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Development of upper limb functions and self-assessment in students with cerebral palsy in inclusive education

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Upper limb movements are essential from a very early age in children's learning processes, and play an important role in school tasks such as handwriting. In cerebral palsy (CP), the functions of upper limbs are often impaired, a factor that affects children's learning success. The aim of this paper is to briefly present the results of research that has been carried out in recent years at the Eötvös Loránd University's Bárczi Gusztáv Faculty of Special Needs Education, investigating the upper limb movements of students with CP and their self-assessment of function. Standardized hand function tests (MACS, QUEST, JHFT, Abilhand-Kids specific to CP) were used to assess upper limb function, and the International Classification of Functioning, Disability, and Health core sets for CP (ICF core set for CP) was used to self-assess functioning of students. The results suggest that CP pupils in inclusive education have a high level of upper limb function in general; they do not generally report serious problems with their own function and their environment, but they rate themselves lower than their peers in special education. Changes during the school year were poorly detectable. The ICF-based self-assessment also highlighted problems that other outcome measure methods cannot detect but may affect school life.

Keywords: cerebral palsy, upper limb motion, self-assessment of functions, school life, somatopedagogy

Introduction

Movement behavior is an integral part of cognitive and social development. Upper limb movements are essential from a very early age in children's learning processes, in becoming familiarised with the outside world, attaining self-sufficiency, and also in compulsory and leisure activities later in kindergarten and school. Fundamental movements develop between the ages of one and seven. Among other things, school-age children are able to perform basic manipulative movements. In elementary school, the child learns to practice natural movements in a changing and increasingly complex environment. During this period, two important factors influence participation and performance: one is the development of the accuracy of spatial and temporal coordination, the other

concerns tasks related to manipulation skills, as well as the intensive development of reaction time and movement speed (Sugden et al., 2013; Boronyai et al., 2015).

Primary school teachers seek to take advantage of these maturation processes as they teach students more and more precise and increasingly complex forms of movement. To mention just one, the acquisition and skill level of handwriting is a particularly important area because it can influence children's psychosocial development and is related to learning outcomes (Feder & Majnemer, 2007; Cahill, 2009). In cerebral palsy (CP), the functions of one or both upper limbs are often impaired, a factor that affects children's learning success. The effectiveness of learning and successful participation in school life can have a stronger effect on the co-education of children at school (including their social inclusion) compared to a state of impeded movement (Zgur, 2012). All of these circumstances have repercussions on the child's self-esteem.

The aim of the current study is to present the results of a pilot research project we have carried out in recent years among the cerebral paretic students of Eötvös Loránd University's Bárczi Gusztáv Faculty of Special Needs Education (ELTE BGGYK). Our studies focused on upper limb movements and the self-assessment of their functionality for students with CP in inclusive education.

The effect of cerebral palsy on a child's development and learning processes

According to a national definition in 2007, "Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems" (Rosenbaum et al., 2007, p. 9). Its importance is demonstrated by the fact that CP comprises the most common and costly chronic damage to the neuromuscular system in children and adolescents (Blohm, 2012; Richards & Malouin, 2013; Hurley et al., 2015; Miller & Bachrach 2017). Depending on the location of the brain damage, the subsequent movement disorder may affect one or the other half of the body or the whole body.

For children with CP, their development is characterised by abnormal sensorimotor development. Other forms of developmental disorder can also emerge in perception, posture, postural control, locomotor, and fine motor skills (Vekerdy & Nagy, 2017). An essential consequence of atypically evolving movement is that it limits the ability to adapt to everyday, changing movement tasks, thus actual participation in everyday activities is impacted (Sugden et al., 2013). It follows that in the case of a child with CP, the pedagogical goals and tasks associated with each age stage are often determined primarily by the tendency of the impairment and severity of the condition (Benczúr, 2017). In terms of hand functions, for example, a typically developing child can grab a hoop lying on the ground at the age of two to six months, shift objects from one

hand to the other at the age of four to eight months, build a tower of toy blocks at the age of nine to eleven months, and copy a circle at the age of twenty-four to forty months. (Sugden et al., 2013, p. 271). In contrast, in the case of CP, grasping objects by hand may not evolve or can only be accomplished in adapted form (Richards & Malouin, 2013). Another consequence is that these difficulties in complex movement influence learning processes (Fótiné et al., 2011; Szenczi et al., 2016). This may be associated with various comorbid conditions, including already extant and consequently evolving perceptual, cognitive, communication and behavioural disorders (Vekerdy & Nagy, 2017).

When examining the hand functions, intellectual abilities, and handwriting development of CP students with unilateral involvement, Tükel Kavak and Eliasson (2011) found the following. Children with CP perform worse in terms of visuo-motor coordination, speed, dexterity, kinesthesia, and graphesthesia compared to their peers displaying typical motor development (TDC). Deficiencies in movement planning also make the movements of the unaffected hand slower and less effective. Although progress can also be seen in these students' performance, the process of learning how to write takes longer. While IQ and age are good predictors for the expected quality of handwriting, these factors do not indicate speed. Another study that also examined environmental conditions additionally found a difference in handwriting between CP students and TDC control individuals (Tükel Kavak & Bumin, 2009).

Sentenac et al. (2013) examined the school education of CP students between the ages of eight and twelve in nine European regions. It was hypothesised that their participation in different types of schools would depend on the child's individual abilities, motor, and intellectual abilities. A total of 818 CP students participated in their study. All of the studied regions used the same definition and classification system for cerebral palsy (*Surveillance of Cerebral Palsy in Europe*). In their research, they recorded children's data (age, gender, major motor functions, intellectual impairment, vision, seizures during previous years, and communication) based on interviews with parents and recorded the particular type of school in which the child is studying. In addition, the Strengths and Difficulties Questionnaire was used to examine students' behavior and emotional well-being. In their research, they found that the most significant determinants of enrollment in certain school types comprised the age and types of impairments (motor skills, intellectual abilities, seizures, and communication) while emotional and behavioural problems were not factored at all. As a result, they found that, depending on the region where they live, two children with the same impairment may have different chances for entering traditional education (Sentenac et al., 2013).

