Good level of phonological skills is a prerequisite for the recognition of single words. It requires a complex phonetic skills, automatization, and also a certain level of visual skills (Mather, N., Wendling, B. J. 2011; Klicpera, Ch., Schabman, A., Gasteiger-Klicpera, B. 2010). In order to improve the pupil's skills to identify individual words correctly and also spelling skills, it is essential to focus the interventions on the development of phonological skills and phoneme-grapheme linking.

Working memory refers to storage of information in short-term memory during processing of incoming information and finding connections in long-term memory. In reading, working memory means decoding and recognizing words or phrases during the memorizing of what is being read. Working memory can also be crucial for reading single words, especially at the beginning of the skills acquisition of reading words, because the transition rules between graphemes and phonemes for each segment of speech must be kept in mind while remaining segments of words are processed. Longer words, in terms of number of syllables have greater demands on working memory. Moreover, the complexity of the specific rules have the effect on the difficulty recognizing the word, since the number of alternatives and combination of a grapheme and phoneme with the pronunciation can affect the ease or difficulty in reading the specific words. If there are more ways to say the word, reading slows down and will not be accurate until the child has mastered a single item.

Semantic processing involves **understanding the meaning of words**. In theory, the word meaning is encoded into a semantic network is also accessed from there. Semantic processing is important for obtaining meaning of the word in the context of reading. One of the problematic areas in the context of reading is comprehension. It is necessary to use and specify procedures to mitigate the inability of comprehension also in this area. First, it is necessary to focus on building vocabulary and motivate students to use words outside the classroom. In addition, pupils should learn to link sentences into more coherent utterances. The main difficulty in understanding and comprehension of the text for pupils with dyslexia is the inability to abstract meaning of the text. It is a complex process that requires understanding of language. The inability to decode words is the subsequent difficulty for pupils with dyslexia. The skill to decode or properly recognize single words is connected with the reading comprehension skill (Fletcher, J. M., Reid Lyon, G., Fuchs, L. S. 2006). Syntax awareness, also called **a flair for language**, refers to the ability to understand the language syntax. This ability also appears to be crucial for the continuity and efficiency of reading and requires anticipation. Syntactic factors can affect difficulty to read single words, such as function words, prepositions and auxiliary verbs that are difficult to include in the semantic network. We can observe the way reading process is acquired with the beginners. Also we can observe how they process information about the words that are trained through reading, how they combine these words in sentences. This leads us to a thought that the ability to handle the syntax may be an important aspect of learning words.

1.3 Choosing strategies in teaching pupils with dyslexia

Just as each pupil is unique, also teachers are aware of their need to know a wide repertoire of teaching strategies from which to choose and edit and modify the most appropriate ones. Teacher's knowledge of pupils' learning styles can help pupils to use strategies that are based on their strengths and allow them to handle the learning process at the same time. The teacher can observe the way pupils learn and interview them about what suits them best.

It is important for the teacher at primary and secondary schools to choose appropriate intervention and strategies. These strategies should aim to enhance the development of neural functions, help to the retrieval of academic skills and partial functions. If the intervention is correctly explained, it is better accepted by the pupil with dyslexia. The way to help pupils with plenty of educational content is to organize information, put them into units and into context. For example: a pupil can remember various areas of knowledge by headings such as change, relationship, society. This sort of mental concept can be successful, and the pupil can recall a lot of information. Drafts also help pupils gather more information, organize and understand them.

1.4 Cognitive strategies for pupils with SLD

Cognitive strategies belong to the strategies that pupils use deliberately to influence their learning and cognition. Metacognitive strategies are understood to be *"human ability to plan, monitor, evaluate procedures, which he/she uses himself/herself during learning and recognition. It is a conscious activity, which leads the person to knowledge about the way of progressing when discovering the world"* (Průcha, J., Walterová, E., Mareš, J. 2001, p. 122). Cognitive strategies research objectives in individuals with specific learning disabilities (SLD) are to construct and validate strategies that help with learning and introduce them to pupils. Experts highlight the importance of informing pupils and familiarize them with strategies that can be learned. They point out to the link between used strategies and support for learning (Swanson, H. L., Harris, K. R., Graham. S. 2003). The ability to manage planning, monitoring and evaluation of used strategies are a part of managing the strategies. Pupils should acquire these elements because they are important for the subsequent learning. The evaluation of particular strategies is needed especially because we can observe whether it is used by the pupil in education, and especially if he/she can link the learnt strategy with regular learning.

Studies focused on the use of strategies in teaching pupils with SLD in basic education are still developing. Researchers usually focus on the effectiveness of some common elements or strategies such as strengthening and setting the goals, instruction such as: coping with anxiety, self-regulation and self-assessment of learning, accurate or clear instruction in mathematics, the use of mnemonics. Strategies using mnemonics for mastering language skills are considered very effective (Swanson, H. L., Harris, K. R., Graham. S. 2003).

Pupils with dyslexia have difficulty in cognitive and metacognitive learning strategies acquisition; some need concreteness and structure to build up a sufficient repertoire of strategies in order to get most in the acquisition of learning. Learning of the pupil using one of several cognitive and metacognitive strategies cannot in any case change a pupil into a strategic pupil, who consistently and willingly makes efforts to learn. It also documented in some research studies. The minimum condition for making a pupil with SLD experienced and using the strategies is to gradually incorporate them into the whole curriculum. Success depends mainly on the mass, school-wide use of learning strategies under the great support of teachers (Swanson, H. L., Harris, K. R., Graham. S. 2003; Bartoňová, M., In Bartoňová, M.,Vítková, M. 2007).

V. Pokorná (2012, p 111) sees a strategy as a mental activity that can be validated; if we don't find it useful, we can think about other strategies. The strategies help us to handle a particular task faster, safely and with less risk of error. Individuals with specific learning disabilities use different ways for processing information than intact pupils. They often repeat the same strategy that they have adopted earlier; they are not very flexible.

2 The consequences of specific learning disabilities in adulthood – qualitative research

The aim of V. Kacelova's research project (2011) supervised by M. Bartoňová was to determine the effects of specific learning disabilities in individuals in adulthood and focus on the perception of the consequences of specific learning disabilities throughout basic education to adulthood. One of the research questions was the following question: *How much influence do the consequences of specific learning disabilities have in the life of an adult with dyslexia?* A number of categories were identified. Considering the content of our report, we addressed the category whose aim was to find a link between the counselling approach and a method of compensation of specific learning disabilities (learning styles) within education, especially in elementary school. All three informants reported that the consequences of specific learning disabilities were compensated in some way; but the answers were different concerning the perception of compensation. They agreed on using compensatory mechanisms most often in the Czech language lessons. *"I felt stupid that I didn't have to do what the others had to and I did not like it. I felt that it was unfair to the others, I felt different."* Compensation for *T.* consisted of writing short dictations, which according to him consisted of the reduction of two or three sentences, but he failed anyway. He never had dictations evaluated only in words or by numbering mistakes. Compensation also related to homework. He did not use compensation in high school, but he was glad because he would not feel good about it. He believed that teaching should be equally challenging for everybody. In the case of *K.*, the compensation was perceived as an auxiliary factor, she had more time to check her work. Sometimes, she was writing a filling exercise instead of a dictation. In elementary school, there was also the period when *K.* was evaluated verbally or by stating the number of mistakes in dictation, but she got a mark for the final certificate. According to her, it was probably the period after the assessment in the counselling centre, when the school received the results of the recommendations from this agency. She wrote homework and entries in the workbooks in the same way as other classmates. *M.* has the feeling that *"when I was completing a filling exercise, I was evaluated better because of specific learning disabilities."* He did not perceive the compensation negatively, because he was not the only pupil with specific learning disabilities in the group.

All the informants stated that they need a quiet environment when studying; they cannot listen to the radio or television. All of them also have to read the text aloud and learn it this way. *M* and *K.* prefer to move while learning. Informants' answers differed concerning time needed for preparation, therefore the length of concentration and consequently the need for breaks, which depended on the length of learning. The informants reported that they did not have to learn intensively for some subjects. It depended on the subject and the issue discussed. Home preparations were not regular for any of them. They all studied only for written exam announced in advance or when they were to be called to the blackboard. They wrote regularly only homework, and sometimes just a part of the exercise, they finished the rest of it at school. *M.* said that he *"would manage to study much of the curriculum at the same time, maybe he would remember it with difficulties, and he does not want to sacrifice the whole day to it" T.* studied alone, his parents studied with him only at the beginning of compulsory education. They dictated dictations and read a book with him. Although he has older sisters, they did not study together with him because he would not respect them. *M.* himself said: *"I cannot think about what I am studying, but what I get into the head, I just repeat it."*

K. studied with her mother, who kept reading everything aloud to her, she listened to her and then responded to questions on a given topic. Her mother sometimes explained the issue. She also practiced dictations at home. Replies to this topic gave me the impression that *K.* studied only when her mother wanted that, because she answered the question concerning the style of studying in high school as follows: *"I did not care that much there because I was my own manager there."* She also acknowledged that leaving the style of studying with her mother and swopping to the style of preparing alone for school was very difficult for her. She studied for previously announced written exams and also when she feared unannounced exams and when she was to be tested of the subject at the blackboard. She was studying for hours.

The informants prefer different styles of interpretation and representation for lecturing at school or for trainings. They prefer practical demonstration, which enables them to understand better topic and graphical representations of topic suits them currently best. They use the graphical representation also for better understanding the issue. It is better for them if there are more examples. They need to feel assured that they really understand the issue that is being discussed.

The informants consistently reported that paying attention is related to the topic. If a topic is interesting for them, it is easier to pay attention. They concentrate better on the information useful for them and remember them better. *"I used to study for* *a very long time but the concentration was shorter."* Consequently, the effect of studying was significantly reduced. *M.* widely uses Facebook and internet but it drives his attention away and he cannot concentrate on studying then. Sometimes, there are days when he can concentrate on studying and it is fast, but sometimes he fails to pay attention and he does not find studying interesting.

The informant with specific learning disabilities reported some difficulties which due to SLDs persisted into adulthood. However, the influence is not so essential to limited them in their job opportunities and satisfying life. All the respondents are relatively satisfied in the current employment or student position and do not think that specific learning disabilities would significantly limit them in the future. We are aware of the fact that the results cannot be generalized to the whole population due to the small number of the informants.

2.1 Educational strategies and approaches planning

When **planning educational strategies and approaches,** the teacher uses knowledge of the pupil's developmental specifics together with the respect for his/her individuality. During instruction, teacher uses strategies and programmes that enable pupils to better develop their potential (cf. Krejčová, L. Mertin, V. 2012). When planning educational strategies, he/she reflects on what the pupils have to learn, on the way of the evaluation of the pupil's success, on the acquired pupil's knowledge, and on what he/she is able to manage. What to do to keep the pupil's attention and emotionally involve them, in what way the pupils will acquire new information and skills? How to get feedback on progress of teaching?

