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# Autonomy in Participation and Health Care and Transition Readiness to Adult Health Care for Young People with Cerebral Palsy

Summary of the Doctoral Thesis for obtaining the scientific degree “Doctor of Science (*PhD*)”

Sector Group – Medical and Health Sciences
Sector – Health and Sport Sciences
Sub-Sector – Sports Medicine and Rehabilitology

Riga, 2023

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## Abbreviations used in the Thesis

| | |
|---|---|
| 95 % CI | 95% confidence interval |
| adj. res. | Adjusted residual |
| GMFCS | Gross Motor Function Classification System |
| ICC | Intraclass correlation coefficient |
| ICD-10 | International Classification of Diseases 10th Revision |
| ICF | International Classification of Functioning, Disability and Health |
| IQR | Interquartile range |
| MACS | Manual Ability Classification System |
| MMSE | Mini-Mental State Examination |
| NICE | National Institute for Health and Care Excellence |
| OR | Odds ratio |
| $r_s$ | Spearman's Rho |
| RTP | Rotterdam Transition Profile |
| TRAQ | Transition Readiness Assessment Questionnaire |
| U.S. | United States of America |
| vs. | versus |
| WHO | World Health Organization |
| WHODAS 2.0 | World Health Organization Disability Assessment Schedule 2.0 |
| α | Cronbach's alpha |

# Introduction

Cerebral palsy is the most common cause of physical disability in children (Vitrikas, Dalton and Breish, 2020), with a general prevalence in high income countries of 1.6 per 1 000 live births (McIntyre et al., 2022). The condition has long been rather linked to the paediatric rehabilitation (Graham et al., 2016), even though a majority of those affected by the diagnosis attain full age and live with it even as adults (Blair et al., 2019). It is a lifelong condition and the life expectancy in non-severe cases can be similar to the general population (Hutton and Pharoah, 2006; Colver, 2012). Therefore, much emphasis has now been put on the transition process from adolescence to adult life of young people with cerebral palsy, both in the promotion of participation, covering different areas of life (Hutton and Pharoah, 2006; Nieuwenhuijsen et al., 2009; Rutkowski and Riehle, 2009; Verhoef et al. 2014; Bagatell et al., 2017), and in the promotion of transition to adult health care in particular (Linroth, 2009; Watson et al., 2011; Okumura, Saunders and Rehm, 2015; Bolger, Vargus-Adams and McMahon, 2017).

It has been previously reported that young adults with CP participate less in activities, such as housing, paid work, and intimate and sexual relationships than their able-bodied peers (Donkervoort et al., 2009; Wiegerink et al., 2010a; Verhoef et al., 2014), and in terms of finances and activities, many are dependent on parental support (Jacobson et al., 2019). Young people also admit that they lack genuine opportunities in life to become independent (Freeman et al., 2018). For patients with cerebral palsy, enhancement of participation may lead to a more effective transition to adult life (Imms and Adair, 2017; Bromham et al., 2019, Hanes et al., 2019), whereas unemployment, decreased autonomy, and insufficient quality of life may be the consequences of an unsuccessful transition process (Chamberlain and Kent, 2005; Magill-Evans et al., 2005).

Although the neurologic damage causing the cerebral palsy is non-progressive, the musculoskeletal system, the neurological and mental state of health is deteriorating over time (Roebroeck et al., 2009; Tosi et al., 2009; Roquet et al., 2018). Adults with cerebral palsy face the same health problems, for example, reduced mobility and ability to self-care (Nieuwenhuijsen et al., 2009), spasticity and chronic pain (Roquet et al., 2018; Flanigan et al., 2020), musculoskeletal deformation in various parts of the body (Green and Hurvitz, 2007; Murphy, 2009; Yoshida et al., 2018), genitourinary problems, (Samijn et al., 2017) and depression and anxiety (Smith et al., 2018). It has been shown that the need for certain medications is also increasing with age, (Roquet et al., 2018) and young people with cerebral palsy admit they do not receive enough information about their health condition (Nieuwenhuijsen et al., 2008). After reaching adult age, young people with functional impairments are no longer eligible for public-paid paediatric health care services, parental involvement in decision making lessens and more autonomous, independent skills of patients are required (Castillo and Kitsos, 2017). Health care transition is one of the areas of general development transition (Crafter, Maunder and Soulsby, 2019).