The concept of special educational needs and inclusive education in public education

In the Hungarian education system, regarding to the 2011 CXC Act. a cerebral paretic child is a special need student. Based on the classification according to need, this disorder figures among those children with physical disabilities (based

on the Guidelines related to the 2020 National Core Curriculum). The 2011 CXC. Act on National Public Education is a new summary concept of children or pupils in need of special treatment. One subgroup of this is the group of children or students with special educational needs (SEN) (Papp, 2019). In the Hungarian language, integration/inclusion also function as synonyms for a form of co-education. Integration has been used as a type of social integration for people with disabilities from the beginning; the term of 'co-education with non-disabled peers' has emerged as the interpretation has evolved (Papp, 2012). Within the international context, it can be generally said that the use of these terms and their definitions are still not clear or uniform (Papp, 2012).

Renowned theorists of inclusive education have repeatedly pointed out that the most important thing is for professionals to define exactly what they assign to the concept of inclusion. School inclusion aims to create an environment that all children can use equally well. That is, it seeks to accommodate not only children with special educational needs, but all children. It always strives to support current underperformers after finding the reasons for poorer results (Kron, 2009; Ainscow et al., 2012). This is why it is important to conduct a thorough examination and evaluation of the factors underlying a student's academic performance. Kókay formulates the concept of inclusive education as the following: "In the terminology of the Hungarian school system, it means ensuring the participation of children with disabilities. In a pedagogical sense, it indicates that the school accepts students with different educational needs" (Kókayné, 2019, p. 552). Inclusive education furthermore takes individual differences into account.

The education of students with cerebral palsy in Hungary

Children with cerebral palsy are able to study at special or mainstream schools in inclusion. An European study conducted between 2004 and 2005 has shown that in certain countries the participation of children with CP in mainstream schools fluctuates between 20 and 93% (Michelsen et al., 2009). In Norway and Portugal, full inclusion is the most significant: in Hungary the two types of schools exist in parallel. It is therefore difficult to estimate the schooling of students with cerebral palsy because little CP-specific population-level data is available (Gillies et al., 2017). The national educational data are usually applied to students with special needs or to subgroups of different types of disabilities. Sixty-eight per cent of special educational needs (SEN) students attend a mainstream school. Most of these students have only one disability in a specific area (e.g., a physical disability) and the disability is typically mild in severity. Seventy-nine per cent of the students with (only) physical disabilities study at a mainstream school and 21% attend a special school (Márkus, 2019a).

Hungary's system of unified special education and conductive education methodology centres are supposed to support inclusion, including to assure the system of support SEN teachers and conductors (conductive education teachers). In Hungary, two pedagogical disciplines address the education and development of pupils with CP: conductive pedagogy and somatopedagogy

(Márkus, 2019a). Since the CP students examined in this study are served by support SEN teachers who specialise in educating students with physical disabilities, it is important to introduce this discipline, which is admittedly familiar to Hungary, but also somewhat known abroad.

The definition of somatopedagogy and its role in the education of CP students

Somatopedagogy (i.e., special needs education for physical disabilities) is one of the specialties of special education and addresses the complex rehabilitation of persons primarily with physical disabilities and secondarily with additional types of disabilities. "Somatopedagogy is a complex system, in which the effects of medical, psychological and pedagogical methods, procedures and tools are achieved in harmony with the individual with physical disability and his/her environment" (Benczúr, 2011, p. 110). Accordingly, it is not a method, but the application of purposfully compiled combination of methods. Based on the results of a complex evaluation, the SEN teachers for students with physical disabilities are supposed to support children and adults (without age limit) in the adaptation of needs-oriented and individualised combination of methods, as a member of the rehabilitation team. Mostly they work in the public education system but may be found in healthcare and social institutions (Márkus, 2019b).

Complex somatopedagogical rehabilitation is based on a complex evaluation and includes movement education, the improvement of communicational skills, cognitive activities, and socialisation. Movement education is the complex of effects that impacts the musculoskeletal system and combines therapeutic and pedagogical methods (Márkus, 2019b). In cooperation with inclusive schools, support SEN teachers for students with physical disabilities provide CP pupils with individual or small-group development while supporting the work of other teachers and offering advice to the school's educators. SEN teachers specialising in somatopedagogy can often work with other professionals in the rehabilitation of CP children. In addition to others, physiotherapists and conductors with partly similar activities.

International Classification of Functioning, Disability and Health as a self-assessment instrument

Approved by the World Health Organisation (WHO) in 2001, the International Classification of Functioning, Disability, and Health (ICF) is an international standard for framing, recording, and measuring functioning and disability. One of the purposes of ICF is to "establish a common language for describing health and health-related states in order to improbe communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities" (EV, 2004; WHO, 2007, p. 5). The question may be raised of why a rehabilitation model and evaluation tool appears in the context of inclusive education. The answer to this question lies in the fact that, by means of its "common language", this classification not only

enables health care workers but also teachers and students to understand their own or other's functional status. This explanation is best shown by the fact that ICF has enjoyed considerable use for many years in non-medical fields (Kullmann, 2012).

Visualisation of the respective experience is not mentioned among the original possibilities of the adaptation of ICF. However, this demand has been present among rehabilitation participants for a long while (Ueda & Okawa, 2003). The use of ICF for this purpose is not yet widespread. It is well known in rehabilitation, that observance of patients' opinion may have an effect on their participation and the efficiency of the rehabilitation. On the other hand, these patients' opinions serve such substantial information, which might not be shown with other appraisal methods (Kullmann & Kullmann, 2018). It is worth to follow up this occurrence in inclusive education to inspect children with cerebral palsy and assess changes while also framing the development plan.

A few words about the structure and use of ICF

ICF analyses the functional status of an individual in their actual environment, in three dimensions: from the perspective of the body, the individual and society. These categories are arranged in two main subdivisions (Functioning and Disability, Contextual Factors). Each part has more components: body functions (b) and body structures (s), activities and participation (d), and environmental factors (e).