Example: Educational strategies planning
When planning, teachers can ask the following questions: What do I want students to learn or to be able to do as a result of this learning experience? How do I evaluate their success? What knowledge do the pupils already have and what they are able to manage? How do I attract and keep their attention? How can I attract the pupils emotionally? What strategy do I choose for acquiring new information and skills? In what way will the pupils acquire and practice curriculum to remember it? In what way will they receive feedback during learning and after learning?

Strategy for attracting attention: If the teachers want to attract their pupils' attention, they need to have a strategy to do so. The activity will focus on: Helping the pupils to focus and keep their attention, to eliminate distractions, to concentrate, to foster independent learning, and to use the "prime time" (i. e. at the time of the pupil's highest concentration). Directing the class activities at the beginning of teaching helps pupils to eliminate distractions, helps concentrate to prior knowledge and leads to paying attention.

2.2 Strategies for secondary school pupils

In the eighties, the Kansas institute focused on teaching and learning strategies for adolescents with learning disabilities. They were guided by the conceptual framework Learning to Learn. It focuses on teaching pupils and students to learn. The team developed and tested a variety of educational strategies that resulted in the Learning Strategies Curriculum. It contains three basic elements: Acquisition, retention and expression of written information (Schumaker 1992 In Swanson, H. L., Harris, K. R., Graham. S. 2003). These elements correspond with tasks which adolescents with learning disabilities in high schools are "struggling" with. The main problem we observe in the following points: The use of technologies – thinking aloud – the instructors model the cognitive strategies for adolescents with learning disabilities. The adolescents are instructed to repeat the individual steps of the strategy verbally until they master them in order to automatize it. The adolescent with SLD is practicing the strategy with control materials (age-appropriate reading). If the pupil masters the strategy, he/she can apply it to a content of the educational field (curriculum) of the relevant school year, and also to increase own learning management. Other important strategies investigated by the research team were cognitive strategies focused on reading comprehension, writing paragraphs and sentences, checking mistakes in written text or writing essays about one's opinion (Swanson, H. L., Harris, K. R., Graham. S. 2003).

3 Conclusion

Learning strategies are pedagogically very important because it is possible to influence their use better than in case of the cognitive style. Metacognitive strategies include pupils' skills to analyse their own presumptions for successful learning. The main study skills for pupils with dyslexia are organization, reading strategies, presentation skills. Teacher focuses on mastering the skills of organization and orderliness in learning habits of pupils. Adopting learning patterns cannot completely eliminate problems of pupils with dyslexia, but their frequent usage improves access to information and ideas as well as it enables them to express themselves clearly. However, if pupils with dyslexia are encouraged to acquire skills, they must be responsible for their development and use themselves.

Preparing lessons depends on teacher's ability to recognize pupils' specificities, their difficulties. He/she has to know how they manifest in the pupils' studies. The pupils obtain much of the information by observation, work samples and different types of evaluation. Teamwork is also important, it allows getting and gathering more detailed information about pupils, it can help evaluate approaches and create effective teaching. Teachers should become the *"observers"* of their pupils.

Previous individual summaries clearly point out to active research on cognitive strategies for pupils with learning disabilities, primarily in the area of creating and laying the cornerstones in this field. In the future, we can expect further research on the issue extended also into math and social studies. In addition, we expect research in at least two other areas. Firstly, we emphasize the development towards the use of structure and planning in particular. Consequently, the approach moves from the cognitive sphere to the metacognitive sphere. The teacher leads pupils to introspection, to completion and a self-assessment of their own learning. To help the pupil develop appropriate strategies, teachers use more flexibility and can use their pedagogical and strategic knowledge and experience. This approach also provides pupil with optimum development opportunities in their own self-managed learning. The effectiveness of this approach depends on the pupil's own efforts to expand the repertoire of strategies. Pupils with learning disabilities tend to have problems in cognitive and metacognitive strategies in learning; some of them need more specific and structured strategies to build a sufficient repertoire of strategies so that they can get the most of them.

Second, the lingering issue of research on cognitive strategies focuses on helping pupils with learning disabilities become strategic learners. We are well aware of the fact that the pupil cannot possibly change into a strategic learner who is consistently and willingly making efforts to learn by acquiring one of several cognitive and metacognitive strategies. The educators agree that success depends primarily on a mass, school-wide use of learning strategies with great headmaster's support and teachers' teamwork. The adoption of learning strategies and approaches used in the reading process cannot completely eliminate the problems of students with dyslexia, but their frequent usage can improve access to information and ideas as well as enable pupils to clearly express their ideas.

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Engaging students in school leadership: Creative approaches to empowerment

(scientific paper)

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Abstract: *This study examines how principals take their lead from students, and use student voice, to create more inclusive and responsive schools, and more responsible models of leadership. I consider issues of student agency and voice within four different public school settings. Further, I consider the challenges all students face, and the ways principals are preparing to address these challenges. In this study I address roadblocks to responsive leadership in urban, suburban, and rural schools using a cogenerative qualitative approach that principals, students, and researchers can use to create new dialogue and shared theories focused on improving both administrative function and the instructional programs of their schools. This approach has revealed a new shared theory which includes young students of various abilities in models of school leadership. Central to this theory is a call for principals and researchers to use more student-driven approaches, so that students can be empowered as learners and leaders in their own right.*

Key words: *Educational Leadership, Student Voice, Inclusive Elementary Education*

1 Introduction

The need for principals to have the time and tools to focus on instruction and student learning has continued to intensify with the introduction of federal accountability mandates such as No Child Left Behind (NCLB) and Race to The Top (RTT)[1]. At

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[1] Federal mandates like these affect virtually every person employed in schools. As a result of these mandates, all schools that accept federal funds must make detailed annual reports on the progress of all children. Each school must also report the progress of four subgroups: minority children, children diagnosed with special needs, children with limited English proficiency, and chidren from low-income families (Powell et al., 2009). Superintendents will use this information to determine which principals are running successful schools and which are not.

the same time, the incongruence between what principals want to do instructionally and have time to do, create dire consequences for school leaders and their work in making a difference in inclusive schools regarding staff and student improvement.

Principals today are spending more time focusing on teaching and learning than ever before. This shift away from the office implies that more direct relationships between principals and the instructional program are necessary if new models of leadership are going to replace earlier models that limited contact with students to matters of discipline, and classroom visits to teacher feedback, supervision, and modeling (Waters et al., 2003). Research into issues of administration has emphasized reflective and inquiry-oriented approaches to working with teachers (Blase & Blase, 1999). As a result, principals now collaborate more with others before making decisions and many employ models of distributive leadership in which adults share in responsibilities that were typically overseen by the administrator (Spillane et al., 2001). Despite these efforts towards reorganization, schools have neglected to include students in more responsive models of leadership, and research has largely ignored the inherent possibilities.

The purpose of this study is to discover whether and how principals have performed in their role as instructional leaders, and to determine by what means their thinking or behaviors associated with this role have been shaped in part by the students they lead. In order to build on what is already known about how students perceive school, learning, and leadership, this study attempts to answer the following questions:

- What, from the perspective of students, are the most significant challenges faced in inclusive schools?
- How do school principals help children cope with challenges they face?

2 Overview

My study's intent is to analyze how principals take their lead from students, and use student voice, to create more inclusive and responsive schools, and a more responsible principalship. In order to describe and explain how principals have used students' perspectives to meaningfully structure their experiences of schools and learning, further investigation into how students can naturally inform the work being done by principals may help to bring students' attitudes and feelings about principals into the dominant discourse on effective leadership practice.

Rather than focus on one aspect of educational leadership (e. g., visibility of the principal), I am focusing on the instructional behaviors of principals as seen through the eyes of the students they lead, the administrators themselves, and my own observations of the interactions between these two often disparate members of the inclusive elementary school community. By capturing the work that's being done in schools where students, principals, and parents are interested in developing a meaningful dialogue about learning and leadership, I have started to better understand how the relationships between students and principals may lead to more efficient instructional programs, increased communication, and student empowerment.

3 Background

Educational Leadership

The principal's role has historically been that of manager. Typical administrative responsibilities in schools have been defined by Portin et al., (1998) as: (a) maintaining safe schools, (b) overseeing the budget, (c) completing and submitting reports, (d) complying with regulations and mandates, (e) coping with teacher and student behavior issues, and (f) dealing with parents. In the 1980s, research into effective schools gave birth to the connection between school leader and school success (Teddlie & Reynolds, 2000). For the first time principals began to pay more attention to student learning in an effort to make schools more effective. More recently the expanding job, and its increasing focus on accountability, standardization, and resource allocation, has necessitated the emergence of an instructional leader (Cooley & Shen, 2003; Walker, 2010), capable of impacting student achievement (Leithwood et al., 2004; Waters et al., 2003).

The changes brought on by No Child Left Behind and Race to The Top have forced principals into the spotlight at a time when many schools are coping with significant changes in the socioeconomic composition of their student body, adjusting to a steady influx of English Language Learners (ELL), and pushing towards inclusion of students with special needs in regular education classrooms.[2] More current descriptions of the leadership role include: initiators of change, educational visionaries, curriculum and assessment experts, special program administrators, and community builders (Darling-Hammond, 2007). School leadership is now widely regarded as second only to classroom instruction as an influence on student learning (Leithwood et al., 2006).

Just as the relationships between principals and schools have changed, so too have the relationships principals are having with teachers and students. Principals are spending more time observing teaching and learning than ever before. The old model of formal, one-person leadership is no longer realistic (Lambert, 1998), and

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[2] Add in the fact that in the past ten years the number of U.S. students enrolled in special education has risen 30 percent, and that three out of every four students with disabilities spend part or all of their day in inclusive classrooms (NCES, 2010), and the balancing act that takes place between the principal and students' agendas becomes even more complicated.

with the increase in job demands principals now collaborate more with others before making decisions and employ models of distributive leadership (Spillane et al., 2001) in which adults share in responsibilities that were typically overseen by the administrator. These models of leadership have, until now, included teacher-leaders, principal-teachers, assistant or associate principals, co-principals, and management service coordinators (DiPaola & Tschannen-Moran, 2003), and provide principals with opportunities to focus more on their capacity as instructional leader (Walker, 2010). Despite these efforts towards reorganization, schools have neglected to include students in more responsive models of leadership, and research has largely ignored the inherent possibilities.

A few arguments have traditionally been advanced in support of school leaders considering student participation and involvement when making decisions.

1. *Teachers and school based support teams have been involved in helping principals make decisions for years. These same arguments apply, at least in theory, to students as well.* While most principals would argue that it is their job to make the decisions that affect their school, many actively involve teachers in conversations about the school's instructional program on a regular basis. This has improved the overall quality of teaching, and made principals into more responsive leaders (Portin et al., 2003). If principals were to involve students in similar conversations about their experiences of teaching, learning, and even leadership, students might also become more empowered as learners, and principals would become even more effective leaders.
2. *All students have a moral right to be involved.* When principals do not involve students, and ignore students' basic needs, such as the need for social/emotional support, autonomy, and respect, students are left to wonder if their principal actually cares (Gentilucci & Muto, 2007). Students have a right to a voice in decisions that affect their experiences of school and learning, and will become more responsible learners if they have a higher morale.
3. *Student involvement enhances cooperation and reduces conflict between all members of the school.* There is evidence that when students' personal needs of accomplishment and meaningfulness are met by adults in schools, students' agendas, goals, and perspectives, will align with those of adults (Allen, 1983). When these goals and perspectives align, students and adults are more likely to work together toward improving student learning outcomes. Active involvement in the school's instructional program will also provide students with opportunities for their voice (as it relates to problems and dissatisfaction) to be heard by those that matter, and who can address their needs before they manifest themselves in a negative way.

