# **Cerebral Palsy**

## A Multidisciplinary and Multidimensional Approach

International Thematic Collection of Papers

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### FUNCTIONAL CHARACTERISTICS OF PEOPLE WITH CEREBRAL PALSY IN THE ADULT AGE

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#### SUMMARY

Cerebral palsy represents heterogeneous set of pathological symptoms that manifest clinically as motor disorders, and which are often associated with intellectual and sensory disabilities, as well as emotional, behavioral and communication problems.

The aim of this paper is to systematize knowledge on adults with cerebral palsy and to identify problems caused by the aging process of this population. A description of the characteristics of their functioning during adulthood will be carried through a review of available literature.

It can be concluded that adults with cerebral palsy are at an increased risk of secondary conditions as a result of primary motor disorders. Numerous problems in emotional, psychological and behavioral domain are registered. The decline in functional abilities and quality of life additionally reduce their independence, especially in activities of daily living, which further limits or precludes their inclusion in all aspects of social life.

This imposes the need for reviewing and reorganizing the necessary professional support of special education and rehabilitation within the framework of a comprehensive, both multidimensional and multidisciplinary approach.

## KEY WORDS: cerebral palsy, adult persons, functional characteristics, functional abilities

#### INTRODUCTION

When it comes to cerebral palsy, it usually refers to the population of children affected by this condition. The interest of professional and scientific public for children with cerebral palsy continues unabated. It is quite reasonable, given that the worldwide prevalence of cerebral palsy during the last half of century is not stable but, as stated by Haak, Lenski, Cooley Hidecker, Li, and Paneth (2009), there has been a progress, and today data indicating 3-4 cases per 1000 children can be found (Yeargin-Allsopp et al., 2008). Just the opposite would be expected given the constant general technological, medical and science progress. However, it appears that all the innovations in prenatal diagnosis, genetic screening, prenatal care and delivery, medical and non-medical monitoring of growth and development of newborns and infants have not resulted in reducing of number of children with cerebral palsy. On the other hand, the same progress influenced the reduction of mortality and life prolonging in people with cerebral palsy (Hutton, 2006; Hemming, Hutton, & Pharoah, 2006; Strauss, Shavelle, Reynolds, Rosenbloom, & Dav, 2007).

However, despite the increase in life expectancy of persons with disabilities, including people with cerebral palsy, it is still lower on average than in the general population (Salvatori, Tremblay, & Tryssenaar, 2003). This also supports the fact that adults with cerebral palsy remain a group at high risk for secondary conditions that compromise the functional abilities and social participation of this population, negatively affecting the quality of life in the broadest sense of the word (Svien, Berg, & Stephenson, 2008).

The aim of this paper is to systematize knowledge on adults with cerebral palsy and to identify problems caused by the aging process of this population. A description of the characteristics of their functioning during adulthood will be carried through a review of available literature.

#### METHODS

The basic search was conducted via Google Scholar – Advanced Search. The following key words were used: adults with cerebral palsy, aging with cerebral palsy, and combining with the key words: functional status, social participation and social integration. The search was limited to the studies published in the period from January 1<sup>st</sup> 1995 to December 31<sup>st</sup> 2011. Also, the search was conducted by the well-known authors and we used the references from the published papers that were found and selected for this study on the basis of the previous search. The insight into the available literature was carried out by a further search of four electronic databases (EBSCOhost, Wiley Interscience, Cambridge University Press, Free Medical), available through KoBSON. The available printed sources were also used. The search was completed in January 2012.

