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## Participation of Children with Cerebral Palsy in Leisure Activities: a Literature Review\*\*\*

### *Abstract*

In recent years, there is a noticeable increase in the interest for social participation of persons with disabilities, including persons with cerebral palsy. This is understandable taking into account the importance of participation in everyday activities, including leisure activities, as a crucial part of a child's development. The purpose of this study was to describe patterns of participation in leisure activities of children and adolescents with cerebral palsy in order to systematize the main findings in this field. A narrative review of the literature on this topic was conducted and yielded 290 papers, 11 of which fulfilled the inclusion criteria. Prevailing lower intensity and diversity of activities did not determine the level of enjoyment nor necessarily indicated that leisure participation was restricted. Participation in leisure activities is

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complex, multidimensional construct influenced by personal, family and social characteristics.

*Key words:*

leisure time, motor disorder, multiple disabilities, participation pattern.

## INTRODUCTION

As a concept, participation was introduced in 2001 in the International Classification of Functioning, Disability and Health – ICF.<sup>1</sup> It is defined as “involvement in life situations” which may be influenced by personal and environmental factors as facilitators or barriers. Participation in everyday activities, including leisure ones, represents crucial part of a child’s development. Its influence on different dimensions of their quality of life has long been recognized.<sup>2</sup> Moreover, the International Classification of Functioning,

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<sup>1</sup> “International Classification of Functioning, Disability and Health (ICF)”, World Health Organization, Geneva, 2001.

<sup>2</sup> Marta Badia, Egmar Longo, Begona M. Orgaz, and Maria Gómez-Vela, “The influence of participation in leisure activities on quality of life in Spanish children and adolescents with Cerebral Palsy”, *Research in developmental disabilities*, vol. 34, no. 9, pp. 2864–2871.

Noemi Dahan-Oliel, Keiko Shikako-Thomas and Annette Majnemer, “Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature”, *Quality of Life Research*, vol. 21, no. 3, pp. 427–439.

Christine Imms, Sheena Reilly, John Carlin and Karen Dodd, “Diversity of participation in children with cerebral palsy”, *Developmental Medicine & Child Neurology*, vol. 50, no. 5, pp. 363–369.

Vicki McManus, Paul Corcoran and Ivan J Perry, “Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland”, *BMC Pediatrics*, vol. 8, no. 1, pp. 50.

Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri, and Jill Maggs, “Participation in home, extracurricular, and community activities among children and young people with cerebral palsy”, *Developmental Medicine & Child Neurology*, vol. 52, no. 2, pp. 160–166.

Keiko Shikako-Thomas, Noemi Dahan-Oliel, Michael Shevell, Mary Law, Rena Birnbaum, Peter Rosenbaum, Chantal Poulin and Annette Majnemer, *Play and be happy? Leisure participation and quality of life in school-aged children with cerebral palsy*, International Journal of Pediatrics, 2012. Available from <http://www.hindawi.com/journals/ijped/2012/387280/>

Disability and Health for Children and Youth – ICF-CY<sup>3</sup> emphasizes participation in leisure activities as important, and defines recreation and leisure as engaging in any form of informal or organized play, sports, arts, culture, entertainment, crafts, hobbies and social activities. Leisure activities are freely chosen, considered enjoyable or entertaining and performed during leisure time when one is not involved in self-care, school or work activities.<sup>4</sup> At the same time, leisure provides opportunities for strengthening of friendships, social skills and competencies improving, achieving both mental and physical health, developing interests, personal identity, and understanding of one's own strengths and abilities.<sup>5</sup> Informal leisure activities are activities with little or no planning and children take part spontaneously, often on their own initiative, while formal activities are structured, with pre-planned rules and goals, primarily organized by adults.<sup>6</sup>

Numerous studies indicated that children with disabilities, including children with cerebral palsy (hereinafter: CP) are at the increased risk of reduced and less diverse participation in formal and informal everyday activi-

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<sup>3</sup> World Health Organization, *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)*, World Health Organization, Geneva, 2007.

<sup>4</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, "Participation and enjoyment of leisure activities in school-aged children with cerebral palsy", *Developmental Medicine & Child Neurology*, vol. 50, no. 10, pp. 751–758.

<sup>5</sup> Noemi Dahan-Oliel, Keiko Shikako-Thomas and Annette Majnemer, *Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature*, op. cit.

Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, "Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy", *Physical Therapy*, vol. 90, no. 12, pp. 1743–1757.

Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.

<sup>6</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit.

Gillian King, Mary Law, Steven Hanna, Susanne King, Patricia Hurley, Peter Rosenbaum, Marilyn Kertoy and Terry Petrenchik, "Predictors of the leisure and recreation participation of children with physical disabilities: A Structural equation modeling analysis", *Children's Health Care*, vol. 35, no. 3, pp. 209–234.

ties, at home and in the community they live in.<sup>7</sup> Given the fact that leisure participation contributes to physical and mental health, and to social life of individuals and their family,<sup>8</sup> we addressed the following research question: What do we know from the literature about the participation patterns of children and adolescents with CP in leisure activities?

Therefore, the aim of this paper is to identify and describe patterns of participation in leisure activities of children and adolescents with CP. The objective will be realized by reviewing of available literature and systematizing of knowledge in this field.

## METHODOLOGY

### *Search strategy*

The literature search was conducted in order to identify all available studies. Following indexing services and electronic databases were included: Scopus, Medline, Web of Science, EBSCO, Medscape, HighWire Press,

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- <sup>7</sup> Robert Blum, Michael Resnick, Richard Nelson and Anne St Germaine, "Family and peer issues among adolescents with spina bifida and cerebral palsy", *Pediatrics*, vol. 88, no. 2, pp. 280–285.  
Christine Imms, Sheena Reilly, John Carlin and Karen Dodd, *Diversity of participation in children with cerebral palsy*, op. cit.  
Gillian King, Mary Law, Steven Hanna, Susanne King, Patricia Hurley, Peter Rosenbaum, Marilyn Kertoy and Terry Petrenchik, *Predictors of the leisure and recreation participation of children with physical disabilities: A Structural equation modeling analysis*, op. cit.  
Malka Margalit, "Leisure activities of cerebral palsied children", *Israel Journal of Psychiatry and Related Sciences*, vol. 18, no. 3, pp. 209–214.  
Clarissa Stevenson, Peter Pharoah and Richard Stevenson, "Cerebral palsy – The transition from youth to adulthood", *Developmental Medicine & Child Neurology*, vol. 39, no. 5, pp. 336–342.
- <sup>8</sup> Rob Forsyth and Stephen Jarvis, "Participation in childhood", *Child: Care, Health and Development*, vol. 28, no. 4, pp. 277–279.  
Mary Law, Gillian King, Susanne King, Marilyn Kertoy, Patricia Hurley, Peter Rosenbaum, Nancy Young and Steven Hanna, "Patterns of participation in recreational and leisure activities among children with complex physical disabilities", *Developmental Medicine & Child Neurology*, vol. 48, no. 5, pp. 337–342.  
Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, "Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy", *Research in Developmental Disabilities*, vol. 34, no. 3, pp. 1001–1010.

SAGE, ScienceDirect, SpringerLink, and Wiley InterScience. Key words *participation* and *cerebral palsy* were used as phrases with predefined terms of appearing in title, abstract and among the keywords, when possible and combined with *leisure* with predefined terms of full-text appearing. The search was limited to peer-reviewed articles published or available on-line in English in scholarly journals from January 2001 to December 2016. The initial search yielded 417 references. In addition, these papers were hand-searched, and 11 relevant articles were added giving a total of 290 papers. After the exclusion of duplicates, 279 papers were collected and screened by titles and abstracts.

### *Inclusion/Exclusion criteria*

On the basis of preliminary exclusion criteria, 241 papers were excluded: 1) inadequate methodological design (review articles, commentaries, editorials, letters, only abstract available), 2) samples that were made up of adults with CP only, 3) motor disorder and its effects on health and functional abilities, or 4) effectiveness of various intervention or treatments on participation in research focus.

After that, 49 preliminary selected articles were examined. Thirty-eight studies were excluded because they did not meet the main inclusion criteria: 1) original research work, 2) a sample or sub-sample made up of pre-school or school-aged children and/or adolescents with CP, 3) assessment of leisure participation level, and 4) in the case of a mixed sample, clear presentation of the results of participants with CP. The search was completed in January 2017. Only the remaining 11 studies were analysed for the purpose of this review. The identification and selection process is presented in a flow chart (Figure 1).