The smallest units of ICF, called categories, are specified with letter-number coding (e.g., d170 Writing). This code continues with the qualifier number, separated by a point. The quality of functional abilities in each category may be assessed on a scale from zero to four, depending on the magnitude of an impairment. When zero (.0) is coded, this value denotes 'no impairment', while four (.4) denotes 'complete impairment'. The rating of the environmental factors is possible on a nine-point scale because all domains are coded as a barrier or a facilitator on a four-point scale. A rating of ".4" denotes 'complete barrier', meanwhile the + sign denotes a facilitator, accordingly "+4" code denotes 'complete facilitator', and "0" denotes 'no barrier, no facilitator' environmental factors (WHO, 2007).

The original ICF was published by WHO in 2001; the full version of ICF provides classification at four levels of detail. The short version of ICF is a two-level system that includes all the domains (WHO, 2007, p. 8). To make the application of ICF easier, faster, and more applicable to everyday use, beyond the aforementioned, two-level system, many developing, ICF Core Sets have been created for specific health conditions. The typically occuring ICF categories that belong to a specific health condition are included in these core sets (Kullmann, 2012). At present, specific core sets for eighty-three conditions are available, out of which fifteen have been adapted to three prominent NDDs – typically diagnosed in childhood – such as CP, autism and ADHD, which have a severe effect on kindergarten or school attendance (Schiariti et al., 2018; https://icf-core-sets.org/en/page1.php).

Schiariti et al. (2018) first studied the practical use of ICF-CY-CP in clinical practice in different countries in the world: this comparison was conducted using descriptive and cross-sectional analyses. The adaptation of ICF Core sets proved a helpful tool for the purpose of selecting appropriate services and provisions. Their experience has shown that in the course of research and clinical practice they would be open to using the ICF-based approach, but the question of how to do so during the examination is a remarkable challenge. To overcome this barrier, in 2017 Schriariti et al published a toolbox with the following title: *Toolbox of Multiple-Item Measures Aligning with the ICF Core Sets for Children and Youth with Cerebral Palsy*. Their study aimed to identify valid and reliable measures while creating a toolbox that would cover the content of each ICF Core Set for children and youths with cerebral palsy. Their result is a guide for professionals worldwide, to seek appropriate measures for their research and clinical work (Schiariti et al., 2017).

The examination of self-assessment of functioning in CP children

Teplin, Howard and O'Connor (1981) examined the self-esteem of fifteen (aged between four and eight years) children with cerebral palsy and compared the study participants to their age-matched control group. They established that the self-esteem of the group was corresponding, however, the self-esteem of children with cerebral palsy was lower with a consequent trend. Russo et al (2008) investigated the self-esteem and quality of life in children with hempiplegic cerebral palsy. Eighty-six pupils (ages three to sixteen years) participated in their study, and their results were compared to an age and sex-matched group. Self-esteem was measured using the Self-Perception Profile for Children and the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children. Quality of life was measured with the Pediatric Quality of Life Inventory. According to their findings, the level of quality of life is poorer and the self-esteem is lower in children with cerebral palsy. Although, in favour of the children with cerebral palsy, significant difference was found in maternal acceptance.

Oliveira et al. (2016) described the application of the ICF Core Sets for Children and Youth with cerebral palsy (from zero to eighteen years) on a nine-year-old child. For the items that could not be described by standardised methods, they asked the patient and his family. According to their findings, by applying the ICF-CY-CP, any patient's functionality can be described objectively and thereby enable a better evaluation of the patient's evolution in the follow-up with rehabilitation. The use of ICF-CY allows the evaluation to be expressed in a language that will allow comparison and preparation of report with administrative and clinical purpose.

In the research literature, few examples exist of using ICF to analyse self-assessment: in recent years, however, interest has grown in conducting standardised evaluation in different health conditions covering ICF categories (Farzad et al., 2014; Leissner et al., 2014; Fox et al., 2015). Similar research has been done with children with cerebral palsy. Andrade et al (2012) assessed

seventy-six children with CP using an ICF-based instrument while also interviewing their parents. The results were compared to the participants' socioeconomic status and type of cerebral palsy. Fontana et al. (2016) used ICF-CY-based questionnaires for very low birthweight children and the longitudinal change was tested. The questionnaires were completed by the parents and a member of the follow-up team. As far as we know, this is the first time that an ICF-based instrument has been used for the self-assessment of functioning for students with cerebral palsy (Lénárt et al., 2018).

Our own study among cerebral paretic children in inclusive education

Examination of upper limb movements and self-assessment of functioning in students with CP in special school

Our first studies were conducted in the 2015/2016 school year at a special school with a larger CP sample (forty-six individuals). At the time, our examinations were still taking place at a special school, an important starting point for our subsequent assessment. Therefore, the purpose of this research is only to describe the most essential details. As very few similar studies have been performed in Hungary, our purpose was to find and test the research methods known in the international literature, which can be used freely but are still little known in Hungary. As a control group, we included a mainstream school's non-CP students from primary and secondary schools (twenty-nine students with typical development and twenty-one students with speech and language disorders). Since the hand function tests would have been too easy for the control groups, they did not perform these taks, but only answered the questions of the International Classification of Functioning, Disability, and Health core set for CP. We performed the same instrumental motion analysis with them as we did with the CP students (Lénárt & Szemenyei, 2015; Lénárt et al., 2017, 2018). Motion analysis clearly showed differences between the two groups.

The differences were also seen in the self-assessment of functionality (b2 Sensory functions, b7 Neuromusculoskeletal and movement-related functions, d4 Mobility, d5 Self-care. Out of the changes recorded during the school year, in this study we only draw attention to the fact that CP students observed significant improvement precisely in those areas where they had previously reported a greater problem compared to members of the two control groups. However, it has also been noted that students in non-special schools (especially those with special needs) often judged their own status more severely than students in special schools. It was this phenomenon that prompted us to compare the self-esteem and upper limb functions of CP students in special schools versus inclusive education.