#### RESULTS

Andersson and Mattsson (2001) have published results of the research aimed at the difficulties in functioning experienced by adults with cerebral palsy, with an emphasis on problems in locomotion, as well as on the ways in which these individuals solve their everyday problems. The study included 221 subjects with an average age of 36 years (range from 20 to 58 years). Demographic data, information on treatments and subjective experience of physical condition were collected by specially designed questionnaire, with special emphasis on mobility problems and difficulties in motion. Most of the sample consisted of participants with spastic diplegia (35%), followed by dyskinetic cerebral palsy (22%) and spastic hemiplegia (21%). Eighty-four per cent of participants lived in their own homes, with or without professional home services help; 61% of them were living alone, 14% lived with a partner, 13% with their parents, 8% were living with partner and children, and 1% were living alone with children, whereas 2% of participants were living with their friends. Twenty-seven per cent of participants reported that they had never been able to walk, while 9% said that they had eventually lost the ability to walk. Fifteen per cent of participants always walked with a walking aid (assistive device) both inside and outside, 39% always walked without a walking aid both inside and outside, while 10% walked without a walking aid inside only. In the subsample of adults with cerebral palsy with walking ability, 35% reported a significantly decreased walking ability, and it was usually noted in people with spastic diplegia before the age of 35 years, due to increased spasticity, balance problems, or lack or insufficiency of rehabilitation treatment. At the same time, 19% of participants reported mobility improvement, and as a reason, regular physical engagement was given. Fifty-nine per cent of participants (65 of 109) could walk independently more than 1000 meters, whereas 15% walked less than 50 meters. According to the authors (Andersson & Mattsson, 2001), the reducing of functional abilities and loss of independence in activities of daily life in adults with cerebral palsy are all directly related to the changes in musculo-skeletal system and the presence of pain and fatigue. Noted deterioration in motor functioning is in accordance with the findings from other studies, such as those conducted by Sandström, Alinder, and Oberg (2004) in Sweden and based on the functional assessment of forty-eight adults with cerebral palsy (mean age 32 years). According to the results presented in this study in one-third of participants deterioration in motor functioning and decline of motor function were found.

In a comprehensive national survey conducted in Australia by Balandin and Morgan (1997), the main focus group consisted of adults with cerebral palsy aged 30 and over. Collected data were related to the functional profile of participants, their health problems caused by the aging process, as well as to the ways in which participants experience these changes. The study included 279 subjects aged 30 to 74, but 74% of participants were between 30 and 49 years old, and only 5% were older than 65. Thirty-two per cent of participants were living in their own home, and opposite to prevailing opinion that adult with cerebral palsy mostly live in nursing homes, according to available data, only 3% of participants reported using this type of accommodation. Thirty-three per cent of participants reported that they were in full or part time employment, while 9% were retired (all older than 40 years). Twentyseven per cent of participants negated any need for assistance in activities of daily living, but on the other hand 28% required daily assistance for 6 hours or more. Physical changes were reported by 77% of participants, and usually in the neck, back, and these changes compromised the walking ability. According to 27% of participants, these changes were also affecting their independence and quality of life. Emotional changes reflected through a daily frustration, fatigue, pain, anxiety, anger and/or depression were also reported. Only 11% of participants claimed that their physical and emotional changes had no impact on their lives. Changes in communication were reported by 8%of participants, while 57% stated that they communicated verbally without difficulties, and 31% communicated verbally with difficulties. In terms of communication, 35% of participants reported using some form of augmentative and alternative communication. Twenty per cent of participants highlighted the difficulties in accessing and using the services of health centers. In the 12 months preceding this survey (Balandin & Morgan, 1997), rehabilitation services within the physical therapy were used by 48% of participants, occupational therapy by 41%of them, whereas 27% of participants were involved in speech therapy, and 16% used a psychological services.

In a study of relationship between the health related quality of life (HRQoL) and functional status in young adults or adults with cerebral palsy, Tarsuslu and Livanelioglu (2010) have concluded that although HRQoL in young adults with cerebral palsy is at greater impact of parameters related to physical condition, in population of adults with cerebral palsy psychological and emotional aspects of functioning are more important as key indicators of HRQoL. Therefore, it is necessary to developed more population specific measures in order to analyze the effect of mentioned factors.