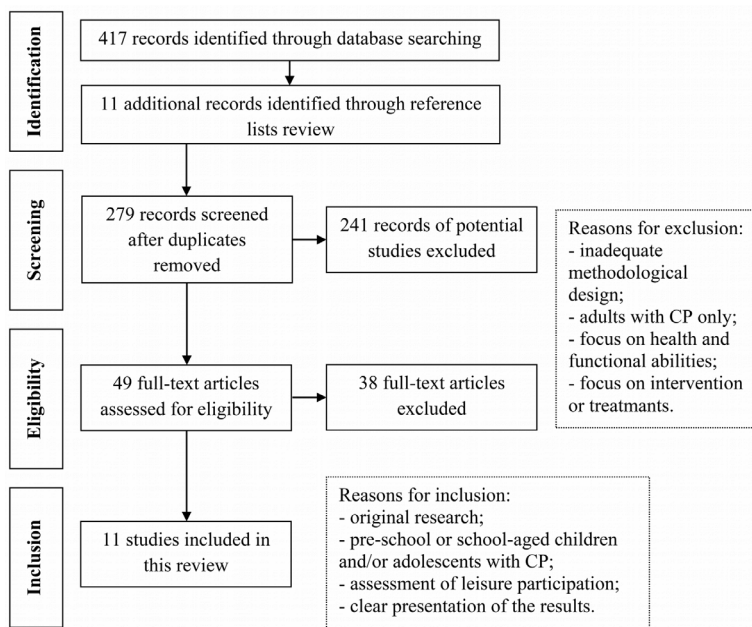


Figure 1. Flow chart on different phases of study selection

## RESULTS

Majnemer and associates<sup>9</sup> found a wide variety of leisure activities, although mostly informal and home-based. High correlations between intensity and diversity were confirmed for formal and informal activities. In both of these domains, there was a high enjoyment level, with the exception of self-improvement activities and skill-based activities when compared to typically developing peers. The enjoyment level was in a weak association with participation intensity in formal activities and moderately associated to intensity and diversity in informal activities.

Typically developing children and adolescents were involved in a wider variety of leisure activities than their peers with CP.<sup>10</sup> Besides, children and

<sup>9</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.

<sup>10</sup> Batya Engel-Yeger, Tal Jarus, Dana Anaby and Mary Law, "Differences in patterns of participation between youths with cerebral palsy and typically developing peers", *The American Journal of Occupational Therapy*, vol. 63, no. 1, pp. 96–104.

adolescents with CP were mostly alone in activities and their participation was usually home-based. No difference was found between diversity and intensity of formal and skill-based activities, nor between the intensity of recreational and active physical activities. This was further explained by interrelations of these activities through school and rehabilitation programs. However, differences between groups were confirmed in the domain of informal activities.

The results of the other study<sup>11</sup> indicated higher overall diversity and intensity in children with CP when compared to adolescents with CP. Generally observed, diversity and intensity were nevertheless low. In other words, 14% of children and 18% of adolescents with CP did not participate in any physical activity during the four months prior to the test. As the authors emphasized, the lower levels of participation in physical activities might affect the health of children and adolescents with CP. Finally, it was not confirmed that children with CP participate more in formal and physical, and adolescents with CP in social activities.

According to Imms and associates,<sup>12</sup> gender, manual abilities and preferences for informal activities are predictors of the diversity of participation in informal activities. Moreover, while overall temperament and socioeconomic status are only weakly associated, environmental variables are not related to participation in informal activities. When it comes to participation in formal activities, in addition to the child's preferences, mainstream school attendance is the only important predictor detected at the environment level.

Kang and associates<sup>13</sup> reported that the model of variables, which included sports and physical functioning, problems with communication or speech, educational placement and the extent to which community recreational activities were obtained, explained 45.8% of the variance of the number of activities engaged in with friends. Specifically, higher levels of participation with friends were associated with the following: higher levels of sport and physical functioning, fewer communication or speech problems, regular versus special education program, and more frequent participation in desired leisure activities. On the other hand, participants whose parents had higher education

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<sup>11</sup> Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.

<sup>12</sup> Christine Imms, Sheena Reilly, John Carlin and Karen J. Dodd, "Characteristics influencing participation of Australian children with cerebral palsy", *Disability & Rehabilitation*, Vol. 31, No. 26, pp. 2204–2215.

<sup>13</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit.

level were engaged in more activities with other people who were not family, explaining 6.3% of the variance in the number of activities.