The rationale for giving students a voice, and involving them in decisions about the work of learning and leadership is clear. Just as teachers have valuable information about the instructional program, students also have information that leaders need to make good decisions. Students also have a need and a basic undeniable right to feel committed and connected to their experiences of learning. When principals do not actively consider students as being valuable to the overall success of the school, and involve students in decisions that effect the work of learning, students in turn get the message that their participation and involvement is not valued by all members of the organization.

Students' Perspectives of Leadership

What is clear is that almost all of the data correlating school leadership with student learning has been collected from administrators, school board members, parents, and classroom teachers (Cook-Sather, 2009). Few studies have examined what students perceive schools do to impact their learning, and of these few studies, the emphasis has largely been on issues such as student satisfaction with school, perceptions of school climate and culture, issues of motivation, classroom management, and expectations of teachers (Wilson, 2011). As useful as these lines of inquiry were, none reveal much about what students think and feel about principal leadership and its effect on academic achievement, arguably the most central aspect of student life (Gentilucci & Muto, 2007).

While the departure from a more traditional, managerial role has been critical for principals that want to appear more accessible to both the students and teachers in their schools (Fullan, 2008), there is evidence to suggest that these new roles only in part fulfill what the students were looking for in a strong instructional leader (Gentillucci & Muto, 2007). Teacher and student engagement data related to these instructional behaviors has been recorded (Quinn, 2002), and secondary students have been able to talk about how they perceive these behaviors (Shultz & Cook-Sather, 2001), but no study to date has considered inclusive elementary school students' perspectives on this topic.

If leadership wants to address issues of instruction more thoroughly they have to begin to find ways to understand what the students think and feel about their experiences of school. Some critics of student perspective research argue that learning, not understanding students' thoughts and feelings, is the primary goal of schooling. While this may be true, it begs the following question; Who is better qualified than the students to tell us what most effectively influences or hinders their learning and academic achievement (Gentilucci & Muto, 2007)?

4 Methods

My multi-site ethnography involves two groups of participants across four inclusive elementary schools. The first class of participants is four principals that I interviewed twice and observed a minimum of four times throughout the spring semester. The second class is made up of focus groups of elementary school students, which I interviewed twice throughout the semester and observe a minimum of four times.

In an effort to draw a representative sample of students I requested that each principal grant me access to groups of students at each grade-level (in kindergarten-fourth grade schools this would mean meeting with five groups of students, in kindergarten-fifth grade schools, six groups, etc.). While some principals were comfortable providing me with the requested number of students, others preferred that I meet with grade levels that they thought will be better able to articulate their feelings and attitudes based on their age. Because age does not appear to be a discriminating factor in this setting, I accepted their offer. Each focus group consisted of between 4–6 students was randomly selected from classrooms at each grade-level and meant to be representative of the overall population of the school (across diversity areas such as race, special education, ELL, etc.).

Implications for conducting focus groups with vulnerable or marginalized populations, including children, have been considered and weaknesses of this methodology have been meaningfully reviewed. Focus groups are not immune to researcher bias, and they come with their own unique set of challenges. Recruitment and data analysis emerge as the two most significant hurdles researchers face when using this approach across a variety of disciplines. My inclusion of the contemporary qualitative research methods literature helped me to focus on more specific issues of reflexivity, narrative inquiry, and ethnographic approaches to using this method in educational contexts and with children. More current approaches to using focus groups across all disciplines, and with marginalized populations, point to incorporating the focus group as a way to summarize a series of observations.

There are a number of strategies that researchers have used when conducting focus groups with children. I have employed several of these strategies in an effort to conduct fun, age-appropriate activities focused on the research topic. One such strategy was the use of a warm-up activity with students from all grades. This involved breaking the ice with the group, and practicing some of the basic skills necessary for participating in a focus group. I introduced the subject at the beginning of the first interview by using a free association activity where students were asked to identify images of various adults and take turns describing the same images. The photographs I showed the students were of a firefighter, a policeman, the president, and finally their principal. A second activity I used to start my second student interview was to introduce the topic in a read-aloud of an age-appropriate children's book about principals (Creech & Bliss, 2001). After the story I asked the students to talk about the story as it related to our first discussion, and as a prompt for our more focused second discussion.

Immediately after introducing the topic using the free association activity I also asked students to provide me with drawings or words they create in response to an initial brainstorm about principals. Words are only one form of communication, and visual representations of experiences can enable others to see as the participant sees and feels (Riessman, 2008). In my attempt to provide the students with an opportunity to tell their story as transparently as possible, visual data was used to capture the perspectives of all students including those that a) struggle to express their thoughts verbally, b) are English Language Learners, and/or are c) more comfortable using imagery to depict their understanding of the research topic. Students were provided with colored pencils, a standard size (8.5" X 11") piece of paper, and were asked to draw what they thought their principal does before my line of questioning began.

Focus groups were conducted twice with each group of students, once at the beginning of the semester after my initial interview with the principal, and once at the end of the semester after my second interview with the principal. The first focus group was focused on giving students opportunities to describe their experiences, relationships with adults, challenges they face in school, support they receive from principals, and the voice they are given in shaping school culture. The second focus group was focused on deeper probing and asked students to talk about data collected from the principals' second interview. Each focus group interview lasted between 30–45 minutes, was conducted by myself, included another adult presence from the site, and was audio-recorded and transcribed for analysis.

I have developed a mixed-qualitative approach based on Elden & Levin's (1991) model of cogenerative learning (see figure 1 below), in order to create a dialogue between principals and students, and develop a shared theory that is action-relevant and can be used to inform and improve their situations in the future. This framework has allowed me to explore: (a) the value of including students (insider's framework) in research, (b) approaches that researchers (outsider's framework) have taken in previous youth studies, (c) approaches that have been taken between students and researchers (cogenerative dialogue), and (d) discuss the value and significance of this collaboration. The bottom two dimensions of the framework will be the resulting theory I develop through my literature review, and the approach I decide to take when conducting my research in the field.[3]

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[3] While this model has been adapted to serve my own exploration of qualitative research methods, it is important to note that this framework could also be used to support the applied work of principals interested in using their students' perspectives of leadership to develop new approaches to leadership.

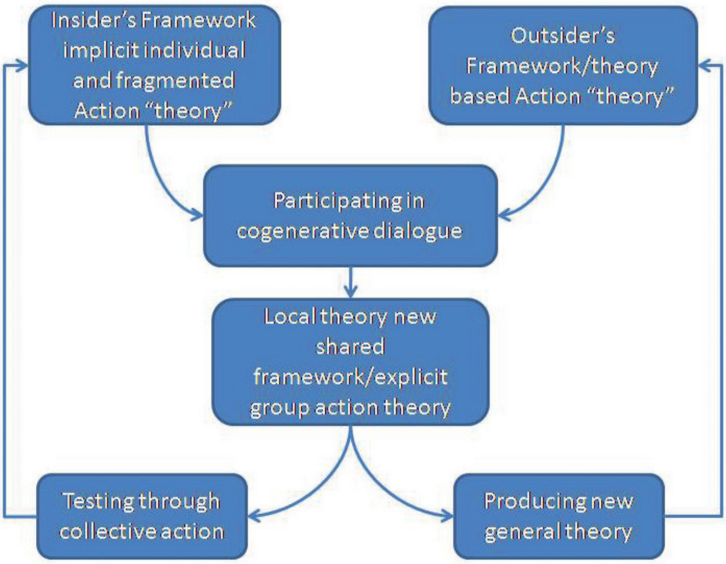

Figure 1: Elden & Levin's (1991) cogenerative model of participative action research

5 Findings

This research study included case studies of four different groups of students and their principals, across four schools in New York State. I addressed two key research questions: (1) What, from the perspective of students, are the most significant challenges faced by students in inclusive schools? (2) How do principals help children cope with the challenges they face? In this section, I will be analyzing themes across all four schools in an effort to find similarities as well as differences. Before I provide the theory that emerged from my conversations and observations with the participants, I will provide first a brief description of each of the schools.

Forest Hills Elementary

Forest Hills Elementary (FH) is our lone suburban site and has the smallest number and percentage of students on the free and reduced lunch[4] list. The students, staff, and principal here make up what may appear to represent the traditional American

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[4] This program provides cash subsidies for free and reduced-price lunches to students based on family income and size. Eligibility is determined via an application process which parents complete and submit each year. Children from families at or below 130 percent of the poverty level are eligible for free meals. Children from families between 130 and 185 percent of the poverty level are eligible for reduced-priced meals. In 2010, more than 31.7 million American students qualified for these services (Isaacs, et al. 2012).

elementary school for many readers. Joseph, an experienced teacher and principal in this district, is also a prominent figure in the community. Joseph took over the FH principalship just eighteen months before this study began, and brought with him 170 new students and nearly a third of the current staff.

One of Joseph's key strengths at FH has been his ability to coordinate the curriculum and help the teachers navigate the school's instructional program. Joseph has also developed a positive school culture where teachers are able to focus primarily on instruction and students enjoy learning. Joseph appears to do an effective job managing his resources, support staff, and a talented group of teachers to meet students' academic and social/emotional needs; as a result, he spends the majority of his time in between the buses and bells managing the ebb and flow of managerial responsibilities that come his way during the course of an average day. These responsibilities include coordinating with other administrators in the district, handling parents' concerns, training teachers around the common core learning standards, and touching base with his support staff around the school to make sure everyone is on the same page and moving forward together.

My extensive observations of students at FH, and my conversations with FH's principal and students, have revealed that these children are happy to be in school, are rarely insubordinate, and are doing well academically. Students' challenges at FH were with specific subjects, or with teachers. When asked how students dealt with the challenges they faced in class, they report that they are likely go to a parent, peer, or sibling before speaking with an adult in school. It was only after mid-way through our final interview that they began to consider their principal as someone they might be able to approach about problems they were having during or outside of school.

Despite (or perhaps, because of) the high level of student achievement at FH, students have had few meaningful opportunities to interact with their principal. Joseph is a strong leader of adults, and spends his time helping them with the challenges they face at his new site, and as a result, students perceive him as someone that is there to spread a clear and consistent message, help the school run smoothly, and occasionally act as a disciplinarian. While Joseph acknowledges the role students play in making the school function, he is not inclined to take their lead or use their voice to support their experiences of school or learning.

Lodi Elementary

Lodi elementary is the smallest site in the study. It is located the furthest from a city center, and has a free and reduced lunch rate of 55 %. There is significant poverty in this rural community and it plays a role in the lives of many of these students. Mark, an experienced teacher and administrator at other rural districts in the region, is passionate about boosting the aspiration rate for students in this area. Mark sees his primary role as making sure he has the best teachers working in each of his classrooms, and that they have the resources they need to help the students achieve. When asked to describe his day Mark talked a lot about state and district initiatives, meetings, observation, and providing teachers with feedback. When I asked Mark to describe the interactions he was having with kids he chose to talk about how he worked to manage behavioral problems at the site. Due to the small size of this rural district, Mark has responsibilities that take him outside of the school more than he would like.