Bottos, Feliciangeli, Sciuto, Gericke, and Vianello (2001) have conducted a retrospective study aimed at the aging process and evolution of functional status of individuals with cerebral palsy through adulthood searching for the implications for new treatment approaches. Seventy-two subjects with cerebral palsy born from 1934 to 1980 were included. Among other findings, presented results indicated that the education level was statistically significantly associated with age, type and clinical form of cerebral palsy, level of motor impairment, and level of intellectual functioning. According to the results on musculo-skeletal status, frequency of severe and multiple deformities was higher in severe forms of cerebral palsy, such as quadriplegia and dystonia, therefore the incidence and severity of deformities were significantly related to medical diagnosis (p<0.01) and clinical type and form of cerebral palsy. On the other hand, age was not as statistically significant determinant. Regarding literacy, 40.3% of participants were illiterate, and at the same time younger participants were more successful at achieving and maintaining literacy. along with participants who had attended regular school, when compared to older participants and participants who had attended special schools. In terms of accommodation, 75% of participants lived with their parents in the family home, 12.5% lived alone, while 12.5% resided in an institution. Type of accommodation was statistically significantly related to the level of intellectual functioning (p<0.05). All participants with severe and profound intellectual disability lived in parental home or in an institution. Twenty-six per cent of participants with normal or borderline intelligence (7 of 27 subjects), and 7.7% of participants with mild intellectual disability (1 of 13 subjects) established their own families or lived independently in their own homes. On the other hand, no statistically significant relation between household and age, motor impairment level, and type and clinical form of cerebral palsy was found. Marital status was statistically significantly related to age (p<0.05), due to the fact that the number of married people was higher among the oldest group of participants. Also, marital status was significantly related to the level of intellectual functioning (p<0.05). Intellectual level was the only determinant statistically related to the employment status (p < 0.01), while neurological diagnosis was not. A total of 66.1% of participants were unemployed, 16.1% had a sheltered employment, while only 17.7% were employed in an open economy and therefore achieved competitive employment. According to the data, participants who achieved independent walking by the age of 3 years managed to maintain this ability longer (p<0.01). However, 75.7% of participants were able to walk in some manner, but a trend of declining or losing of this ability over time had been noted, as well as a decreasing of the distance that participants were able to cross independently during single walking session. Generally, locomotion was statistically significantly related to diagnosis, i.e. clinical type and form of cerebral palsy, as well as to the level of motor impairment (p < 0.01). At the same time, there was a high correlation between locomotion and intellectual functioning level, but without statistical significance. Only 13.3% of participants with severe intellectual disabilities achieved independent walking level, compared to 59.3% of participants with normal or borderline intelligence, also only one participant out of 16 with severe

intellectual disability maintained independent walking (6.25%) versus 10 of 27 of participants with normal or borderline intelligence (37%). Loss of walking ability usually occurred between 20 and 40 years of age and according to the statements of participants, it represented a major source of frustration. Seventy-one per cent of participants, mostly those with severe motor impairment as well as those with the most severe forms of cerebral palsy, such as quadriplegia, were using a wheelchair as a assistive device. Patients with mild or moderate motor impairment, and those with diplegia and hemiplegia, were rarely using mobility assistive devices. Following the functional status and functional ability through different age groups, the authors have concluded that there is an evident decline and/or loss of certain, mostly motor abilities, such as independent walking or mobility. According to their opinion, the traditional approach based primarily on achieving and maintaining of independent walking should be complemented by orientation towards the achievement of functional independence of people with cerebral palsy.

With the aim of acquiring insight into the level of functioning of adults with cerebral palsy, van der Dussen, Nieuwstraten, Roebroeck, and Stam (2001) have published the results of descriptive cross-sectional study in which the focus was on evaluation of assistance needed in selfcare activities, level of mobility and communication, level of education, housing situation and daily occupation. The study resulted in findings of high levels of independence in young adults with cerebral palsy in activities of daily living, and high both mobility and communication level. However, data analysis highlighted weak social integration of this population, both in education and employment domains, as well as in sports activities. At the same time, high independence rate in activities of daily living is in accordance with results of other studies (Turk, Geremski, Rosenbaum, & Weber, 1997). On the other hand, the highest completed level of education, employment status and sport activities practicing were relatively lower when compared to peers from general population. The research sample consisted of 80 participants (41 males and 39 females), aged 21 to 31. As an assessment instrument, a structured questionnaire was used. This questionnaire was based on a self-assessment of participants or on a assessment of their parents/care-givers and it collected demographic data, and also data on mobility, housing, daily activities, education and communication. An adapted version of the Barthel Index of the Activities of Daily Living (Collin, Wade, Davies, & Horne, 1988) was an integral part of this questionnaire. Quadriplegia and hemiplegia were the most common types of cerebral palsy (56.3% and 33%, respectively), while as the most frequent clinical forms were spasticity (71.3%) and athetosis (15%). In the domain of self-care and mobility at home, according to the Barthel Index, 45% of participants were fully independent in the activities of daily living, 30% were largely independent, 6% required assistance in specific activities, 12.5% were largely dependent, while 6% were fully dependent on assistance: 7.5% were immobile within their own home. Participants reported that they often needed assistance in activities of bathing (32.5%), and dressing/undressing (31.3%), followed by personal care (26.3%) and feeding (23.8%). Ninety-four per cent of participants communicated. However 22.5% had difficulties verballv in telephone. communication bv As а non-verbal methods of communication, participants were using sign language and eyes or hands indication. Some form of secondary education had completed 53% of participants, however 15% had never attended school, 12.5%had attended a special school for the multiple handicapped children. In an unadapted houses lived 47.5% of participants. Almost one third of participants (32.5%) lived alone, and at the same time, 30% lived with their parents, and 37.5% were living in the community. Next, 12.5% were married or living with a partner. Two thirds of participants were employed, and 16% in an open economy, while 13% were employed in sheltered workshops. Twenty-one per cent of participants participated in some sport activities.