The comparison of the functions of upper extremities and assessment of functionality-based on self-assessment – in CP children in inclusive and special education

In the 2016/17 school year, we examined eight cerebral paretic students participating in inclusive education. The study areas included gross motor function (GMFCS), functional level of upper limb movements (MACS), degree of difficulty of daily self-sufficient movements (Abilhand-Kids specific to CP), and self-assessment of functionality (ICF core set for CP). (The methods are presented in Chapter 7.3.) The study results were compared with the gender- and age-matched members of the original sample of CP students in special education.

CP students studying in inclusive education performed significantly better in the areas of gross motor function and self-sufficient movements. In short, they solved tasks that required ordinary hand movements significantly better. Although the functional level of upper limb movements (MACS) also showed better results among those cerebral paretic students who attended in inclusive education, the difference was not significant. Thus, based on expert evaluation, the mobility status of these CP students proved better than the mobility status of the fitted control group in a special institution.

A comparative analysis of the ICF categories showed that in most categories, functional states are assessed similarly by members of the two study groups. It is also common to find that, broken down by individuals, both the pupil in inclusive education and the pupil in a special education institution rate their condition more negatively, but no trend can be detected.

In some categories (b164 higher-level cognitive functions, b710 mobility of joint functions, d230 carrying out daily routine, d415 maintaining a body position), students in inclusive education rated their functional status more negatively. This may be because they compare themselves to their non-disabled schoolmates and found their functional status more limited in this comparison. In the category of 'Looking after one's health' (d570), we found that pupils in inclusive institutions say that maintaining their health is more problematic and not as important compared to students attending a special education school. While inclusive school's CP students have an average of two to three hours of personalised adaptive physical activities per week, students at a special education institution receive five personalised adaptive physical activities lessons per week. The swimming pool in the special school and the various optional sports activities also contribute to their healthy lifestyle. In the canteen, children can choose from several menus, including a diet one. In the case of mainstream school CP students, they found it less important and possible to pay attention to their health due to the lack of or less opportunity for daily physical education, school sports, and health-related activities.

Students in inclusive schools found their extended family (e315) and products and technology for education (e130) less supportive compared to students at a special education institution. The reason for the difference between the latter may be that the special education institution is extremely well-equipped:

students can receive personalised teaching aids, for example. Meanwhile, based on our observations and interviews, students attending inclusive education receive minimal help and study under nearly the same conditions as their typically developing peers (Hegedüs, 2018). Our examination of CP students in inclusive education was repeated six months later. Minor changes were also detected in all areas, which generally indicated improvement, yet these changes were not significant in either area (Hegedüs & Lénárt, 2018).

Six-month follow-up of development in upper limb movements in CP students in inclusive education on the grounds of professional assessment and self-assessment

After the presented pilot research, we performed examinations utilising the tested measuring methods on an extended sample and with the aim of exploring:

- the global movement condition of pupils with CP in inclusive education, with special regard to the functions of the upper limb
- how they asses their own functional status,
- what connection can be found between the measurable characteristics of the upper extremities and the self-assessment, as well as
- how the measured characteristics change after six months based on the assessment of the professionals and the participants' own self-assessment

Following previous agreement and provision of research ethics[1], the research started in May 2019 and its follow-up finished in November 2019. With the assistancs of some inclusive schools of Budapest, we were able to examine pupils in their own conventional environment.

Methods

Sample

We aimed to involve every pupil with CP who is provided an support teacher (specialised in somatopedagogy) by the system of special education and attends the aforementioned special school: Mozgásjavító' Kindergarten, Elementary and Specialized Secondary School, Unified Special Education Methodology Centre and Students' Residence in Budapest. Altogether we selected fifteen pupils in the pattern, and thirteen (eight boys and five girls; aged between seven and eighteen years with the average age of 11.5 years) students participated in the follow-up study. The enrollment criteria were the following: normal intellect, diagnosis of cerebral palsy, and perceptible functional limitation in at least one of the upper extremities.

Research methodology

The set-up was based on the experiences of the previous pilot studies and can be described as follows. The students' SEN teachers classified the global

[1] All participants received a written research briefing. The consent form had been signed by the parents of children and participants aged 16 or above. Participation was voluntary.

functional level of their locomotion (Gross Motor Function Classification System – GMFCS) and upper limb functions (Manual Ability Classification System – MACS). To assess the upper extremities skills, we applied three tests: the Quality of Upper Extremity Skills Test (QUEST), the Abilhand-Kids Scale, and the Jebsen Hand Function Test (JHFT). For the self-assessment, the ICF Core Set for children and youth with CP was used. We tried to assess every student in one sitting, which took about forty-five minutes. In every case, the first methods comprised the tests for measuring upper limb functions, followed by questions from the ICF core set. At the end of the session, we recorded the classification into the GMFCS and MACS categories. Below contains an elaboration of the methods and the examination process.

Self-assessment of functions

In the study, we applied two relevant age-related ICF core sets (6-14 and 14-18) developed by Schiariti et al (2015). We used these two core sets as one contracted 42-category brief set, which was complemented with d445 Hand and arm use category. Every student was examined face-to-face, in a separate room. Firstly, we explained their task: they would hear statements which they have to assess by themselves. Afterward, the ICF categories were read to the participants. If it was necessary, with their explanations and inclusions and/or exclusions of the given categories of the two-level system. In the case of uncertainty, they had the opportunity to ask questions, and clarifications were provided. We encouraged students to express their opinions, especially if they were not able to decide easily between the level of qualifiers. Hence, the level of qualifiers was frequently asked first in a narrative form, and secondly by making the explicit qualifier. If the statements of the student were not corresponsive, additional clarifying questions were asked. The final word always remained with the pupils.