Because Mark's walk-throughs are largely focused on observing the adults in the building and providing them with feedback on their practice, many of the students perceived Mark to be more of an office principal, who works behind the scenes to make sure they are supported academically and to make sure they are safe and cared for in school. When I asked students about their challenges at Lodi, they spoke about tests, and classes where they had trouble with content, and when I asked how Mark helped them with their challenges they naturally responded that Lodi's teachers were the ones they would go to for help with these problems. Students here were very responsive to questions Mark posed during our first interview, and a meaningful dialogue developed between the two that was focused on direct leadership behaviors such as Mark's approaches to speechmaking, and his passive role as observer during walk-throughs, as well as indirect leadership behaviors such as the program schedule, open house, and the classroom makeup.

Mark, who admitted he had not thought about using student voice before this study, began to see real value in how students' perspectives could be used to inform his work, and empower students as learners. While Mark has given students opportunities to make decisions that reflect those traditionally made by student governments in the past, he remarked that he could now see the value student voice had for impacting his approaches to leadership, and mentioned that he considered the students' comments as useful to his work.

Everton Elementary

All of the students at Everton Elementary receive free and reduced lunch, and of the four schools in this study it has the highest percentage of students diagnosed with special needs. Students and staff at Everton are dealing with a range of challenges unique to urban education, in a community where crime rates are high, and parental involvement in their children's education is low.

Leah, who has 25 years of experience working as a teacher, a staff developer, and an administrator in this urban district, was brought to Everton two years ago to manage the school through a situation of crisis. At Everton the challenges students' face outside the school often manifest themselves inside the classrooms. As a result she is as responsible for keeping the building functioning, as she is for providing the instructional support her students so desperately need. Leah's key responsibilities included her role as a resource allocator for students, someone who listens to students and looks at what they need, an instructional leader of teachers, and someone who is actively involved in shaping the school culture. During my visits to the site it became clear that Leah has little choice as to how her days are spent. While systems have been set up to deal with academic and behavioral supports for kids, Leah spends most of her time at Everton putting out fires. Despite the frenetic pace of her work, she has managed to maintain her poise and serves as an excellent role-model to students who value her patience and passion for working with kids.

Students at Everton listed distractions in the classroom, physical challenges of the building, and misbehavior as their biggest challenges in school. Leah helps these students cope with these challenges by being actively involved in working with students in classrooms, and students seem to thrive on the extra support she provides. Leah's focus is on making sure the students first feel safe and supported in communities where she says "high-levels of academic and emotional support do not come naturally to many parents, and student efficacy often begins to diminish as early as the second grade." While some of the students were distracted and even aggressive during focus groups, others saw their principal as a teacher, a counselor, and even a caregiver. The students also remarked that she tries to keep their expectations high, and focused on going to college.

While Leah has spent most of her time at Everton reacting to problems associated with urban schools, she manages to keep a positive outlook on the work that she is doing. Near the end of the study Leah mentioned that she would like to develop a student cabinet whereby she could ask students about problems they were facing academically, in an effort to get students more excited about learning, and adults prepared to develop more responsive approaches to working with kids.

Carter Elementary

Carter is another urban site where nearly every student qualifies for free and reduced lunch, and where there is a low-rate of students succeeding academically. The largest school in this study, Carter also serves as a beacon for this community and provides a range of services to help students and their families experience some degree of stability and success in their lives. Despite the challenges faced by students outside of the school, the new principal here appears to have everything under control.

David arrived at Carter midway through the school year and has already had a significant impact on the school culture. David is the youngest of our four principals, and the only African-American principal in this study. David delegates most of his managerial responsibilities to his support staff, which frees him up for more instructional contact with students. The majority of David's time is spent in Carter's classrooms where he is able to monitor student progress, have direct instructional contact with students, and observe teachers. David has created a school climate where teachers are valued as professionals, and has taken responsibility for developing the work of his teachers and students. This principal's work with students, has allowed him to develop specific student-driven approaches to reform, in an effort to streamline the instuctional program, and provide opportunities for meaningful student involvement.

Students' perspectives at Carter reflected the seriousness and sense of urgency David brings to his work everyday. Students identified their key challenges as being confrontataion in the classroom, bullying, and factors outside the school that get them off track. All of the students interviewed at Carter cited their principal as someone they could go to for help in dealing with a range of obstacles to learning. All of the students at Carter also saw their principal as someone who helps them learn, and who is out-of-the-office and available to students when they need him. Still, these students wanted more of the instructional and social/emotional support he provides them. They were also able to respond to very grown up questions posed by their principal that even adults rarely feel confident enough to address when talking about schools.

David has not been afraid to defy tradition and go against the grain in an effort to provide his students with academic and behavioral supports they were not receiving before his arrival at Carter. The appearance and feel of the school, the nature of the instruction taking place in the classrooms, and students' comments all reflect what this new principal is about. David also chose to talk about his approaches to leadership and the role kids play in making schools work from the vantage point of a servant or guide.

6 Conclusions: Toward a Theory of Engaging Students in School Leadership

In the following passage I will present a new shared theory on how principals can create more responsive approaches to school leadership by including students' perspectives on school and school leadership in their own agendas, strategies, and goals. By better understanding principals' perspectives of leadership (and their agendas, strategies, and goals) researchers and practitioners can see how they are connected or developed in response to those of the students. Findings indicate that when principals look inside of their school for help with solving problems faced by their students, instead of looking outside of school, more authentic and transformational approaches can be developed to create schools that are more responsive to students' needs.

Schools teach kids about how to deal with problems based on how principals deal with their own challenges. Research demonstrates that when teachers develop strategies designed to meet students' academic and psychological needs, they can promote their students sense of responsibility and voice in the classroom (Schneider, 1996). When teachers set up systems to actively engage students in their own learning (such as cooperative learning, self-assessment, student-teacher contracts, etc.), students become more responsible and are able to self-direct more of their behavior over time (Gossen, 1992). Many teachers however are reluctant to give students opportunities like these and can get caught up in (and even contribute to) the same self-defeating mindset of their students (Schneider, 1996). Teachers and even principals have for years attributed causes for failure to any number of causes out of their direct control (e. g., lack of resources, poor parenting, etc.).

While principals have long been regarded as the school managers, they are also in a unique position to show a larger population of students that they can or cannot have a voice based on the work that they do. This has far-reaching effects on the students and their future role in society. It also has a direct impact on how teachers choose to run their classrooms and structure their interactions with kids. While most principals in this study agreed that a big part of their job was making sure they had the best teachers possible, and that teachers were the ones capable of impacting change, principals invariably shape the work of the teachers, and enact policies and practice that affects the way teachers teach, and students learn.

Even though principals today are supposed to spend more time focusing on teaching and learning than ever before, there is evidence that students and student learning often take a back seat to the work of adults in school. Conversations and observation at these schools also indicated that there is a discrepancy between what some principals say, and what they actually do. While some principals acknowledge the value student driven approaches to school leadership have for empowering kids, I found limited evidence that principals actively use student voice or interact with students directly in an effort to address problems in their schools.

Findings from the field indicate that this is not because principals can not or do not have the time to use more student-driven approaches to guide their instructional program. Instead, this research has found that principals choose to use these approaches based on whether or not they value receiving direct input from kids. Principals choose to let students' perspectives affect their agenda, strategies, and goals based on whether or not they believe this is important. While some principals may be unaware that such a choice even exists, and instead take more traditional and managerial approaches to their work, there is evidence that some principals are aware that there is a choice, and still make an active decision to not give students opportunities to share how they think and feel about school.

Principals who are not using student-driven approaches to guide their principalship are left with personal inclination or externally derived models in their quest to provide structure to the school's instructional program. Many of these choices were based on assumptions principals have about what students are capable of contributing to a discussion on what does or does not work in schools. These assumptions were largely based on (1) whether or not it had occurred to principals that using student voice was a possibility, (2) perceived competence as it relates to a student's age, and (3) preconceived notions about whether or not students should have a say in their experiences of school. These assumptions existed when principals develop and demonstrate leadership behaviors that underestimate what students are capable of contributing to the school. While every principal in the study was willing to engage in an indirect conversation with students about the challenges they face, few principals actively look to see what students think about school, and even fewer use student voice to shape their approaches to leadership.

At our suburban site, students shared stories about teachers that made them feel uncomfortable, and by the end of the study, began to realize that the principal was someone that could help them with their problems. At our rural school, students wanted their principal to develop some new approaches to his interactions with students, and also provided some ideas for restructuring school events like open house and assembly. At one urban site, students' behavior during focus groups alone demonstrated that they were having trouble engaging with the instructional program. They also cited a range of physical factors around the school (such as the condition of the classrooms and hallways), and factors inside the classroom (such as disruptive students and overwhelmed teachers) as hindrances to their learning. At another urban school students spoke openly about how they wanted more of the direct instructional and social/emotional support the principal was already providing.

At the root of many of the assumptions made by principals was a reluctance to concede or modify their current position of authority and adopt a more shared approach to making decisions in schools. This autonomy, which gives principals their sense of professionalism and a feeling of control over their school can also get in the way of collaboration with staff and students, and communication structures which might allow for alternative forms of interaction. Opportunities to make adjustments to the instructional program and to impact student learning outcomes are lost when leaders take more autocratic approaches to making important decisions in schools.

Both my review of the literature and research data from the field indicate that principals who increase student responsibility and use student voice to drive their instructional leadership have empowered students as learners. This empowerment has resulted in better behavior, increased engagement in the instructional program, and the development of a more shared set of goals between students and staff. Principals have done this by playing a more visible and accessible role school-wide and in classrooms, and by having more direct instructional contact with the students. Outside of the classrooms these principals have also been able to speak with students about problems that affect their learning inside and outside of school. The data suggest that instructional leaders can develop more specific goals using a vision which is shared by the students, reflects student concerns, and in which students had a voice in creating, if they want to create, a school climate that is more inclusive, conducive to learning, and better equipped to respond to change.

Research that seeks to understand principals' perceptions of how schools best operate, and then places adult perspectives alongside those students have about school, can develop a better understanding of how students and principals can work together to create more equitable and excellent schools. Principals' direct and indirect approaches to promoting the instruction that takes place in their schools has a significant impact on students' experiences of education. By better understanding how principals think about the approaches they take, students' learning outcomes and teacher efficacy can be enhanced. Principals and students play key roles in shaping school culture, and enter school with similar goals. These shared goals include an intention to succeed as participants in the academic program, as well as a strong desire to be supported socially and emotionally. Principals willing to explore their perceptions of students and student learning in depth are better able to understand their relationships with students, and the role they play in determining the success of both the school and the principalship.

Students' thoughts and feelings matter and can provide schools and the research community with new evidence that be used to inform the existing research on instructional leadership and administrative function in the field. This study has shown that principals are interested in what younger students have to say about their work. It has also helped principals realize the value these perspectives have for shaping their work as school leader.