According to the study conducted by Murphy, Molnar, and Lankasky (2000) which included 101 adults with cerebral palsy, living independently in the community (in non-institutional accommodation), aged 27 to 74 years (mean age 42.6 years), two thirds of participants (67%) lived independently without the help of parents or relatives (34% with and 33% with no personal assistant or attendant), while 53% were competitively employed in an open economy. It turned out that the type of employment was in a higher correlation with cognitive abilities than with motor or communication disorders. The authors have concluded that during the last decades there was noticeable increasing of number of people with cerebral palsy who achieved an adequate employment and lived independently despite moderate to severe level of primary motor disorders.

During the sixties of the twentieth century (Crothers & Pain, 1959 cited in Murphy et al., 2000), 26% of people with cerebral palsy were employed in an open economy, with the highest employment rates observed in individuals with hemiplegia. At that time, in individuals with extrapyramidal deficits, employment rate was determined by the intellectual status, functional abilities and speech, while those with spastic quadriplegia or mixed form of cerebral palsy were unemployed. Hansen (1960 cited in Murphy et al., 2000) has conducted a research in Denmark that included 1127 subjects with cerebral palsy and found that the rate of employment in the open economy was only 10% for qualified workers, and that 12% of employees were unskilled. Next, on a sample of 125 adults with cerebral palsy, Ingram (1964 cited in Murphy et al., 2000) found that 21% of participants were employed, whereby the majority were employed at the workplaces that did not require special vocational training. In addition, a small percentage of participants were employed in sheltered workshops (3.2%) or involved in the process of vocational training (7%). As adverse factors, severe levels of disability, presence of cognitive dysfunction, auditory, visual or speech deficits, as well as the prejudices and negative attitudes were all highlighted. All subjects with mild level of hemiplegia or diplegia, and a quarter of participants with moderate levels of disability were employed, and at the same time independent in all activities of daily living, while all participants with severe levels of disability were unemployed. The results of study from 1966 (Klapper & Birch, 1966 cited in Murphy et al., 2000) indicated that over 50% of adults with cerebral palsy were employed, which was quite a high percentage. However, only 19% of them were employed in an competitive, open economy. Still, despite that, over 60% of participants were completely financially dependent on their families.

A few studies had a functioning of adults with cerebral palsy analyzed with the aim of determination of relation between the level of daily physical activities and levels of social inclusion and social participation in their research focuses (van der Slot et al., 2007; Tarsuslu & Livanelioglu, 2010). Physical activities are defined as activities based on a movement, such as maintaining and changing of posture or mobility (van der Slot et al., 2007), while social participation is defined through the inclusion of people in different social situations and activities, according to the International Classification of Functioning, Disability and Health – ICF (WHO, 2001).