In the course of the assessment of functional abilities, the students were able to qualify their functional state between 0 and 4. 0 denoted 'no impairment', 1 denoted 'mild problem'; 2 denoted 'moderate problem'; 3 denoted 'severe problem' and 4 denoted 'complete problem'. Qualifying the environmental was based on a positive and negative interval scale between .4 and +4. Although the meaning of the numbers is similar to the use of the previous qualifiers, the lack of sign indicated which environmental factor acts as a facilitator (+) or a barrier (-) (WHO, 2007). The time for filling in the assessment was variable in each case and ranged from those who required little explanation, whose responses generally took fifteen minutes. The timeframe increased proportionally with the number of added clarifying questions and examples.

Ordinal Scales

A recognised classification tool in CP, the Gross Motor Function Classification System (GMFCS) is based on the self-initiated movement and use of assistive devices (Palisano et al., 2007; Vekerdy & Nagy, 2017). It is a five-level system to describe the following gross motor function: sitting, walking, and use of

mobility devices. The Manual Ability Classification System (MACS) was developed for children with cerebral palsy, aged between four and eighteen years (Eliasson et al., 2006). MACS describes five levels, which are based on the pupil's self-initiated abilty to handle objects in everyday life. Children with minor limitations are placed on Level I and children with severe functional limitations are usually found at Level V. The children's functional state has been established by their SEN teachers, based on these two ordinal scales.

Examination of upper extremities

ABILHAND-Kids specific to cerebral palsy children scale is a measure of manual ability to manage daily activities. It consisted of twenty-one bimanual tasks and is rated according to difficulty: impossible, difficult, easy, or not attempted in the last three months. According to the authors' experience, rating by parents is the most reliable (Arnould et al., 2004). Basilio et al (2016) confirmed that the use of ABILHAND as a questionnaire in adult chronic stroke patients is appropriate. Based on the positive experiences garnered in our previous research with CP children, we also decided to ask the children themselves.

The Jebsen Hand Function Test (JHFT) assesses fine motor skills during the performance of daily activities and consists of seven items: writing a short sentence; turning over cards; picking up small common objects; simulated feeding; stacking checkers; picking up large light cans; picking up large heavy cans. The testing always began with the non-dominant hand (Jebsen et al., 1969).

Total score is the sum of time taken for each item. Officially one item can not last longer than two minutes, but since in Hungary these evaluation methods have not been used in children with CP, we did not interrupt the assessment after two minutes. The longest time required almost four minutes more for students to complete the item regarding 'writing a short sentence' with the non-dominant hand. It took approximately twenty minutes to complete the JHFT.

Contrary to the rest of the assessment tools, JHFT is not freely accessible. In Hungary, ELTE BGGYK was the first institution to buy the test kit for a target population that includes patients with hand disabilities or hand dysfunctions. It is subsequently appropriate for the examination of children and youth with CP. The first test of JHFT in Hungary – with the participation of stroke patients – was conducted by the academics and students of our faculty (Földi et al., 2018). As far as is known, our team was the first to attempt the same on an individual with CP.

The Quality of Upper Extremity Skills Test (QUEST; Dematteo, et al., 1992) consists of four domains: A - dissociated movement (independent finger movement; shoulder items, elbow items, wrist items; grasps); B – grasp; C – weight bearing; D – protective extension (protective arm reaction); and 33 activity items separated among the domains. The children had to be in a predetermined position and we demonstrated each task. During the examination of dissociated movement and gasp domains, the children had to

sit on a chair and we examined the weight bearing and protective extension domains on a polifoam floor mat. In the course of assessment, both hands are scored separately and the scores are totaled at the end of each domain. The total testing time was approximately twelve to fifteen minutes.

The results are displayed based on a narrative data analysis and descriptive statistical methods. The changes and correlation between the different results were analysed using Wilcoxon test, Spearman correlation and paired sample t-test (corresponding to the level of the measurement level of scales). P values of less than 0.05 were considered as statistically significant.

Results

Measured characteristics of participants and changes during the semester

Based on the rank scales, most of the CP students enrolled in the study (eleven individuals) moved around independently, without any aids (GMFCS Level 1). Some required minor assistance or aids to relocate (GMFCS 2, 3). Based on MACS scores, the majority (eight individuals) used objects easily and successfully and manipulated them well. The rest required less help with everyday manipulation activities (MACS, 1, 2, 3). Nor were there any major obstacles to judging day-to-day self-sufficiency activities. Most of the activities listed in the Abilhand-Kids checklist were considered easy by the students. Difficulties were indicated in some cases, but none of the activities were considered impossible. The total scores of the QUEST upper limb functional assessment also showed a value close to the maximum 100 (mean 89.3, standard deviation: 19.43), but significantly different values (27.64) were also received. In the ICF-based assessment most of the students did not report a problem (0), but some pupils reported more serious difficulties in some areas than others.

Out of the Jebsen Hand Function Test subtests, the *Writing* and *Simulated feeding* tasks proved the most difficult. All tasks were performed faster with the dominant hand, but the performance of the two hands correlated with one another ($r = 0.5\text{-}0.95$, $p < 0.05$). This means that the student who performed the tasks faster with the dominant hand also performed faster with the non-dominant hand.

We started our control studies six months after the first one. During the re-admission of *Abilhand-Kids*, we found that there was a minimal decrease in the number of activities deemed easy and revealed a proportional increase in the number of activities that were difficult to perform. Based on an analysis completed with the Wilcoxon test, no significant change was observed.

After repeated examinations of the *Jebsen Hand Function Test* tasks, we found a significant improvement only during the "Large, heavy objects" subtest (dominant hand $t = 2.575$, $p < 0.024$; non-dominant hand $t = 2.317$, $p < 0.039$). In general, however, for most tasks both the dominant and non-dominant hand activities took less time to complete, the most spectacular result was shown in writing, card turning, simulated feeding, and moving light objects.

An exception to this is the "Checkers" subtest, in which seven out of thirteen students took longer to complete the task during the second time with the non-dominant hand; for the dominant hand, five participants needed more time during the control study.