Students have also been affected by this study. Students felt empowered when adults took the time to ask them about their challenges. When asked about what they would like to see done differently, some students were quick to ask for more instructional support from their principals. Others remarked that they would like to see their principals develop new ways of approaching their administrative function. Still others spoke openly about their teachers and peers, or about how their principal could help support them socially and emotionally.

In each school students had different sets of challenges and adults helping them with these challenges. In all of the schools however, students were clear about what they could use to help them learn better, and in each of these cases, principals were in a position to adapt their agendas, goals, and strategies to those of their students. Principals that underestimate student agency, have trouble addressing diversity, and fail to make themselves accessible to their students limit their own opportunities for reform.

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(reviewed twice)

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Action research in home-based early intervention of developmental disorder children

(overview essay)

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Abstract: *This article mainly reports the action research in the home-based early intervention implemented on 20 developmental disorder children aged 0–6 years in Chongqing downtown, which lasted 4 years and aimed at the exploration of the service mode and the transdisciplinary team cooperation mode of the home-based early intervention implemented on the developmental disorder children aged 0–6 years in Chongqing downtown. All team members (professionals and family members) worked together to develop the individualized family service plan (IFSP). A variety of methods was used to record and share personal reflections, observations and assessment, formally and informally, within the team. The result shows that the home-based early intervention service mode has active influence on the children and their families, but the professional integration of transdisciplinary team cooperation mode is much difficult, affecting the results of early intervention.*

Key words: *developmental disorder children; home-based; transdisciplinary team cooperation; early intervention; action research*

1 Introduction

According to “sampling survey on the disorder children aged 0–6 years in China, 2001”, China has about 1.417 million disorder children, the number of which is increased at a rate of 0.199 million per year. Among them, the disorder children needing rehabilitation training or service account for 68–75 %, while those accepted rehabilitation training or service account for only 10.46 %, indicating that most disorder children that need rehabilitation training or service are up-brought at home. In Chongqing Municipality, the monitoring data of birth defects based on population conducted from October 1, 2008 to September 30, 2011 shows that there were 166 cases of birth defect among 22,250 perinatal infants, with the total incidence rate being 0.007461 %, or 0.0097 % and 0.00692 % in town and village respectively. (Chunyan He, Gaodong Zhang, et al, Chongqing Medicine, 2012). It can be seen that there are many developmental disorder children, but there are not enough organizations that can provide early intervention services in Chongqing, with a large gap existing between the supply and demand. At present, the early intervention modes against developmental disorder children in Mainland China mainly include family mode, center mode and family-center mixed mode. A part of developmental disorder children, after diagnosis in hospitals, rarely accept professional rehabilitation and education training apart from single medical treatment. A part of parents of developmental disorder children try to find early intervention resources for their children, but are always in the absence of professional guidance or unable to find suitable resources, or the existing resources are not well integrated and have not played their maximum efficacy, finally resulting in part of children missing the critical period of early intervention and affecting the development of children potency. Based on the status of early intervention of developmental disorder children in Chongqing Municipality and in reference to some advanced experiences, several senior teachers engaged in early intervention mode in Chongqing have taken the lead in exploring the home-based early intervention mode, and this action research has lasted 4 years and 20 children and their families have benefited therefrom.

In this research, home service teachers directly visited the family of developmental disorder children, giving guidance to the patents how to bring up their children and transferred their rehabilitation training technology to the parents or the main caretakers of children, so as to strengthen the bringing-up knowledge and skill of parents and assist family members to understand the growth and requirements of their children. In addition, the teachers also delivered personal lectures and organized group interactive activities and parent growth group activities to help parents find professional resources and integrate relevant resources. In the provision of children oriented treatment and special education services, parents are the main decision makers and participants and the key of services is the transfer of early intervention technology to the parents or the main caretakers of children and the provision of support to the parents, so that the children can gain the maximum development through early intervention and the families can improve their capacities.

2 Methodology

2.1 Object

The objects of this research are 20 developmental disorder children aged 0–6 years and their parents (or the main caretakers: parents, grandparents or nursemaids). Among them, 16 are boys and 4 are girls, including 3 children with fragile X syndrome, 6 children with developmental delay, 3 children with infantile autism, 3 children with Down's syndrome and 5 children with cerebral palsy. The relevant specialized persons participated in the research are 3 teachers engaged in special education as well as a pediatrician, a physical therapist, a speech therapist and a psychological consultant.

2.2 Action research procedure

2.2.1 Planning: collection of relevant research and practice information in the early intervention of developmental disorder children, understanding the development situation of early intervention in many aspects from background, theoretical basis and service mode to implementation achievements. Drawing up a set of home-based early intervention service procedure with reference to the advanced experiences and in combination with the native actual ecological and existing resources: **Acceptance – assessment – holding individualized family service meeting – drafting an individualized family service plan (IFSP) – executing the individualized family service plan (IFSP) – service assessment – continuous service or referral/settlement – individual track and follow-up visit.**

2.2.2 Action research cycle: operating as the drafted home-based early intervention service procedure, serving successively 20 developmental disorder children and their families, 4 months as a cycle, with the execution time of each individual family service plan being 3 months and the visiting teacher providing visiting service once a week and 1.5 hours at a time. The teachers performed one-to-one teaching or rehabilitation training to the children, made assessment and recommendation on the behaviors of children in family environment, exchanged teaching strategies with parents, adjusted and designed some family activities according to family situation and directed parents how to continue teaching in family environment. In the course of implementation, individual assessment record, family interview record and visiting service log were completed. The implementation procedure of home-based early intervention was assessed every 6 months to understand the execution of the service procedure, highlighting the assessment of the execution of individualized family service plan, the change of abilities of children and their families and the transdisciplinary team cooperation between relevant professionals. Continuous summarization in connection with individual case researches: assessment, comprehensive study and judge, drafting and implementing the actual experiences in various aspects including IFSP, adjusting and perfecting the home-based early intervention service procedure.

2.2.3 Assessment: Home-based assessment was adopted in this research with children and their families as objects, aimed at understanding the requirements of developmental disorder children and their families, the capacities, resources and study environment of children, the relation and interaction between children and their main care takers. The procedure of measurement is a continuous systematic procedure of disciplinary team cooperation. Children assessment: Curriculum-based assessment was adopted by selecting Portage early education instruction manual of Wisconsin, US as reference to understand the ability level of children in every development fields of daily life, action, language, social behavior and cognition. In addition, environment and ecological assessment was performed through self-compiled "environmental analysis sheet" and "environment adjustment card". In the assessment of children study characteristics, "Neuropsychological development diagnosis scale of children aged 0 to 4 years" and "Denver development screening scale (DDST)" were used to understand the development level of children and "Children's temperament assessment sheet" was selected to understand the temperament level of children. Family assessment: The characteristics and requirements of families were understood through family visit, family interest survey, family environment assessment and parent characteristics survey.

3 Results

3.1 Influence of home-based early invention to the children: As seen from the arrangement at present of developmental disorder children who accepted to visiting service, among 20 cases, through home-based early intervention service for 2–6 cycles, 55 % of the children was successfully referred, 20 % was enrolled into common kindergartens or primary schools, 35 % was enrolled into special education institutions and 20 % of the children and their families continuously selected visiting services. Compared with the children in the same age group who have not accepted home-based early intervention, the rate of entering into kindergartens and common primary schools as well as the routine study, life and basic learning ability is high.

3.2 Influence of home-based intervention on families: 75 % of the families were satisfactory with the home-based early intervention service mode. The upbringing capacity of families, including upbringing style and skill, problem-solving ability and behavior management ability, was lifted for 25 % in average, and the understanding, acceptance, adaptability and consciousness of right were also improved.

3.3 The cooperation between the staff of transdisciplinary team in the early intervention is much difficult, mainly manifested in lack of relevant professional persons and not easy to adjust the time to discuss individual cases, especially for pediatricians and therapeutists.

4 Discussion

4.1 Procedure of home-based early intervention

4.1.1 Detection and referral period: the method of early detection of children with developmental disorder is complete. More and more disabled children can be discovered by antenatal examination, neonatal screening, children protection, children neuropsychological diagnosis and other measures; however, as to the publicity method of the early intervention, the three systems, medical treatment, education and disabled federation which operate independently has led to insufficient knowledge of the meanings, service content and effect at a large number of parents. After the early detection of children with developmental disorder, some organizations didn't know that there are relevant institutions to which the developmentally disabled children can be transferred to or didn't intend to transfer because there was a limited number of organizations which can provide early intervention.

4.1.2 Assessment period: Because the three organizations, i. e. medical treatment, education and disability federation, which are mainly in service of developmentally disabled children, have been in operation independently according to different system and service mode with different assessment methods, a child often needs to receive many assessments and many assessment reports from different organizations, some of which are not very helpful to the follow-up early intervention with woefully inadequate interaction between professions.

4.1.3 Placement and intervention period: Due to insufficient resources, some developmentally disabled children usually choose to go to hospital, early special educational institutions or disability federation rehabilitation center to take the simple drug therapy, early special education or rehabilitation training, or take many early intervention services in many institutions tiredly.

4.2 Home-based Assessment

Home-based assessment includes both children and families. Different families have different requirements of early intervention, professional needs, service needs, information needs, spiritual needs and economic needs, in order of proportion of the number of people who require early intervention. Families hope early intervention focuses on the needs of children. It is when professionals demonstrate their strength in early intervention service, improve children's ability and gradually build trust in family members that parents reveal the needs of theirs and the family's.

4.3 Drafting and implementation of Individualized Family Service Plan (IFSP)

As the questionnaire survey and the in-depth interview show, families hope that early intervention focuses on children, which is also the reason they take part in early intervention. According to the analysis of IFSP, about 80 % are targeted at children. It is the hope of families that services will be centered on children and the chief approach is home-based early intervention to meet the needs of children.

4.4 Cooperation between relevant professional teams

Many departments like hygiene, population and family planning, civil administration, education, labor and social security and disability federation, etc. are involved in early intervention. The barriers between different departments and regions and the overlapping business operations lead to the incompleteness of the work system of early intervention and planning and coordination work mechanism. The main factor that influences the cooperation between professional teams is the mutual support between professions, professionals, institution resources and institutional sectionalism: all institutions are holding affirmative attitudes towards the integration service of professional teams, but the dilemma to build trans-disciplinary integration teams lies mainly in the shortage of human and institutional resources. At present, the three large systems, i. e. medical treatment, education and disability federation in Chongqing, are carrying on early intervention service and have developed their service mode. However, due to the different professional background, the emphasis, the intervention modes and content are quite different, which results in the selection of a child among several institutions, such as Ningning, a child with cerebral palsy with epilepsy and intellectual disability, who needs to go to the hospital to take regular outpatient services, medicine to control epilepsy, acupuncture, massage to relieve muscle tension; and an-hour cognitive training in a special educational organization, an-hour physiotherapeutic in a disability rehabilitation center and more than three hours on transportation every day.