Comparing the evaluated levels of daily physical activity and social participation of adults with hemiplegic cerebral palsy and adults from general population, with the identification of potential determinants of everyday functioning, van der Slot et al. (2007) assumed that the differences occurred in certain domains of social participation, but not in terms of level of daily physical activities. This cross-sectional study, conducted in the Netherlands, included 16 subjects (7 males and 9 females) with hemiplegic cerebral palsy, aged 25-35 years, and an equal number of subjects from general population, with no statistically significant differences in terms of gender or age. Age and gender of participants, body mass index (BMI), body fat percentage (measured by skinfold thickness), muscle tone determined by the Ashworth Scale (Ashworth, 1964), and levels of functioning and participation, were all evaluated as potential determinants of everyday physical activity. The highest achieved level of education was taken as an insight into the cognitive level, while for determination of the functional level in different domains modified functional independence test was used (the Functional Independence Measure - FIM; Keith, Granger, Hamilton, & Sherwin, 1987). This instruments were used only in subjects with cerebral palsy. Daily physical activity was monitored using a system called "Activity Monitor" (AM; Temec Instruments BV, Kerkrade, The Netherlands). AM is based on long term monitoring of movement of participants, and on the measurement of mobility over the information recorded by special sensors (accelerometers) attached to specific points on the body. Data on duration, velocity and precise time of occurrence of each individual motor activity (lying, sitting, standing, walking, using wheelchairs, and other forms of mobility), as well as data on posture changes, acceleration and changing of position of individual body parts, and on general motility were collected. For the quantification of participation in family, working and social environment, the following instruments were used: subscale for the assessment of occupational activities within the Craig Handicap Assessment and Reporting Technique (CHART; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992), and the Community Integration Ouestionnaire (CIO; Willer, Ottenbacher, & Coad, 1994). Data on the type, duration and frequency of sports activities were obtained from the questionnaires specially designed for the purposes of this study. Statistically significant differences were found in BMI of participants with cerebral palsy compared to healthy participants (p=0.04). Also, male participants with cerebral palsy had lower percentage of body fat compared to healthy male participants (p=0.006). The highest level of education achieved by participants with cerebral palsy was significantly lower than those in the control group (p=0.06). There was a high level of independence in performing of functional activities according to the results of FIM test. According to CHART, adults with cerebral palsy spend more time on activities such as reading or watching television (p=0.06) or doing handicrafts, for example (p=0.02). At the same time, with a statistically significant difference, they spend less time doing volunteer work, according both to CHART (p=0.02), and CIQ (p=0.006). The total score on CHART ranged from  $6\overline{3}$  to  $2\overline{53}$  in the group of participants with cerebral palsy, and from 62 to 168 in the control group. The total score of less than 100 indicates the presence of occupational handicap which, according to the results, had 10 adults with cerebral palsy and 3 adults from typical population. Also, the level of achieved social integration determined by CIO showed no significant differences between these two groups. Further analysis showed that 5 participants with cerebral palsy who lived alone had higher total CIO score compared to 9 participants with cerebral palsy who lived with their partner, parents or others (p=0.04). According to the authors' conclusions, adults with hemiplegic cerebral palsy did not differ from control subjects at the level of daily physical activity measured by AM system. However, these conclusions should be reconsidered taking into account the fact that this study included a small sample, and that all participants with cerebral palsy were able to move independently and had high independence level in functional activities performing according to FIM test. Also, normal muscle tone or slightly elevated muscle tone of the lower extremities on hemiplegic side were clinically confirmed in the majority of participants with cerebral palsy. Therefore, as a result, a relatively high achieved level of participation in various areas of life was noted, such as the overall employment rate of 87.5%. The achieved level of community integration defined according to CIQ was not significantly different between two groups. Differences were found on some parameters. Participants with cerebral palsy spent more time in passive leisure activities, such as watching television, but less in volunteering. As the authors (van der Slot et al., 2007) explained, this might be caused by the influence of other factors, e.g. environment attitudes, not by the health status or the primary impairment. The availability of transport services and support for sports activities given through the health system in the Netherlands are all facilitating environmental factors. As potential determinants of everyday physical activity levels in the group of participants with cerebral palsy following factors were found: frequency of sport activities, duration of sport activities, time spent in sport according to CHART, and the satisfaction of activity level.

#### DISCUSSION

In this study, the characteristics of functioning of adults with cerebral palsy were defined based on selected empirical data on their locomotor and functional communication skills, their health status, employment and occupational activities, their psychological, emotional, behavioral, educational and socio-economic status, as well as on their social competence and social inclusion and participation.