Focusing on the participation intensity, Palisano and associates<sup>14</sup> came to result that the model of factors related to a child, family and services together explained 32% of its variance. Higher participation intensity was associated with higher enjoyment, better gross motor function, more effective adaptive behaviour, younger age, and higher levels of family orientation towards activities. Gender, health and physical activities, as child characteristics, and family income, as family characteristic, had no effect on the participation intensity, nor did processes of services. This last finding was interesting considering that primary caregiver education and family structure had, as the authors highlighted, influence on processes of services.

Shikako-Thomas and associates<sup>15</sup> found higher diversity and intensity of engagement within informal activities than in the formal ones. The most frequent were social and recreational activities, opposite to skill-based and self-improvement activities. Social activities had the highest enjoyment level (mostly done with other people). In contrast, the lowest enjoyment level was noted in self-improvement activities (usually done alone or with a close family member). Additionally, it was confirmed that diversity and intensity were decreasing with age, with the exception of social activities. Attending special school was associated with a lower diversity of participation in recreational, active physical, social and self-improvement activities, but also with a lower intensity in active physical, social and self-improvement activities. Differences in leisure participation were found by motor functioning. Ambulatory and manual ability limitations were factors of participation in all activities, with the exception of skill-based activities.

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<sup>14</sup> Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, "Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy", *Developmental Medicine & Child Neurology*, vol. 53, no. 2, pp. 142–149.

<sup>15</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.

In a population study conducted in nine regions of seven European countries, Michelsen and associates<sup>16</sup> found less frequent participation in many, but not all domains of everyday activities in the group of children with CP than in the group of children from the general population. Regional variations were found in the magnitude of these differences, additionally. A possible explanation of variations between regions could be explained by environmental differences, considering that certain factors (such as special school attending) were not associated with a further reduction of participation in most areas of everyday life.

A prospective longitudinal study on the stability of participation in leisure activities pointed to a significant decrease, important for their health, functioning and collective quality of life.<sup>17</sup> In particular, there was a decline in diversity and frequency in recreational activities, activities based on skills and self-improvement activities in a period of school age (6–12 years) to adolescence (12–19 years). Only the participation in free social activities remained stable. The diversity of active physical activities was slightly increased, yet their frequency was decreased. There was a decline in the level to which participants with CP had expressed how much they had enjoyed these activities. Preferences, as a selection of a certain type of activities or the way in which an individual wants to participate in some extracurricular activities, remained unchanged with the exception of recreational activities.

Longo and associates<sup>18</sup> confirmed lower diversity, lower intensity and a high level of enjoyment. Personal and environmental factors were stronger determinates than family ones. Informal activities were characterized by higher diversity and intensity levels when compared to formal, although with no difference between their enjoyment levels. Statistically significant differences were noted in relation to five activity types. The results indicated higher both diversity and intensity in social and recreational than in skill-based,

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<sup>16</sup> Susan Michelsen, Esben Flachs, Peter Uldall, Eva Eriksen, Vicki McManus, Jackie Parkes, Kathryn Parkinson, Ute Thyen, Catherine Arnaud, Eva Beckung, Heather Dickinson, Jérôme Fauconnier, Marco Marcelli and Allan Colver, "Frequency of participation of 8–12-year-old children with cerebral palsy: a multi-centre cross-sectional European study", *European Journal Of Paediatric Neurology*, vol. 13, no. 2, pp. 165–177.

<sup>17</sup> Annette Majnemer, Keiko Shikako-Thomas, Norbert Schmitz, Michael Shevell and Lucy Lach, "Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy", *Research in Developmental Disabilities*, vol. 47, pp. 73–79.

<sup>18</sup> Egmar Longo, Marta Badia and Begoña Orgaz, "Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy", *Research in Developmental Disabilities*, vol. 34, no. 1, pp. 266–275.

self-improvement and active physical activities with the lowest level of enjoyment in self-improvement activities. Low diversity and intensity do not indicate a restricted participation if one takes into account the importance of engagement in the activities of one's own choice. Earlier, addressing the issue of a relationship between participation and quality of life of school-age children with CP, McManus and associates<sup>19</sup> indicated an association between the impairment level and participation in everyday activities, including the leisure ones. In other words, higher levels of impairment were followed by diminished participation.

## DISCUSSION

Multiple determination of participation in leisure activities by the characteristics of child and adolescent with CP, and by the characteristics of their families, has been confirmed in numerous studies. Results pointed to motor functioning,<sup>20</sup> and impairment level,<sup>21</sup> followed by age,<sup>22</sup> certain characteristics of family participation, motivation and behavior<sup>23</sup> as the key factors of participation in leisure activities of children and adolescents with CP.