In a second assessment of the *Quality of Upper Extremity Skills Test*, we found a positive change in three students, one outright, while no or a negative change was observed in the other students. The changes were not significant in any of the subtest cases. We will now review the results of *ICF-CY for CP* follow-up study according to the ICF chapters. We mention only those categories in which we were able to detect changes within six months.

Body functions

Within the *mental functions (b1)* chapter, the motivation category has been found more problematic by almost the half of the students. In the sleep functions (b134), six students reported changes in the positive direction, while out of them one prominently improved. Higher-level cognitive functions (b164) exhibited change in nine students with seven out of the nine changing in a positive direction. In total it is revealing that, in most cases, the functions were assessed better or worse only with one qualifier.

In the *sensory functions and pain (b2: b210, b280)* chapter the quality and quantity of the changes were negligible based on our observations. The *Neuromusculoskeletal and movement-related functions (b7)* chapter includes the mobility of joint functions (b710), muscle tone functions (b735), and control of voluntary movement functions (b760). In every category, almost half of the students exhibited a change: the distribution of the changes in positive and negative direction is also approximately 50/50.

Activities and participation

Learning and applying knowledge (d1) includes solving problems (d175). The results of the control study in this category were similar to the original study, but two students denoted 'no difficulty (0)' instead of 'severe difficulty (3)'. One pupil indicated larger impairment: instead of 'no difficulty (0)', he indicated 'severe difficulty (3)'.

The *General tasks and demands (d2)* chapter includes the following categories: carrying out daily routine (d230) and managing one's own behaviour (d250). In both categories, at least half of the children perceived changes. The ratio was fifty-fifty in both, referring to negative and positive directions. Almost in all cases the pupils gave higher or lower qualifiers with two levels.

Conversation (d350) belongs to the *communication (d3)* chapter: only one student indicated any change. During the control study he indicated 'mild difficulty (2)' instead of 'no difficulty (0)'. In all categories for the *mobility (d4)* chapter, nearly half of the pupils perceived changes. We found outstanding deviation on the following chapters. In the fine hand use (d440) category 11 students reported change, two out of eleven were larger: one of the students gave a better qualifier with two levels, and one student gave a worse qualifier

with three levels. In maintaining the category referring to body position (d415), we observed changes in two students: one noted larger difficulty with three levels and one reported a smaller difficulty with two levels. We did not note remarkable changes in the categories of hand and arm use (d445) and moving around (d455). The *Self-care (d5)* chapter includes the next categories: toileting (d530) and eating (d550). We did not experience outstanding changes in toilet usage and eating, but in the case of d550, more students indicated larger difficulty in the control study. The third category in this chapter is looking after one's health (d570): nine children perceived changes, two of them denoted larger difficulty, but none of them was significant. In the categories of *interpersonal interactions and relationships (d7)* chapter we did not observe any remarkable change. The *Major life areas (d8)* chapter includes the following categories: school education (d820), acquiring, keeping and terminating a job, recreation and leisure (d920). We did not find outstanding change in these areas.

Environmental factors

We experienced change in the products and technology for personal use in the daily-living (e115) category of the *Products and technology (e1)* chapter. Nine pupils perceived changes: those who perceived change in a positive direction gave better qualifiers with two levels; two of the students denoted noticable change in a negative direction.

In the *Products and technology for personal indoor and outdoor mobility and transportation* category we found changes in seven students. In four cases out of seven, we were not able to get an appraisable answer during the original study, but in the follow-up all of them denoted 'complete facilitator (+4)' or 'substantial facilitator (+3)'. In one case we perceived remarkable deterioration. In the *Products and technology for education* (e130) category we discovered changes in nine students with three out of the nine displaying a remarkable alteration in a positive direction.

In the *Products and technology for culture, recreation and sport* (e140) category, we found change in two cases, out of which only one was remarkable: 'no facilitator (0)' changed to 'complete facilitator (+4)'.

In the category of *Design, construction, and building products and technology of buildings for public use* (e150) we noticed change in five cases; four out of five moved in a positive direction with one out of these four displaying remarkable change: he indicated 'complete facilitator (+4)' instead of 'no facilitator (0)'. Changes were found in the *Support and relationships (e3)* chapter. In the *Immediate family* (e310) category, five students perceived change, one of them noticeably as he recorded 'complete facilitator (+4)' instead of 'mild facilitator (+3)'.

In the *Friends* (e320) category, we found change in five cases: three students moved in a positive direction, with one demonstrating remarkable change in that she gave 'substantial facilitator (+3)' qualifier instead of 'mild facilitator (+1)'. The changes that occurred in a negative direction were remarkable: one student denoted a 'complete barrier (4)' qualifier instead of 'complete facilitator (+4)'. In the *Personal care providers and personal assistants* (e340) category, we found changes in five cases. All of these moved in a negative direction,

with two showing marked change: these students indicated a larger extent of impairment with two and four levels (Z=-2.060, p<0.05). In the *Individual attitudes of friends*, in the *attitudes (e4)* chapter, we denoted changes in seven pupils. Four cases displayed remarkable impairment: two children denoted lower qualifiers with two levels, and two with three levels. Even though the change did not achieve significance, a trend (Z=-1.848, p=0.065) did emerge.

In the *Societal attitudes* (e4619 category, we found changes in six students: in two cases this alteration occurred in a positive direction. Both were remarkable in that they denoted improvement mounting to two levels. In four cases where we perceived impairment, the qualifier was lower by two and three levels. In the *Services, systems and policies (e5)* chapter we were able to collect more data during the follow-up study. In general, we did not experience any remarkable change within the categories, but in many cases, we were still able to observe improvement.

Although we could measure significant changes only in two categories, we may deduce – by the changes of the quailifiers – that there still is a trend for improvement in the following categories: higher-level cognitive function (b164), solving problems (b175), fine hand use (d440), hand and arm use (d445), looking after one's health (d570), products and technology for person use in daily living (e115), products and technology for personal indoor, and outdoor mobility and transportation (e120). We could meanwhile observe noticable impairment in two categories: personal care providers and personal assistants (e340), individual attitudes of friends (e420).