Adults with cerebral palsy are population with multiple problems and difficulties as seen from the medical, economical, legal, and above all, from the social aspect. During the past two decades, numerous studies were primarily focused on the assessment of specific functional abilities in adults with cerebral palsy, on the effect of personal and environmental factors in relation to the impact of aging process on the functional loss and functional impairment in adults with cerebral palsy, then on the impact of primary condition in relation to the occurrence of secondary and associated disorders, as well as on the determination of quality of life of this population. Impairment or loss of functional abilities were confirmed by numerous authors. Various studies have confirmed the progression of impairment and decline of various functional abilities in adults with cerebral palsy (Andersson & Mattsson, 2001; Ando & Ueda, 2000; Andren & Grimby, 2004; Bottos et al., 2001; Gajdosik & Cicirello, 2001; Jahnsen, Villien, Aamodt, Stanghelle, & Holm, 2004a; Jahnsen, Villien, Egeland, Stanghelle, & Holm, 2004b; Murphy, Molnar, & Lankasky, 1995; Murphy et al., 2000; Overeynder & Turk, 1998; Sandström et al., 2004; Strauss, Ojdana, Shavelle, & Rosenbloom, 2004; van der Dussen et al., 2001). Studies were mostly focused on the determination of health status in adults with cerebral palsy (Klingbeil, Baer, & Wilson, 2004; Murphy et al., 1995; Turk et al., 1997; Turk, Scandale, Rosenbaum, & Weber, 2001) or on the specific demographic and social aspects, such as educational status,

employment rate or marital status (Andersson & Mattsson, 2001; Bottos et al., 2001; Murphy et al., 2000).

Summarizing the results, it can be concluded that as the most frequent problems are reported those related to musculo-skeletal system in the form of reduced muscle strength and reduced muscle function in general, as well as the occurrence of pain and higher level contractures (Ando & Ueda, 2000; Gajdosik & Cicirello, 2001; Murphy et al., 1995; Overeynder & Turk, 1998). The consequences are the most obvious in daily life activities with direct impact on the certain aspects of social participation, such as engaging in employment or occupation activities, but also in basic functional abilities, such as the ability to walk (Jahnsen, Villien, Stanghelle, & Holm, 2003; Jahnsen et al., 2004a; Jahnsen et al., 2004b; Murphy et al., 1995; Sandström, 2007; Schwartz, Engel, & Jensen, 1999; Turk et al., 1997). Compromised mobility and balance problems increase the risk of falls and fractures (Overeynder & Turk, 1998). Limitation of daily physical activity with predominantly sedentary posture further exacerbates these problems and leads to a growing risk of various diseases of vital organs and vital systems, while reducing of functional independence, exclusion from social activities and weakening of social networks have a negative impact on quality of life (Gajdosik & Cicirello, 2001; Overeynder & Turk, 1998; van der Slot et al., 2007). At the same time, studies have indicated a similar life satisfaction level in comparison to general population, but also a fact that the subjective impression of their own health status is associated with the occurrence of pain and functional deterioration, and not with the level of functioning itself (Furukawa, Nshiyama, Nii, & Ushida, 2001; Sandström et al., 2004). It turned out that in the communities that include adults with cerebral palsy, both their health status and functioning within the social field are better and improved (Heller, Ying, Rimmer, & Marks, 2002).

Moreover, it can be pointed out that adults with cerebral palsy are at an increased risk of secondary conditions as a result of primary motor disorders. Numerous problems in emotional, psychological and behavioral domain are registered. The decline in functional abilities and quality of life additionally reduce their independence, especially in activities of daily living, which further limits or precludes their inclusion in all aspects of social life.

Maintaining functional independence, particularly mobility and independent functioning, at the highest degree and for longer period of time, is especially important during the transition of individuals with cerebral palsy from adolescence into adulthood and elderly age. At the same time, the positive environmental factors, such as physical support and social support through positive attitudes without prejudice, can facilitate the process of social participation which should be considered not only from the aspect of functional ability and health, but also in terms of overall quality of life of population of people with cerebral palsy, which is consistent with previous research, both empirical (Fresher-Samways, Roush, Choi, Desrosiers, & Steel, 2003; Hammal, Jarvis, & Colver, 2004), and theoretical (Milićević & Potić, 2012).

#### CONCLUSION

Ageing of people with cerebral palsy and specific consequences that this process has on their social integration occupy an increasing attention of scientific public worldwide. This imposes the need for reviewing and reorganizing the necessary professional support of special education and rehabilitation within the framework of a comprehensive, both multidimensional and multidisciplinary approach.