The National Institute for Health and Care Excellence has published guidelines for a successful transition, which calls for relevant recommendations to be taken into account at both individual, institutional and national level (National Institute for Health and Care Excellence [NICE], 2016). Specific transition rehabilitation programs have been developed in European countries, such as the Netherlands (Kenniscentrum Zorginnovatie Hogeschool Rotterdam, 2021), the United Kingdom (The Association for Real Change, 2021), the United States (Got Transition, 2022) and elsewhere.

Currently, there are no evidence-based transition pathways to adult life designed for young people with cerebral palsy living in Latvia in the context of participation and health care; besides, it should be noted that historically healthcare-providing services have not been equally developed between different

parts of Europe (Tragakes et al., 2008; WHO, 2015; Behmane et al., 2019). In order to establish and implement a targeted and successful transition path to adult life, it is essential to clarify the level of autonomy of young people with cerebral palsy living in Latvia in participation and health care, and the level of transition readiness to adult health care, as well as the contributing and delaying factors.

## Research questions of the Thesis

1. To what degree have young people with cerebral palsy achieved autonomy in the domains of participation and health care?
2. What is the transition readiness level to adult health care for young people with cerebral palsy?
3. How strong is the correlation between the level of functioning, related disorders, contextual factors and of the level of health and disability for young people with cerebral palsy, and the level of autonomy for young people in participation and health care, and the transition readiness to adult health care, and whether and how do these aspects affect the transition readiness to adult life?
4. In which domains of health and disability there are significant differences between young people with cerebral palsy and the reference group?

## Aims of the Thesis

Primary – to identify the following aspects in young people with cerebral palsy:

1. Autonomy in the transition to adult life in the context of participation and health care.
2. Transition readiness from paediatric to adult health care.
3. Factors relevant to the transition and factors affecting it.

Secondary – to identify the level of health and disability of young people with cerebral palsy and to identify the level of significance of the difference through comparative analysis with a reference group of same-aged peers.

## Objectives of the Thesis

1. To identify the number of young people living in Latvia who have been diagnosed with cerebral palsy and who are at the age of the transition.
2. To identify the degree of functioning, related disorders and contextual factors of the young people with cerebral palsy included in the study, their degree of autonomy in the transition to adult life in the context of participation and health care, their readiness to transit from paediatric to adult health care and the level of health and disability.
3. Identify the relevance and impact of the degree of functioning, related disorders, contextual factors and of the degree of health and disability of the young people with cerebral palsy (1) on the degree of autonomy in the transition to adult life in the context of participation and health care, (2) the readiness to transit from paediatric to adult health care, as well as to determine the impact of autonomy on the transition from paediatric to adult health care.
4. To identify the contextual factors and the degree of health and disability of young people in the reference group, and to carry out a comparative analysis between young people with cerebral palsy and the reference group in terms of health and disability, determining the degree of importance of the differences.
5. Based on the results of the study, to depict (1) the current degree of autonomy of young people with cerebral palsy in the context of participation and health care, and the readiness to transit from

paediatric to adult health care, (2) the factors associated with the transition process and factors affecting it, (3) the significant differences in the level of health and disability between young people with cerebral palsy and the reference group.

6. Put forward practical proposals based on the results of the study for the successful transition of young people with cerebral palsy to adult life.

## Scientific novelty of the Thesis

Until now, the transition to adult life specifically for young people with cerebral palsy in autonomy of participation and health care and the readiness of transition from paediatric to adult health care has not been studied in Latvia. The results of the study indicate the relevance of a justified and structured transition in the context of rehabilitation in Latvia, including social rehabilitation and general health care. The results are valid for young people with functional impairments living in Latvia, their relatives and persons involved in their health care and promotion of social skills. Besides, the publication of data fills a scientific gap between Western Europe, the United States of America, Australia and Scandinavia and the Baltic Sea Region, since there are different traditions and a varying development rate in health care, including rehabilitation, among the countries in Europe and worldwide.