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<sup>19</sup> Vicki McManus, Paul Corcoran and Ivan J Perry, *Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland*, op. cit.

<sup>20</sup> Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri, and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.  
Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.

<sup>21</sup> Vicki McManus, Paul Corcoran and Ivan J Perry, *Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland*, op. cit.

<sup>22</sup> Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.

<sup>23</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.  
Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.

Higher levels of motor and cognitive abilities of children with CP, better communication skills, regular inclusive schools attending, family and peers support, may be the factors that affect participation.<sup>24</sup> The severity of motor impairment was singled out as a factor that reduces and limits participation,<sup>25</sup> in addition to ambulatory and manual ability limitations.<sup>26</sup> Intellectual abilities were identified as a predictor of engagement in social activities. These findings support recommendations of a maximum possible functional development of school-age children with CP, especially when taking into account the association between level of impairment and participation in active physical and self-improvement activities.<sup>27</sup>

Diversity and intensity of overall participation in leisure activities are decreasing with age,<sup>28</sup> with the exception of participation in social activities.<sup>29</sup>

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- <sup>24</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit.  
 Egmar Longo, Marta Badia and Begoña Orgaz, *Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy*, op. cit.  
 Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.  
 Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.
- <sup>25</sup> Vicki McManus, Paul Corcoran and Ivan J Perry, *Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland*, op. cit.
- <sup>26</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.
- <sup>27</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilingaryan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.
- <sup>28</sup> Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.
- <sup>29</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.

Recently, King and associates<sup>30</sup> examined differences in diversity of leisure activity types and confirmed that the youngest mostly took part in recreational activities. It was reported previously by other researchers that the age was determinant of participation.<sup>31</sup> However, considering the level of enjoyment in leisure participation, authors reported that the highest level was noted in social activities and that it was not influenced by age.<sup>32</sup> Nonetheless, the higher enjoyment level was associated with the higher intensity or frequency of involvement. When it comes to gender, as a personal factor, its potential influence on participation intensity was not confirmed.<sup>33</sup> Yet, boys were rarely engaged in skill-based and self-improvement activities,<sup>34</sup> reporting less enjoyment in comparison to girls.<sup>35</sup>

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<sup>30</sup> Gillian King, Christine Imms, Robert Palisano, Annette Majnemer, Lisa Chiarello, Margo Orlin Mary Law and Lisa Avery, "Geographical patterns in the recreation and leisure participation of children and youth with cerebral palsy: A CAPE international collaborative network study" [Abstract], *Developmental Neurorehabilitation*, vol. 16, no. 3, p. 196.

<sup>31</sup> Eva Beckung and Gudrun Hagberg, "Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy", *Developmental Medicine & Child Neurology*, vol. 44, no. 5, pp. 309–316.

Mary Law, Gillian King, Susanne King, Marilyn Kertoy, Patricia Hurley, Peter Rosenbaum, Nancy Young and Steven Hanna, *Patterns of participation in recreational and leisure activities among children with complex physical disabilities*, op. cit. Sigrid Østensjo, Eva Brogren Carlberg and Nina Vollestad, "Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment", *Developmental Medicine & Child Neurology*, vol. 45, no. 9, pp. 603–612.

Clarissa Stevenson, Peter Pharoah and Richard Stevenson, *Cerebral palsy – The transition from youth to adulthood*, op. cit.

<sup>32</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.

<sup>33</sup> Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.

<sup>34</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.

<sup>35</sup> Batya Engel-Yeger, Tal Jarus, Dana Anaby and Mary Law, *Differences in patterns of participation between youths with cerebral palsy and typically developing peers*, op. cit.

Participation in a variety of leisure activities was noted in school-age children with CP, although these activities were mainly informal<sup>36</sup> and less frequent.<sup>37</sup> Activities were usually taking place in a home setting,<sup>38</sup> implying less physical, but also less social engagement.<sup>39</sup> This pattern of participation in leisure activities had been found previously in a population of children with physical disabilities.<sup>40</sup> Predictors such as less severe motor impairment, less intellectual impairment, and regular schools attendance, explained higher variety of activities.<sup>41</sup>