Although cerebral palsy is not considered to be progressive disease but medical condition, it can be concluded that the evolution of consequences certainly does not stop reaching adulthood. Noted functional decline in all evaluated areas raises the need for designing of rehabilitation strategies that are capable to respond to all of the changes brought by the aging process and that are oriented primarily to maintenance of functional independence of people with cerebral palsy, at the most possible extent and through the longest period of time.

It is often stated that rehabilitation strategies should primarily be directed towards the achieving and maintaining of functional independence, particularly in the domains of activities of daily living, especially as the aging process inevitably leads to decreasing of mobility. However, it is not enough. It is essential to constantly monitor the functional status in general, and to adapt rehabilitation programs to the current state of each individual with cerebral palsy, which can be achieved only through both multidimensional and multidisciplinary approach.

Therefore, positive trend of changes in the social participation process and full social integration of population of adults with cerebral palsy are to be expected only by the improvements in rehabilitation strategies, improvement and expansion of service centers, with appropriate legal regulations and changes in the inclusive educational system.

#### REFERENCES

- 1. Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine & Child Neurology*, *43*(2), 76-82.
- 2. Ando, N., & Ueda, S. (2000). Functional deterioration in adults with cerebral palsy. *Clinical Rehabilitation*, 14(3), 300-306.
- 3. Andren, E., & Grimby, G. (2004). Dependence in daily activities and life satisfaction in adult subjects with cerebral palsy or spina bifida: a follow-up study. *Disability & Rehabilitation*, 26(9), 528-536.
- 4. Ashworth B. (1964). Preliminary trial of carisoprodal in multiple sclerosis. *Practitioner*, 192, 540-542.
- 5. Balandin, S., & Morgan, J. (1997). Adults with cerebral palsy: What's happening? *Journal of Intellectual & Developmental Disability*, 22(2), 109-124.
- Bottos, M., Feliciangeli, A., Sciuto, L., Gericke, C., & Vianello, A. (2001). Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental Medicine & Child Neurology*, 43(8), 516-528.
- 7. Collin, C., Wade, D. T., Davies, S., & Horne, V. (1988). The Barthel ADL Index: a reliability study. *International Disability Studies*, *10*(2), 61-63.
- Fresher-Samways, K., Roush, S. E., Choi, K., Desrosiers, Y., & Steel, G. (2003). Perceived quality of life of adults with developmental and other significant disabilities. *Disability and Rehabilitation*, 25(19), 1097-1105.
- Furukawa, A. IH., Nshiyama, M., Nii, E., & Ushida, A. (2001). A Study on the Subjective Well-Being of Adult Patients with Cerebral Palsy. *Journal of Physical Therapy Science*, 13(1), 31-35.
- Gajdosik, C. G., & Cicirello, N. (2001). Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, 21(4), 49-68.
- 11. Haak, P., Lenski, M., Cooley Hidecker, M. J., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine & Child Neurology*, 51(4), 16-23.
- 12. Hammal, D., Jarvis, S., & Colver, A. (2004). Participation of children with cerebral palsy is influenced by where they live. *Developmental Medicine & Child Neurology*, 46(5), 292-298.
- 13. Heller, T., Ying, G., Rimmer, J. H., & Marks, B. A. (2002). Determinants of exercise in adults with cerebral palsy. *Public Health Nursing*, 19(3), 223-231.
- Hemming, K., Hutton, J. L., & Pharoah, P. O. (2006). Long-term survival for a cohort of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 48(2), 90-95.
- 15. Hutton, J. L. (2006). Cerebral palsy life expectancy. *Clinic in Perinatology*, 33(2), 545-555.
- 16. Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J. K., & Holm, I. (2004a). Musculoskeletal pain in adults with cerebral palsy compared with the general population. *Journal of Rehabilitation Medicine*, *36*(2), 78-84.
- 17. Jahnsen, R., Villien, L., Stanghelle, J. K. & Holm, I. (2003). Fatigue in adults with cerebral palsy in Norway compared with the general population. *Developmental Medicine & Child Neurology*, *45*(5), 296-303.
- Jahnsen, R., Villien, L., Egeland, T., Stanghelle, J. K., & Holm, I. (2004b). Locomotion skills in adults with cerebral palsy. Clinical Rehabilitation, 18(3), 309-316.