4.5 Situation analysis (SWOT)

4.5.1 Strengths

- The complete maternal and child hygiene system enables the early screening and the early intervention of children with developmental disorder.
- Parents have a high acceptability of early intervention; they actively take part in the plan and have played an important role.

4.5.2 Weakness

- There is a lack of source of law and policy guarantee in the early intervention of children with developmental disorder, such as the emergency rehabilitation program specific to the poor disabled children of 0–6 years old co-launched by China Disabled Persons' Federation and Ministry of Finance, which is a periodical program, whose service mode is short of system guarantee.
- The insufficient publicity of early intervention and insufficient knowledge of parents often lead to the missing of relevant resources and best service opportunities.
- There is a short supply and uneven distribution of early intervention resources, failing to ensure the fairness and principle of proximity of resource utilization, which has made many children with developmental disorder unable to receive timely service. There is a large gap between supply and demand.
- Although early intervention is a kind of service of humanization, multi-profession, trans-disciplinary team cooperation, the coordination of the trans-disciplinary work is not easy. Parents and children still need to run here and there, tiredly.

4.5.3 Opportunity

- Our country and all levels of government have gradually paid attention to early intervention, and China Disabled Persons' Federation has put forward that "Rehabilitation services will be available for everyone in 2015" and launched emergency rehabilitation program specific to the poor disabled children of 0–6 years old.
- A lot of state-run special schools of the compulsory education stage and civilian-run special educational institutions have begun early intervention service to respond to the requirements.

4.5.4 Threat

- At present, the early intervention work system has not been completed, planning and coordination work system has not been established, and there is no standard service process of the early detection, early diagnosis and early intervention for developmentally disabled children, or a lack of effective connection between working links, which will cause the delay of the best opportunity of early intervention.

- The lack of cooperation between all relevant profession services and institutional sectionalism both make it difficult to integrate the trans-disciplinary teams, directly exerting influence on the effect of early intervention.

In summary, although a quite effective intervention technology has been concluded gradually for the treatment of millions of children who need early intervention, a system has not formed, with some operation technologies too scattered to guarantee the service quality. I suggest that the government introduces related policy, laws and regulations to ensure the universality and effectiveness of the early intervention and construct the implementation plan for the service to enhance the exchange and cooperation between organizations and professions and form consensus and tacit understanding between relevant professions and personnel to make up the insufficient manpower and resources; moreover, the assessment methods and instrument for children development should be integrated to facilitate the referral of individual cases and resource sharing.

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EEG Biofeedback in individuals with multiple disability in Slovakia

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Abstract: *This contribution discusses the possibility of application of neurotherapy carried on through EEG Biofeedback in Slovakia. A part of this contribution consists of partial research results carried on in the whole territory of Slovakia. One of the research goals was mapping the basic characteristics and the course of neurotherapy realized through EEG Biofeedback (neurotherapists' qualification, diagnosis qualification, clients' age, success rate in the area of sensomotorics, EEG Biofeedback in individuals with multiple disability etc.). Represented results were being found by means of questionnaire survey. In the conclusion the contribution contains brief casuistry of child with multiple disability.*

Key words: *neurotherapy, EEG Biofeedback, individuals with multiple disability, Down syndrome*

1 Introduction

During recent years a greater attention has been payed to the EEG Biofeedback in our conditions. It's increased application has been more apparent from sixties of the 20th century. It represents not only the acquisition of new information in basic areas of research, e. g. research of neurobiologic mechanisms of organism in the area of neuroplasticity, but also its application and its use in numerous indications apart from ADHD, ADD, epilepsy, autism etc. A more recent field, in which EEG biofeedback may be of good use is multiple disability. However, this issues still suffers from lack of interest both worldwide and in Slovakia. This fact is proved by thin volume of professional publications not only in our country but also on a global scale. From this reason, we tried to find by research investigation more data and conditions of EEG

Biofeedback application in Slovakia. First in general, then in the area of application in individuals with multiple disability. More detailed findings are presented below.

2 Theoretical implications

Theoretical implications concern the multiple disability and the field of neurotherapy carried on through EEF Biofeedback in general and with regard to the multiple disability.

Multiple disability

More recent definitions of multiple disability reflect influence of new paradigms, changes in philosophy and approach to these people. Overall, a man as a human being is emphasized, he should be approached holistically and all modalities creating his entity should be taken in consideration. Numerous definitions are characteristic in descriptive manner. The authors accentuate the extent of support, care from society and environment where individuals live, possibilities to assert in their life, development of personality in the process of education or individual's positives and strong traits.

Vašek (2003, p. 37–38) identifies the term "multiple disability" with formation of new quality of disability different from simple sum of present handicaps and disabilities. He explains this new formation of quality from the perspective of interactions and mutual overlapping of participating handicaps or disabilities, thus so called synergic effect, i. e. new quality of disability is formed. In author's opinion, this multifactorially, multicausally, and multisymptomatologically conditioned phenomenon determines substantially individual functionality of individual's compensating mechanisms. In simplified form, it expresses relations between individual factors that affect and determine multiple disability as follows: $MD = f(D_1, D_2 \ldots Dn, Sye, Cm)$. The result of this pattern expresses that multiple disability (MD) is function of concurrence of participating disabilities or handicaps (D1, D2…Dn), synergic effect (Sye) and compensating mechanisms (Cm).

Vašek defines "the multiple disability" also from special educational point of view as data flow disorder. This author's implication (2001, p. 163–164) originates from above mentioned findings when he states, that *"basically, it is about possibility of receiving, processing, preserving and operating the data within limited sensoric canals or difficulties associated with transformation of data to knowledge due to mental disability, as well as communicative difficulties due to expression disability"*. Simply, the difficulties associated with multiple disability *may occur in reception of data, in its central processing, expression or combined. In general one can state that multiple disability may occur in various numerous combinations in which inter-individual differences require* *strictly individual approach. Afore mentioned implications and definitions are used by other Check colleagues such as Vítková (2006), Ludvíková et al.(2005) and others.*

Neurofeedback, EEG Biofeedback

Tyl, Sedláková (1996), Palatová (1999), Tyl, Tylová (2003), Bálint (2006), Hammond (2006), Haward-Jones (2007) and others briefly define neurofeedback as monitoring of human brain activity with perspective of chance to influence it. It is a manner in which brain waves are managed through biologic feedback based on operant conditioning. Many studies use the terms like neurotherapy, neurofeedback, EEG biofeedback, brainfitness, taking them for synonyms.

Striefel (2004, quoted by SABN, 2010) alleges the differncies between the terms neurotherapy, neurofeedback and EEG biofeedback. He considers neurotherapy a clinic application of EEG Biofeedback, biofeedback of blood flow (HEG), audiovisual stimulation (AVS) and other suitable practices designed to change the cortical activity in order to achieve visible benefit. It is based on paradigm of psychophysiological self-regulation, self-transaction, "I see" phenomenon, but without reduction of operant conditioning model. Then he states that neurotherapy is mostly applied as separate training method, usually 2–3 times weekly with duration at least 35–40 min. On the contrary, neurofeedback is considered to be a concrete, separate therapeutic modality. Neurofeedback uses electroencephalographic (EEG) biofeedback, feedback of blood flow (homoencephalogram HEG), audiovisual stimulation (AVS) and other practices (CT, fMRI) in order to change the cortical activity, to change the consciousness, to modify physiological and psychological functioning. The term neurofeedback does not imply medical model and it is often associated to such application as peak performance training, specific performance optimisation and others. The author considers EEG Biofeedback a direct process of operant conditioning, in which client uses feedback from specific EEG parameters (frequencies, durations, amplitudes) in order to modify biophysical and electrophysiological operations of own brain.

January 10, 2009 International society for neurofeedback and research (ISNR) and its headquarters ratified definition of neurofeedback. The definition is of more descriptive and lengthy feature, hence we mention only some sections (ISNR, 2010). Neurofeedback (NFB), similarly to biofeedback uses monitoring tools, which provide detailed data on every single moment of individual's physiological functioning condition. A feature that differs NFB from other forms of biofeedback consists in focusing on central nervous system – the brain. The essence of the NFB training is based on both findings about brain in the area of applied neuroscience and varied data clinical practice. Except for brain activity, individual's behavioural, cognitive and subjective aspects are taken into consideration in NFB, thus necessity for holistic approach to individual in his bio-psycho-social context is met. The introduction of neurotherapy application requires assessment of brain activity (e. g. QEEG, EEG, fMRI…) and indivisual's psychological condition.

Most common indications are ADHD, ADD, autism, defects in autism spectrum, epilepsy, specific defect in learning (dyslexia, dyscalculia…), various addictions, post traumatic disorder, depressions, sleep disorders, pains, brain injuries and others (Tyl, 1997, Tyl, Tylová, 2003, Janský, 2006, Niv 2013, and others). However, if changes in neurons are taken into consideration, neurofeedback affects and induces change in EEG activity frequency and amplitude, what may influence acceleration of CNS maturation. Thus it is possible to assume a considerable success and asset of neurotherapy even in the areas of psychopathology, various disorders, handicaps and disabilities like diagnoses displaying multiple disability (compare Drtlíková, 2007 quoted by Gabarík, 2011). Professional literature rarely discusses the issues of EEG Biofeedback application in multiple disability. This is proved by current significant lack of theoretical and practical findings concerning EEG Biofeedback application in particular group of people both worldwide and in Slovakia. Given the character and substance of multiple disability, it is not surprising. In research it is very difficult to meet requirements from the perspective both of the methodology and creating homogeneous experimental and control group.

Apart from epilepsy or autism, cases of child cerebral palsy belong to most primary published casuistries relating to other diagnosis displaying multiple disability. Experts from Germany, Austria and Italy – Neuper, Műller, Kűbler, Birbaumer a Pfurtscheller (2003), in order to establish communication through computer, successfully attempted to influence the production of brain waves of 32 years old man with cerebral palsy on the basis of EEG and computer interface. A year later (2004) Bachers, psychologist and director of Neurofeedback Foundation publishes a case of 13 years old boy with child cerebral palsy who experienced significant improvement in behaviour, reduction of aggressiveness, improvement in communication, experiencing, reduction of excessive neuromuscular irritability and overall intellectual and emotional self-possession. This was achieved following 200 sessions, in fourteen days lasting intervals, with 20 minutes session durations, with localisations on central sensomotoric band. After 4 years the boy experienced increase in IQ by 24 points (IQ 72) in verbal part of WISC-III. The same year Margaret Ayers (2004) published in USA her most successful case of a boy called Jamie (9 years old) who could not speak, was blind, could not read Braille script, with cerebral palsy, by school staff taken for autistic and severely intellectually retarded and not capable to learn. Similarly to Bachers, the author applied neurotherapy on sensomotoric cortex with progressive inhibition of theta brain activity. The author does not describe in more detail duration and length of therapy, but she refers to positive changes in speech and motorics. The boy began to speak, feel, compose the music, dance and play the piano.