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- <sup>36</sup> Egmar Longo, Marta Badia and Begoña Orgaz, *Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy*, op. cit. Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilingaryan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit. Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit. Keiko Shikako-Thomas, Noemi Dahan-Oliel, Michael Shevell, Mary Law, Rena Birnbaum, Peter Rosenbaum, Chantal Poulin and Annette Majnemer, *Play and be happy? Leisure participation and quality of life in school-aged children with cerebral palsy*, op. cit.
- <sup>37</sup> Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.
- <sup>38</sup> Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy*, op. cit.
- <sup>39</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilingaryan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.
- <sup>40</sup> Mary Law, Gillian King, Susanne King, Marilyn Kertoy, Patricia Hurley, Peter Rosenbaum, Nancy Young and Steven Hanna, *Patterns of participation in recreational and leisure activities among children with complex physical disabilities*, op. cit. Malka Margalit, *Leisure activities of cerebral palsied children*, op. cit.
- <sup>41</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit. Egmar Longo, Marta Badia and Begoña Orgaz, *Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy*, op. cit. Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer and the QUALA Group, *Picture me*

Besides, King and associates<sup>42</sup> confirmed association between motor impairment and diversity given that the lowest levels of participation in recreational, active physical and self-improvement activities were detected in the group of children/youth with the most severe motor limitations. Children with behavioural difficulties were more involved in recreational activities, while the presence of hyperactivity implied less enjoyment in skill-based activities.<sup>43</sup>

The available studies results are contradictory when reviewing the role that resource and/or service centres may have in leisure participation. Majnemer and associates<sup>44</sup> emphasized the importance of rehabilitation services in providing information to beneficiaries about available (adapted) recreational activities, along with the association between rehabilitation services and skill-based activities, and higher enjoyment levels in active physical activities. The influence of services was recognized in the extent to which children and adolescents with CP were engaged with friends.<sup>45</sup> Nevertheless, Palisano and associates<sup>46</sup> found no statistically significant association between the participation intensity and provision of services or the extent to which services met beneficiaries' needs.

Child's functional abilities and preferences, and family participation were identified as direct predictors of participation of children with physical disabilities in both formal and informal leisure and recreational activities in a model presented by King and associates.<sup>47</sup> Family intellectual-cultural

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*playing – A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy, op. cit.*

<sup>42</sup> Gillian King, Christine Imms, Robert Palisano, Annette Majnemer, Lisa Chiarello, Margo Orlin Mary Law and Lisa Avery, *Geographical patterns in the recreation and leisure participation of children and youth with cerebral palsy: A CAPE international collaborative network study*, op. cit.

<sup>43</sup> Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.

<sup>44</sup> Ibidem.

<sup>45</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit.

<sup>46</sup> Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.

<sup>47</sup> Gillian King, Mary Law, Steven Hanna, Susanne King, Patricia Hurley, Peter Rosenbaum, Marilyn Kertoy and Terry Petrenchik, *Predictors of the leisure and*

orientation was added as a direct predictor of formal participation. Parents' perceptions of unsupportive environments, family cohesion and supportive relationships for the child were identified all as indirect predictors in this model. The influence of family orientation towards activities was highlighted further in a similar model introduced by Palisano and associates.<sup>48</sup> Longo and associates<sup>49</sup> recently presented a somewhat different model of predictors. Family factors were less associated with participation in leisure activities. In other words, leisure participation was determined more by personal and environmental than family factors. However, it is important to note that factors originating from the family lose their influence in period of adolescence during which persons with CP take initiative in choosing and engaging in leisure activities, primarily with friends and peers, whereas parental influence is being reflected through the planning and providing of access to organized recreational activities.<sup>50</sup> In addition, over the years, only diversity of active physical activities is slightly increasing whereas frequency and level of enjoyment are mostly decreasing. It is important to note that, in spite of overall decline in participation, preferences remain stable.<sup>51</sup>

## CONCLUSION

A total of 11 studies that described and examined leisure participation of children and/or adolescents with CP was included in this review. Generally, overall results were encouraging; prevailing lower intensity and diversity of activities did not determine the level of enjoyment in participation nor necessarily indicated that participation was restricted. Therefore, based on all presented

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*recreation participation of children with physical disabilities: A Structural equation modeling analysis*, op. cit.

<sup>48</sup> Robert Palisano, Margo Orlin, Lisa Chiarello, Donna Oeffinger, Marcy Polansky, Jill Maggs, George Gorton, Anita Bagley, Chester Tylkowski, Lawrence Vogel and Mark Abel, *Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy*, op. cit.