In conclusion, as regards the changes that may have occurred within six months, we did not observe significant improvement in the results of ABILHAND-Kids and QUEST. Relative to the outcome of JHFT, one subtest showed significant improvement, however, in other subtests we observed discernible changes in positive direction. During the assessment of the ICF categories, we did not find relevant difference between the two measurements. In general, we experienced improvement in more cases or nearly consistent results; whilst impairment was observable in fewer cases, but it was more tendentious.

Relation between the results of different examination techniques

We have investigated the correlation between the results of upper limb and relocation movements both at the first and the second measurement process. We have also compared the test results with those specific FNO-categories related to upper limb functionalities or relocations, (b735 Muscle tone functions, b760 Control of voluntary movement functions, d440 Fine hand use, d445 Hand and arm use, d460- Moving around in different locations) as well as all the ICF chapters. Previously, we used chapter-based comparison (Fontana et al., 2016) which enabled us to evaluate the students not only by categories, but by chapters, too. We have measured a significant correlation between the two rating systems, GMFCS and MACS (r=0.753, p<0.01). This means that, as the upper limb functionality deteriorates, larger movements start to become more and more hampered.

The *Gross Motor Function Classification System* showed measurable significant correlation with the following IFC categories: in the first measurement period, the d 465 Moving around using equipment ($r=0.603$, $p<0.05$), in the second measurement period b760 Control of voluntary movement functions ($r=0.670$, $p<0.05$), d460- Moving around in different locations ($r=0.713$, $p<0.01$) and trend-like correlation with the category d440 Fine hand use ($r=0.525$, $p=0.065$).

The bigger, merged categories showed significant correlation in the second measurement period with the following categories: b7 Neuromusculoskeletal and movement-related functions ($r=0.625$, $p<0.05$), d4 Mobility ($r=0.561$, $p<0.05$), and a trend level with the a d7 Interpersonal interactions and relationships ($r=-0.533$, $p=0.061$). The strength of these significant correlations are viewed as moderate.

The *Manual Ability Classification System* was correlated with the ICF categories b760 Control of voluntary movement functions ($r=0.631$, $p<0.05$) and b7 Neuromusculoskeletal and movement-related functions ($r=0.729$, $p<0.005$) during the second measurement period. The results show that the evaluation of the specialists on the upper limb functionality are similar to students evaluating their own relocation capabilities. These also display moderate correlations.

The *Quality of Upper Extremity Skills Test* showed strongly significant correlation with the e5 Services, systems and policies merged ICF category at the first measurement period. Here, despite the measured high values, the results should be rather trend-like as the number of measurements taken were rather small. The results suggest the higher the measured upper limb score given by the disabled people, the worse score was given by them for the surrounding services, systems and regulations. In the second measurement period, the QUEST shows significant correlation with the following ICF categories: d445 Hand and arm use ($r=0.629$, $p<0.05$), merged category of d2 General tasks and demands ($r=0.582$, $p<0.05$), and trend-like correlation with the Self-care ($r=0.531$, $p=0.062$). The strength of all the measured correlations is either weak or moderate. In every case correlation between variables was positive which suggests – based on the scale interpretation of the tests – that the higher the score the specialists gave for an upper limb functional state, the more troublesome rating was given for these functions by the disabled people.

The evaluation of the *Abilhand-Kids* did not show any significant correlation with either of the examined categories in the first measurment period. There was, however, significant negative correlation with the categories of chapter of *Learning and applying knowledge* ($r=0.669$, $p<0.01$) and positive correlation with the categories of chapter *Self-care* ($r=-0.544$, $p<0.05$). This means that disabled people tend to rate their functions of studying and application of knowledge worse but give better ratings for self-sufficiency as better practical upper limb functions appear. The measured correlations display moderate strength in both cases.

The *Jebsen Hand Function Test* showed correlation with the other results in several cases. The classification scales (i.e: GMFCS, MACS) and JHFT showed correlation in two sub-tests, the Picking up small, common objects and the

Moving large empty cans subtest (r=0.7, p<0.01). In case of the QUEST, the *Page turning* subtest of JHFT showed correlation with the subtest of QUEST B (Grasp and release) QUEST D (Protective Extension) and JHFT construction of a disc tower task with QUEST A subtest (Dissociated movements) (r=0.5, p<0.05). We found multiple correlations with the categories of FNO-based functional self-assessment (e.g. b117 Intellectual functions, b710 Mobility of joint functions, d175 Solving problems, d570 Looking after one's health, d710 Basic interpersonal interactions). However, there was no correlation between everyday activity list of Abilhand-Kids and the JHFT test.

On the whole, it can be stated that the two assessment periods produced multiple correlations between self-assessment of students and upper limb functionality measured by specialists. These correlations can usually be found between subtests and categories.

Discussion

Summary of the results of previous research

Based on the results of our research, we have observed the following findings.

- The examined participants – students with cerebral palsy in inclusive schools of Budapest – do not have serious impairments in their upper limb function and gross motor function while their results approach physiological standards. The children's movement are usually on a higher funcional level than their peers' in special school. This phenomenon is in accordance with the published educational data of the antecedents in literature, which affirmed that students in inclusive education mostly fall within only one major disability category and the cases are less severe (Márkus, 2019a). The significance of the tests is that they are able to draw attention to smaller deflections and specific areas for improvement.
- Based on the ICF Core sets, the students did not indicate outstanding problems, but in general they assessed their own funcionality and their environment – acting as a facilitator – lower than their peers attending special schools. Daniel and King (2010) studied the effects of students' placement versus non-placement in an inclusion classrom. Among the examined students, teachers and parents also participated and the data collection process consisted of gathering information from various locations and individuals, which involved the students' self-reported self-esteem analyses. According to their findings, the results showed that students placed in inclusion classes tend to have lower self-esteem compared to students in non-inclusion classrooms.
- It has been determined that the changes within a half-year period are not remarkable. This result may be explained by the following: the short interval between the original and follow-up studies and the fact that the students reached high scores during the first examination. At the same time, one (picking up large heavy cans) of the subtests of JHFT showed significant improvement. This type of task did not appear in the other tests and this

function may be related to the the smaler children's physical development. This fact also confirms the necessity for multifaceted measurement.