Another area (study) is EEG Biofeedback applied in 7 children with Down syndrome, aged 6–14 years, who participated in 60 sessions. The training began with inhibition the delta and theta and following decreased amplitudes of these frequency bands SMR and beta activity was increased. Surmeli, Ertem (2007), a psychiatrist and psychologist from Istanbul, Turkey declared positive changes particularly in the speech area, memory, attention, behaviour and balance of these children. Later, in 2010, the above mentioned authors published another study of 23 participants with Down syndrome with medium mental retardation, aged 7–16 years. Based on numerous diagnostic methods (QEEG, WISC-R, DPC-P, TOVA) they found out significant improvement in almost all participants not only in parental questionnaires but also in improvement in exact results like results QUEEG and DPC-P. They also pointed out that despite two cases did not display improvement in total IQ, improvement was achieved in individual subtests, what can be considered a success, too.

Also Yu, Kang, Jung (2012) from South Korea researched changes of brain waves and cognitive functions in children with cerebral palsy through neurofeedback. 28 children divided into experimental and control group were provided this therapy which consisted of 30 min. long sessions 2× weekly during 6 weeks. Both groups recorded statistically significant differences in spectral frequency by 50 %. Similarly, statistically significant differences were displayed in experimental group in all subtests LOCTA (Loewenstein Occupational Therapy Cognitive Assessment) in comparison with control group.

In Slovakia, there are two generations of professionals occupying with the issues of neurofeedback. It is an older generation represented primarily by Dr. Krivulka who as one of the first introduced and applied this therapy in the territory of Slovakia. He trained many neurotherapists working in various territorial units of our country. He rather recommended application of EEG Biofeedback in ADHD, ADD, tinnitus, specific learning disabilities etc (SABN. 2010). During recent years a new group of professionals stemming from speech therapists, psychologists, special educationalists, parents of handicapped children and others has been creating. This creation happens under the supervision of young, skilled neurotherapists representing so called new biofeedback generation, an institution called Biofeedback Institute Ltd. (newgenerationbiofeedback.eu). This organisation operates internationally (Checko-Slovak) – in Check towns Jihlava, Praque, Stonařov, in Slovakia in Therapeutic centre Bibiana in Prešov and it provides training of high quality in this area. Right this institution is one of the few that occupies with individuals with multiple disability. In its practice it has many skills with severely and deeply mentally (multiple) retarded persons. In the conclusion of this article we cite brief casuistry by Mgr. Bibiana Naďová, clinical speech therapists, brainfeedback therapist, EEG laboratorian working in Prešov in Therapeutic centre Bibiana and in Biofeedback Institute Ltd. in the Check republic.

3 Research

Considering the partial amount of data on EEG Biofeedback application in Slovakia in general and its application in special education and in pedagogy of individuals with multiple disability we carried on a research in December 2012. One of the primary goals of the research was to find out current status of application of neurotherapy carried on through EEG Biofeedback and possibilities of its use in intervention areas of special education in Slovakia (primarily in counselling centres focused on the work with pupils with health disabilities). The area of our interest was also the extent to which EEG Biofeedback was applied in individuals with multiple disability and in which parts of life it brought benefit etc. The principal method for data collecting was exploration method – a questionnaire distributed to various institutions and to experts from various areas.

In the initial phase of our research we focused on educational counselling and prevention school institutions, www.uips.sk, department of clinical speech therapy, licensed departments of clinical pedagogy, licensed departments of special pedagogy, neurological ambulances, organisations within the competence of Ministry of Health of SR as well as on certificated therapeutists in the area of psychophysiology – neurofeedback and biofeedback and psychologists registered in Association of Psychologists. From these organisations and experts we selected those using EEG Biofeedback (EEG BFB). Then we addressed 280 organisations and experts (of which 204 were educational counselling and prevention school institutions). 168 subjects of total number answered that they did not use Biofeedback (of which 146 were educational counselling and prevention school institutions), 35 subjects did not answer at all and 77 organisations stated they used EEG Biofeedback (of which 24 were educational counselling and prevention school institutions), what is 48,05 % return (in view of educational counselling and prevention school institutions, the questionnaire return was 55,81 %). Total number of respondents was 46. Despite low return we decided to assess the gained data. Hypotheses were verified through statistic software “R”: MS Excell. Testing of all hypotheses was based on central limit theorem by which transformation of binomial variables can be limit considered as normally divided variable. P-value was calculated by normal division distribution function. Zero hypothesis was accepted on 5 % level of significance, i. e. if p-value is ≥ 5 %, zero hypothesis is accepted, otherwise rejected.

Research questions and hypotheses

The research questions focused on four areas: course and manner of EEG BFB application in general in Slovakia then in individuals with multiple disability, therapists’ attitudes to this therapy, and benefit of EEG BFB for clients. For the purposes of this article we select two hypotheses. First hypothesis was as follows: neurotherapists – special pedagogues work more with individuals with multiple disability than neurotherapists – psychologists. Second hypothesis: neurotherapists working with individuals with multiple disability consider neurotherapy carried on through EEG biofeedback more ineffective in comparison with other neurotherapists.

Results

From the collected data we select the following. In questionnaire research we found out that EEG BFB was more frequently used in private institutions (63,04 %) than in state owned ones. Most of respondents came from Prešov county (26,09 %), least from Banská Bystrica county and Trnava county (6,52 %). EEG BGB is used mostly by women (86,69 %). Most frequently stated age of therapists was 50–60 years (30,43 %), but also aged 30–40 years and 40–50 years (26,09 %). From the perspective of primary qualification there was prevalence of pedagogy professionals (43,38 %), followed by professionals – psychologists (36,69 %). Other professions like speech therapists, doctors, health care workers, or other qualifications were represented similarly (6,52 %). EEG BFB is applied most frequently in diagnoses: F90–F98 Behaviour disorders and emotional disorders originating mostly in childhood and in youth (ADHD, ADD, behaviour disorders…) – 93,33 %, F81 Specific disorders of school faculties development – 60,00 %. Diagnoses often displaying multiple disability are represented as follows: G40 epilepsy – 11,11 %, F84 pervasive developmental disorders (autism, autism spectrum disorder) – 17,77 %, various injuries – traumas, inflammations, post stroke conditions, brain palsy and other paralytic syndromes (G83), mental retardation (F70–F79) – 26,67 %. Interesting is a fact that 13,33 % of respondents deal with speech and language developmental disorders, developmental dysphasia or stuttering. Other diagnoses or indications are neurotically or stress conditioned and somatomorphic disorders (F40–F48) – phobia, anxiety, depression, other mental disorders like emotional unstableness, organic mood disorders, migraine (24,44 %), addiction syndrome (4,44 %), burnout syndrome (4,44 %), sleep disorders (13,33 %), others (26,67 %). A non-clinical area belongs to indication, too – sportsmen, managers etc (13,33 %). Categories by age which are provided EEG BFB most frequently are as follows: 6–10 years (7,47 %), 11–15 (54,35 %) – i. e. school age of children. It is pleasing that respondents stated even pre-school age – less than 6 years.

In the second group of questions we provided EEG BFB in individuals with multiple disability. We were interested if neurotherapists worked with multiple disability and if they did, in what manner. We found out that 21 of 46 respondents (45,66 %) worked with multiple disability, most frequently two times weekly (71,43 %) with longest session lasting 40–49 min (83,33 %). Most frequent number of sessions were 100 with duration approximately 1 year and longer (47,05 %) what is closely related to length of practise of neurotherapists. Concerning the life of clients, they benefit from EEG BFB mostly in education (70 %), behaviour (60 %), personal and home life (60 %). Therapists point out the possible contraindications, e. g. extreme restlessness, incomprehension of instruction, incapability to focus, dysfunctional family, severe mental retardation etc. A remarkable opinion is the presence of "contraindication" in the form of " bad therapist" what is proved by numerous facts coming from our research. For the purpose of modification of EEG BFB training, respondents state necessity for application of special-educational principles and methods, adjusting the environment or adapting the training, but they do not state more detailed characteristics. One of biggest troubles related to multiple disability are troubles with clients with multiple disability and necessity for individual approach.

The third and fourth part of this article include issues on the respondents' opinion about effectiveness, parental view or indications of concrete changes of their clients. 44 of 46 (95,65 %) respondents consider EEG BFB effective with identifying most common changes in behaviour improvement, reduction of impulsivity, hyperactivity and somatic restlessness. The object of study was also the sensomotoric area, where 73,91 % respondents register positive changes. The changes mostly related to graphomotorics, visual differentiation, auditory memory, fine motorics or improvement in spatial orientation. 84,62 % respondents – parents view the EEG BFB positively. In addition, the parents claimed lack of information on this therapy in the public or people having inadequate expectations. Neurotherapists also mentioned increased demands on parents (regular session attendance, financial coverage of the therapy etc.). Another observation is that parents experience sceptic or negative attitude of neurologists, psychiatrists or other physicians. It should be noted that the respondents encountered negative parental attitude towards the therapy what might result from above mentioned "contraindication" in the form of inadequate neuroterapists' qualification. The overall attitude of neurotherapists to the EEF BFB is similarly positive – 78,57 %. Only one respondent claimed the contrary. Another opinion consists in comprehension of complex approach to client and not overestimating the therapy and the necessity for improving one's professionalism or cooperation and motivation of clients and their parents. In the first hypothesis we came to the conclusion that according to test of normal variable p-value equals to 12,96 %, what is more than 5 %. On the basis of this result, we cannot reject the zero hypothesis that neurotherapists-special educationalists does not work with individuals with multiple disability equally or less then neurotherapists – psychologists. The first hypothesis has not been proved correct.

In the second hypothesis we assumed that neurotherapists working with individuals with multiple disability consider this therapy carried on through EEG Biofeecback more effective compared to others neurotherapists. In the similar we detected p-value 11,47 % greater than 5 %. From this reason it was not possible to reject zero hypothesis that neurotherapists working with individuals with multiple disability consider the neurotherapy carried on through EEG Biofeecback equally ineffective compared to other neurotherapists. The second hypothesis has not been proved correct, too.

4 Conclusion and discussion

The research results indicate several important moments. First, there is a lack of institutions focusing on the EEG Biofeedback in Slovakia. Most of them operate in private area where client must pay for the services. We know from the experience that parents having children with multiple disability often come from poorer social conditions. Obligation to pay for service considerably limits possibilities of use of the therapy. Given this fact, however, it is necessary to realize a shift in the general perception of providing the services by providers, businessmen, public as well as the view of providing the services in other countries of European Union and all the world. These highly specialized services are much more developed in other countries than in Slovakia. Surprising is that EEG Biofeedback is mostly used in the eastern Slovakia, especially in Prešov county. On the beginning of the research we assumed that neurotherapy would be mostly used in economically more developed regions of Slovakia like Bratislava country. The results indicate that Bratislava country belonged to counties with the least number of institutions using EEG BFB.

The issue concerning the financing, service availability and their applicability is closely related to state legislative conditions and adjustment of various systems designed for state functioning. During recent years we can see the deepening gap between private and state sector. Therefore it is necessary to appeal more to state authorities and institutions for further optimization the functioning of individual sectors, thus increase life quality of people.