- 19. Keith, R. A., Granger, C. V., Hamilton, B. B., & Sherwin, F. S. (1987). The functional independence measure: a new tool for rehabilitation. *Advances in Clinical Rehabilitation*, 1, 6-18.
- 20. Klingbeil, H., Baer, H. R., & Wilson, P. E. (2004). Aging with a disability. Archives of Physical Medicine and Rehabilitation, 85(Suppl 3), S68-73.
- 21. Milićević, M., & Potić, S. (2012). Činioci socijalne participacije dece sa cerebralnom paralizom. Socijalna misao, 19(2), in press.
- 22. Murphy, K. P., Molnar, G. E., & Lankasky, K. (1995). Medical and functional status of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 37(12), 1075-1084.
- 23. Murphy, K. P., Molnar, G. E., & Lankasky, K. (2000). Employment and social issues in adults with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, 81(6), 807-811.
- 24. Overeynder, J. C., & Turk, M. A. (1998). Cerebral Palsy and Aging: A Framework for Promoting the Health of Older Persons with Cerebral Palsy. *Topics in Geriatric Rehabilitation, 13*(3), 19-24.
- 25. Salvatori, P., Tremblay, M., & Tryssenaar J. (2003). Living and aging with a developmental disability: Perpective of individuals, family members and service providers. *Journal of Developmental Disabilities*, *10*(1), 1-19.
- 26. Sandström, K., Alinder, J., & Oberg, B. (2004). Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disability & Rehabilitation*, 26(17), 1023-1031.
- 27. Sandström, K. (2007). The lived body experiences from adults with cerebral palsy. *Clinical Rehabilitation*, 21(5), 432-441.
- 28. Schwartz, L., Engel, J. M., & Jensen, M. P. (1999). Pain in persons with cerebral palsy. Archives of Physical Medicine and Rehabilitation, 80(10), 1243-1246.
- 29. Strauss, D., Ojdana, K., Shavelle, R., & Rosenbloom, L. (2004). Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation*, 19(1), 69-78.
- 30. Strauss, D., Shavelle, R., Reynolds, R., Rosenbloom, L., & Day, S. (2007). Survival in cerebral palsy in the last 20 years: Signs of improvement? *Developmental Medicine & Child Neurology*, 49(2), 86-92.
- 31. Svien, L. R., Berg, P., & Stephenson, C. (2008). Issues in aging with cerebral palsy. *Topics in Geriatric Rehabilitation*, 24(1), 26-40.
- 32. Tarsuslu, T., & Livanelioglu, A. (2010). Relationship between quality of life and functional status of young adults and adults with cerebral palsy. *Disability & Rehabilitation*, *32*(20), 1658-1665.
- 33. Turk, M. A., Geremski, C. A., Rosenbaum, P. F., & Weber, R. J. (1997). The health status of women with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, 78(12), S10-7.
- 34. Turk, M. A., Scandale, J., Rosenbaum, P. F., & Weber, R. J. (2001). The health of women with cerebral palsy. *Physical medicine and rehabilitation clinics of North America*, 12(1), 153-68.
- 35. van der Dussen, L., Nieuwstraten, W., Roebroeck, M., & Stam, H. J. (2001). Functional level of young adults with cerebral palsy. *Clinical Rehabilitation*, *15*(1), 84-91.
- 36. van der Slot, W. M., Roebroeck, M. E., Landkroon, A. P., Terburg, M., Berg-Emons, R. J., & Stam, H. J. (2007). Everyday physical activity and community participation of adults with hemiplegic Cerebral Palsy. *Disability* and Rehabilitation, 29(3), 179-89.
- 37. Whiteneck, G. G., Charlifue, S. W., Gerhart, K. A., Overholser, J. D., & Richardson, G. N. (1992). Quantifying handicap: a new measure of long-

term rehabilitation outcomes. Archives of Physical Medicine and Rehabilitation, 73(6), 519-526.

- 38. Willer, B., Ottenbacher, K. J., & Coad, M. L. (1994). The community integration questionnaire. A comparative examination. *American Journal of Physical Medicine & Rehabilitation*, 73(2), 103-111.
- 39. World Health Organization (2001). International Classification of Functioning, Disability and Health – ICF. Geneva: WHO.
- 40. Yeargin-Allsopp, M., Van Naarden Braun, K., Doernberg, N. S., Benedict, R. E., Kirby, R. S., & Durkin, M. S. (2008). Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: A multisite collaboration. *Pediatrics*, 121(3), 547-554.

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