In conclusion, the ICF-based self-assessment did not show significant changes, but large individual differences were noticeable. Some surprisingly large changes also occured. In such cases, the possible presence of a mistake resulting from the mode of questioning and data recording must be taken into consideration. Yet we also have to consider that the ICF always reflects the actual state. This is why it is not improbable that a youngster – going through many emotional and physical changes – assesses his/her friends as a 'complete facilitator (+4)' in May, and six months later, during the follow-up study, the student qualified the same category as a 'complete barrier (.4)'. If taken out of context, the example typically refers to an area in which we are able to collect information only from the children and which indirectly affects their school performance.

When evaluation the changes, our results can hardly be in accordance with the antecedents in literature, since the examination of hand function on individuals with CP is a little investigated area (Klevberg, 2017). In themselves, these outcomes are not definitively appraisable, yet still calls for teachers who are working in practice to focus on which partial area should be improved or altered.

– A comparison of the different results shows that the subtests which measure the similar scope of activities and functions correlated to one another. The results which show the connection between the movement ability classification tests and the – at first sight outlandish – categories of ICF may be even more interesting. For example, the negative correlation between the interpersonal interactions and relationships (d7) and GMFCS shows the better functional level of the locomotions, the worse the quality of interpersonal interactions is assessed. Similar correspondence appeared also with the categories of *Services, systems and policies* (e5). Accordingly, individuals with mild disabilities are more critical with the individuals in their milieu. Other correlation results imply that the assessment of the activities related to movements and self-sufficiency are similar in the professionals' and students' opinion.

Observations of methodology

We did not have the possibility to assess all the tests in one sitting with every student. The children's tempo, the severity of involvement proved determining, and the age of the students also impacted the needed time. Younger pupils were more motivated, viewed the tests as more entertaining, while for the juveniles it was just a 'mandatory task'.

During the assessment of ABILHAND-Kids it occured in some cases that students considered an activity to be easy that was not necessarily justified by their state of motion. In such cases, we requested the opinion of their SEN teacher responsible for providing their adaptive physical activities. It has been observed many times, that we did not presume, for example, that zipping up

a zipper is an easily doable task. Even so, the participants had independently developed special adaptive techniques that enabled them to complete this kind of task at nearly the similar tempo and level of quality as their peers displaying typical development.

During the assessment of JHFT, the most important aspect was the positioning: every child had to sit properly while everything was placed in front of them according to their height. Younger students considered this test as 'the most entertaining' and were exceptionally motivated. This circumstance meant that it was more often necessary to warn them to start the subtests only after the signal. We consider as a limitation of the method, that the youngest participant was eight years old, while the oldest was twenty years old, yet, despite differences in age and body size, they had to use the same tools. This aspect was specially notable in grasping and lifting with the hands, during the picking up large light and heavy cans subtests. However, the test contains items of stock size that must not be changed.

With the use of ICF Core sets, we aimed to gather the concerned individuals' opinions about their own state of motion, attitudes, relationships, and social status. The assessment of the questionnaire in the first period took a very long time, and even lasted almost an hour. However, as we became more accomplished at questioning, the needed time decreased. For the fluent using of the questionnaire, practice is required, but it is available to everyone, if used regularly. The learning tools are accessible on the WHO website (https://icf.ideaday.de/en). It is worthwhile to provide explanations and demonstrations for better understanding of those questions which are more abstruse, especially for younger children.

Based on our findings, the students gladly discussed these questions since the questions were related to specific areas that are important to them. We observed that – mainly for the younger students – it was harder to answer some questions about services, systems and policies or societal attitudes. In most cases, this difference arose from their age or living space because they had not had any actual experience in the given area.

During the assessment of the questionnaire, the experience emerged that it is worthwhile to have conversations face-to-face only with the students, without their teachers' presence, since in this way, the children are able to give their opinion without any control, which can be different from their teachers' opinion. It also happened that the children asked us to talk with them privately and not to show their answers to the teachers. These aspects do not mean that the teachers can not participate in the questioning. Instead, it is important that they not act as a supervising entity: they should be there as a helper and questioner to ensure the atmosphere and conditions that make it possible for the students' own opinion to be recorded, without any influence. This may cause differences between their opinions, but after discussion and interpretation, it may lead to closer cooperation, confidence, and more precise goal setting. This approach is in accordance with the ICF ethical principals.

Conclusion

The presented studies were based on expert and self-assessment of upper limb functionality in children with cerebral palsy attending inclusive education. The aim of our studies is to ensure the development of an appropriate measurement protocol for special educators/somatopedagers involved in inclusive education. The basic condition for successful development is a correct, thorough, and regular condition assessment. Although methodological publications for the inclusive education of children with cerebral palsy have been published from time to time (Sárközi, 2010; Péntek & -Dózsa, 2020), they rarely go into sufficient detail on test procedures. The methods we use and recommend can be mastered by other professionals.

To detect individual differences and small changes, it is important to rely on multiple data sources. Moreover, if the assessment conditions for a test are not strictly fixed, it is worthwhile to utilise several approaches within the cases in question. For example, in the case of a self-completion checklist, it is also important to ask the child's parents or teachers or check the implementation of the given task. It is definitely worthwhile to involve the students themselves in the studies in order to reveal and take into account their opinions, experiences, and intentions. This is actually possible with children of any age: it is merely necessary for the researcher to pose the right questions.

We intend to repeat the studies, performed on a larger sample and allowing for the development of age subsamples. Indeed, some of our results so far may be related to age characteristics. We consider it important to involve other participants in future ICF-based studies, such as parents and teachers, and special education teachers, so that we can compare different opinions.

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