Another view on low number of institutions providing EEG BFB is related to necessity of high professionalism demanded from therapists, necessity of interdisciplinary knowledge, cooperation with other experts, sufficient patience and assertiveness, all these encountering numerous obstacles. In according to respondent cooperation with physicians, neurologists is often problematic and connected with great scepticism resulting from insufficient knowledge about the topic. Another topic for discussion is the general public awareness of the neurotherapy and reparation the negative opinion about its ineffectiveness.

In view of special education it is pleasant that EEG BFB is dealt with mostly by experts from this area, possibly psychologists. Thus we can assume covered necessity of individual approach to clients with ADHD, ADD, as well as individuals with multiple disability. Despite this, experts point out the problems concerning applicability of concrete methods, techniques or special educational principles in their practice. Thence the necessity for further education and supply new, clearer findings and their usage in the area of multiple disability-related pedagogy. Another point of interest for neurotherapists is demand for data in this highly specialized area of neurotherapy. Here we can see necessity for connection several sectors like medicine, health care, pedagogy, psychology and others, all this in the form of discussions, courses, lectures carried on in the educational institutions.

In addition, on the basis of respondents' statement we can polemise the quality of provided trainings concerning the biofeedback and neurofeeedback. From numerous telephone interviews and from own experience we can confirm that there exist many trained experts in neurotherapy who took the trainings for inadequate and sketchy. This finding results in question that how it is possible and which institution provides know-how of high quality. What do to with trained ones who invested much money any efforts but do not work with this therapy right due to mentioned reason? One of the solutions may involve various educational activities focused on completion the necessary knowledge and gain adequate erudition in applying this therapy.

Similarly, it is evident that almost all neurotherapists describe positive effects and asset of neurotherapy in broad range of diagnoses. This may result in more economic investment the finances on drugs, health care accessories etc. and more effective providing health and special educational services. Taking into consideration the fact that significant improvement in brain activity functioning in such severe diagnoses like central nervous system disorders, posttraumatic conditions, child cerebral palsy etc. happens within one year (how much sooner in less severe diagnoses) and that how much money end efforts is spent on the help these people we can express the opinion that with proper application of EEG BFB, faster and more effective use of their potentials and increase in their life quality may happen. Given this fact an idea occurs that expert working with multiple disability burnout very quickly just due to very low feedback on provided interventions from their clients. In case that experts see the improvement and their work fruitful in shorter period, we assume that they will have more motivation, enjoy and sense of success.

There are many areas which can be discussed, however, for the purpose of this article, we consider the above mentioned as sufficient for further reflecting and inferring further steps towards the progression. One of the steps is necessity of further research.

Casuistry

As a demonstration of EEG Biofeedback with multiple disability we select a case study of a child, carried on by Mgr. Bibiana Naďová in Biofeedback Institut in Prague. The child is 8 years old girl with diparetic child cerebral palsy, light retardation, strabismus, auditory disorder, delayed speech development, impulsivity, hyperactivity.

Personal history: a child from 2. pregnancy without complications, premature birth (26th week) without complications, too. For a small birth weight, prematurity and the complications in postnatal period (frequent infections, meningitis) placed to incubator for 4 months. Diagnosed with cerebral palsy, diparetic from (tiptoe walking, introduced physiotherapy by Vojta) associated strabismus (for correction an occluder for dominant eye recommended). Suspect extensive hearing error (she refused a hearing aid) which resulted in inadequate comprehension the speech followed by delay in speech development. S. communicated with screaming, reluctant to express in another way, e. g. signs commonly used by her family. I case the people around did not understand or did not met expressed requirement, dissatisfaction was again expressed with anger, reluctance, scream. She behaved socially similarly to individuals with autism spectrum disorder. Internal and external irritability and low capability of concentration associated with hyperactivity. From infancy she displayed continuous motoric restlessness. S. is very smart and curious. Due to these socially and educationally hardly suggestible expressions a suspect for associated light mental retardation of S. was expressed. Motorics was characterised as awkward. Graphomotorics inaccurate, content and formally under average. Hygiene habits observed, without assistance. Present very low ability to focus, impatience, impulsivity, expressions of motoric restlessness, awkwardness, and unwillingness to communicate largely preclude any education (testimony of mother and school teacher from the preparatory grade period in special kindergarten). Physiotherapy uses practices by Vojta, speech therapy, reflex therapy, basal and neurodevelopmental stimulation, craniosacral therapy etc. Following special kindergarten she attended 1. grade of preparatory level in special elementary school. Nowadays she attends 1st class of elementary school for hearing impaired.

Family history: S. lives in complete family with older brother (10 years old) who is her model. The brother was hyperactive in preschool age, approximately at 7 years of age hyperactivity ceased inadvertently. Both parents shared care of S., mother more active.

Introduced therapy NFB. Main objective of training was total satisfaction mainly of regulation of hyperactivity, impulsive behavioural expressions, communication development, improve the movement coordination. The role of the therapist was accelerating the brain activity to necessary frequencies. Training protocol of general stabilisation set to inhibit slow delta and gradual increasing electric brain activities to faster the delta, theta, prealpha, alpha and finally SMR.

Summary: S. participated in 180 sessions during 2 years (from 6. to 8. year of age). S. uses hearing aid which she refused and tore down before. She communicates with narrative speech (simple terms), added with signs. In according to mother she tries very much to communicate, properly articulate, what she cannot say there she uses signs. The concentration time considerably extended, hyperactivity decreased (constant running around the room at home and at school ceased) she watches fairytales in normal speed – before 32× accelerated. Mather claimed that S. could concentrate on 1–2 word in reading on the beginning of school year, three lines of text at the end of semester, but reading speed did not increase. In NFB training she is able to concentrate during whole time, before it was a problem to endure in first 5min long round. Behaviour displayed sedation, minimal signs of impulsive reactions. First time in her life mother experienced the moments when S. played alone and whole hour, does not require continuous attention of her parents or brother, sleeps peacefully through the night. In motoric area both mother and school teacher observed slight improvement in movement coordination. She handles writing well, writes clearly, can write alone even first words from memory. In the baseline EEG was fundamental activity of delta high amplitude, i. e. immaturity of CNS for the child's developmental phase (after 6th year prealpha up alpha should be displayed). After 100th session and control EEF there was observed prealpha and alpha as basic brain activity, but with remnants of the delta and theta.

Conclusion

The article discusses EEG Biofeedback in individuals with multiple disability in Slovakia. We submitted partial results from research in the field. We believe the findings may become basis for both further research and application of neurotherapy.

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Quality of life of an individual with sensory impairment: Modern word or hot issue?

LUDÍKOVÁ, L., 2012. *Pohledy na kvalitu života osob se senzorickým postižením.* Olomouc. ISBN 978-80-244-3286-1.

Reviewed by Hana Majerová

Quality of life, a modern concept and a practical phenomenon that has been reflected in projects carried out by many institutes in recent years. The publication 'Views of the quality of life of persons with sensory impairment' reflects a range of approaches in special education with a common denominator – requirement for a full life of an impaired individual. The authors of the publication Libuše Ludíková et al. (Dita Finková, Lucia Pastieriková, Kateřina Stejskalová, Martin Fink, Ivana Horvátová, Hana Joklíková, Petra Tomalová) provide an insight into specific areas of life of a person with sensory impairment.

An individual's view of what is quality could be subjective to a large extent if we did not know the current research and practice-based theoretical background. The present 206-page publication outlines the aspects of the quality of life of personas with visual and hearing impairment at various ages.

The book is divided into the following 7 chapters:

1. Quality of life – theoretical background
2. Quality of life of children with visual impairment with an emphasis on the quality of life of children with ROP
3. Quality of life of pupils with visual impairment
4. Quality of life of employees in school-based counselling centres
5. Quality of life of students with visual and hearing impairment at Palacky University, Olomouc
6. Employment as one of the indicators of the quality of life of an individual with hearing impairment in adulthood
7. Quality of life of seniors with visual impairment in the context of the degree and quality of awareness

The content and focus of the publication provide clear and attractive information about the quality of life of persons with sensory impairment. The theoretical framework is aptly supported by a practical dimension. The text is enriched with graphs and tables enabling quick understanding of the results of the research. The grammar of the text is of a high level and the literature used by the authors corresponds with the topicality and professional focus of the issue.

The reflection of the quality of life will always be subjective because an individual's life cannot be a quantity but is always a quality that should be 'lived to the fullest'. Such living is in many aspects a question of personal understanding, life philosophy, and cognitive as well as emotional approaches. The life of an individual with sensory impairment in various ages and the professions of persons intervening in the target group are the areas that should be further monitored and investigated.

A professional undoubtedly influences the quality of services rendered to impaired individuals. Similarly, an individual with sensory impairment actively affects the feelings of own personal satisfaction with life. The publication 'Views of the quality of life of persons with sensory impairment' can be considered a successful overview of this multidimensional issue.

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Information for authors

Basic information about the JEP

Journal of Exceptional People (JEP), should be based on 2 times a year publishing period in both electronic and traditional – printed form. To guarantee professional standards of the Journal we have applied to the front of special needs teachers, psychologists, therapists and other professionals in the U.S., Finland, Spain, Slovakia, Hungary, China, Russia, Poland and other countries. Above mentioned scientific journal aspires to be registered into the international database of impacted periodicals (Journal Citation Reports).

Journal of Exceptional People (JEP) will provide research studies and articles on special education of exceptional people. This area covers individuals with disabilities and, on the other hand, gifted persons. The *Journal* will focus on publishing studies and articles in the field of education, social science (sociology) and psychology, special thematic issues and critical commentaries. The publishing language of the *Journal of Exceptional People* is to be English exclusively.

The periodical is going to be published since the year 2012 by the **Institute of Special – pedagogical Studies at Palacky University in Olomouc**.

Instructions for authors

Scope of the article is strictly given – mustn't be more than 20 **pages** formatted according template (including list of references, images, tables and appendices). The body of the text shall be written in letters of Times New Roman size 11 b. Different styles are undesirable, use the normal template and also please avoid numbering of pages. The final version of the articles ought to be formatted to the paragraphs. The Editorial Board reserves the right to refuse contributions.

The file should be saved under the same name with the surname of first author and sent in a format with the extension doc or docx (MS Word 2007 and upper versions). Before sending a file with the paper it is required to scan for possible infections or viruses. Authors are responsible for content and linguistic aspects of the contributions. Please, do not number pages. Images, graphs and tables should be numbered according to the example (***Figure 1:*** *Preparatory exercise* [Times New Roman 11 b, italics]).

It is highly recommended to spend the necessary time correcting the paper – every mistake will be multiplied. Posted papers unsuitable for printing will not be published! Ensure appropriate division and balance between the various parts of the contribution and aesthetic placement of pictures and diagrams as well as their quality. Terminological correctness and formality are required.

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Section headings should be numbered and written, as described in following manual: standard signs, symbols and abbreviations are to be used only. Monosyllabic preposition are ought not to figure at the end of the line, but at the beginning of the next line – they can be shifted using the "hard returns" CTRL + SHIFT + SPACE.

The list of literature and references to resources ought to follow these norms and directives: ČSN ISO 690 and ČSN ISO 690-2 or Publication Manual of the American Psychological Association APA.

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Formal criteria:
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