<sup>49</sup> Egmar Longo, Marta Badia and Begoña Orgaz, *Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy*, op. cit.

<sup>50</sup> Lin-Ju Kang, Robert Palisano, Margo Orlin, Lisa Chiarello, Gillian King and Marcia Polansky, *Determinants of social participation – with friends and others who are not family members – for youths with cerebral palsy*, op. cit.

<sup>51</sup> Annette Majnemer, Keiko Shikako-Thomas, Norbert Schmitz, Michael Shevell and Lucy Lach, "Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy", op. cit.

findings, it can be concluded that participation in leisure activities is complex, multidimensional construct influenced by personal, family and social characteristics.

Lack of activities performed in the community, specifically outside the home<sup>52</sup> and outside the curricular and extra-curricular school activities should be considered carefully. It represents a sensitive domain of participation and synchronized and coordinated engagement of both family and social structures is required in order to promote active social inclusion and participation, and to increase life quality. Adolescence, as a period of transition into adulthood, is especially vulnerable due to both overprotection and lower expectations from parents, and to limited peer and school participation. The solution requires the cooperation of parents, services and resource centres arguing. A better environment for children and youth with CP could be created in this direction. Besides, if opportunities were provided and options offered, children and adolescents with CP could engage in activities of their own choice, appropriately to their age, individual abilities and preferences. The role that health and rehabilitation services have in this process should be further clarified, since there are conflicting results about their influence on the overall participation of persons with CP, and therefore on participation in leisure activities.

The importance of this issue is particularly evident when the basis of participation is seen through the development of social relationships and positive interactions within given environment. Understanding this process, and individual and mutual influence of specific factors on the way persons with CP spend their leisure time, represent the first step in removing barriers, in finding the ways for gaining positive social experiences, and in encouraging individuals to be actively engaged in society.

Practical implications of these findings and conclusions are found in the creation of better support models and individual support programs, as well as more effective rehabilitation programs and services, in accordance with presented determinants of participation. Engaging in activities outside of daily or school routine, at the earliest age, could serve as an opportunity for children with CP and their families to gain social experiences that would facilitate a

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<sup>52</sup> Egmar Longo, Marta Badia and Begoña Orgaz, *Patterns and predictors of participation in leisure activities outside of school in children and adolescents with cerebral palsy*, op. cit.

Annette Majnemer, Michael Shevell, Mary Law, Rena Birnbaum, Gevorg Chilinyan, Peter Rosenbaum and Chantal Poulin, *Participation and enjoyment of leisure activities in school-aged children with cerebral palsy*, op. cit.

Margo Orlin, Robert Palisano, Lisa Chiarello, Lin-Ju Kang, Marcia Polansky, Nihad Almasri and Jill Maggs, *Participation in home, extracurricular, and community activities among children and young people with cerebral palsy*, op. cit.

process of their future transition to adulthood, with an optimal support of close and wider social environment. This needs to be investigated additionally by further enlightening of predictors. Participation of children and adolescents with CP should originate from their free choice, with respect to their needs and preferences, and directed towards improving their quality of life.

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## PARTICIPACIJA DECE I ADOLESCENATA S CEREBRALNOM PARALIZOM U AKTIVNOSTIMA SLOBODNOG VREMENA: PREGLED LITERATURE

### *Apstrakt*

Poslednjih godina primetan je porast interesovanja za participaciju osoba sa ometenošću, uključujući i osobe s cerebralnom paralizom. To je razumljivo imajući u vidu značaj participacije u svakodnevnim aktivnostima, uključujući aktivnosti slobodnog vremena, kao ključnog dela razvoja deteta. Cilj ovog rada bio je da se opišu obrasci participacije dece i adolescenata s cerebralnom paralizom u aktivnostima slobodnog vremena kako bi se sistematizovala ključna saznanja u ovoj oblasti. Izvršen je pregled istraživanja i izdvojeno je ukupno 290 radova, od kojih je 11 ispunilo kriterijume uključivanja. Preovlađujući manji intenzitet i raznolikost aktivnosti ne određuje nivo zadovoljstva učestvovanjem, niti nužno ukazuje da je ova participacija ograničena. Participacija u aktivnostima slobodnog vremena je složen, multidimenzionalni konstrukt koji je pod uticajem ličnih, porodičnih i društvenih karakteristika.

### *Ključne reči:*

slobodno vreme, motorički poremećaj, višestruka ometenost, obrazac participacije.