The cross-sectional study mainly describes the transition for young people with cerebral palsy living in Latvia: (1) the degree of autonomy in participation and health care, (2) the readiness to transit from paediatric to adult health care, (3) the factors associated with the transition and the factors affecting it. This highlights the possible changes in health care of young people with cerebral palsy at the age of transition, potentially improving their autonomy, participation, health self-control, integration and reducing health risks in the future and the socio-economic burden for the relatives of such young people.

# 1 Material and methods

## 1.1 Conceptual model of the study

The conceptual model (Figure 1.1) represents the descriptive information of young people with cerebral palsy and the reference group, including the results of the WHODAS 2.0 and a description of young people with cerebral palsy, drawing on RTP and TRAQ results.

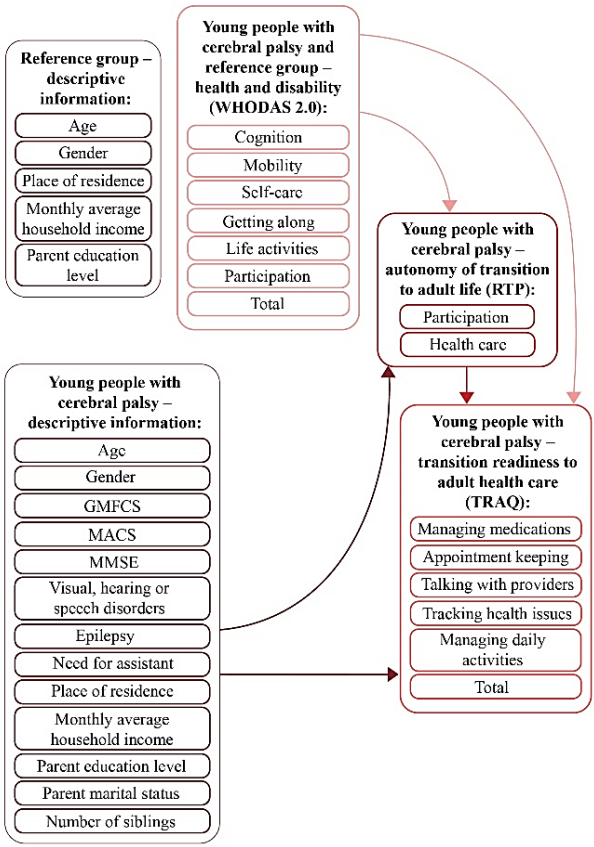


Figure 1.1 **Conceptual model of the study**

WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, RTP: Rotterdam Transition Profile, TRAQ: Transition Readiness Assessment Questionnaire.

The arrows indicate the links analysed in the study between the independent and dependent variables and the potential impact of factors on autonomy in participation and health care (RTP) and transition readiness to adult health care (TRAQ).

## 1.2 Study design, population and setting

Study design – cross-sectional, analytical. Most of the potential participants were sought through the electronic database and paper records of the state limited liability company "Children's Clinical University Hospital". By applying the inclusion and exclusion criteria, the study includes 81 persons with cerebral palsy.

Inclusion criteria:

- the participant at the time of the study is 16–21 years old;
- primary diagnosis: cerebral palsy (G80, ICD-10).

Exclusion criteria:

- inaccurate diagnosis (other than G80, G80.0, G80.1, G80.2, G80.3, G80.4, G80.8, G80.9, ICD-10), n = 5;
- moderate to severe mental disorders and / or generally severe physical condition (including palliative care patient), n = 82;
- moderate or severe cognitive impairment (MMSE < 24 points), n = 2;
- currently living and / or having grown up in a social institution, n = 7;
- emigrated from Latvia, n = 1;
- the participant and / or his / her parent refuses participation, n = 10;
- does not respond to a telephone call (dual attempt), n = 9;
- insufficient and / or missing up-to-date contact information, n = 23;
- dead, n = 5.

A reference group was used to compare the level of activity and participation among young people with cerebral palsy and able-bodied peers. The selection process for both groups is illustrated in Figure 1.2.

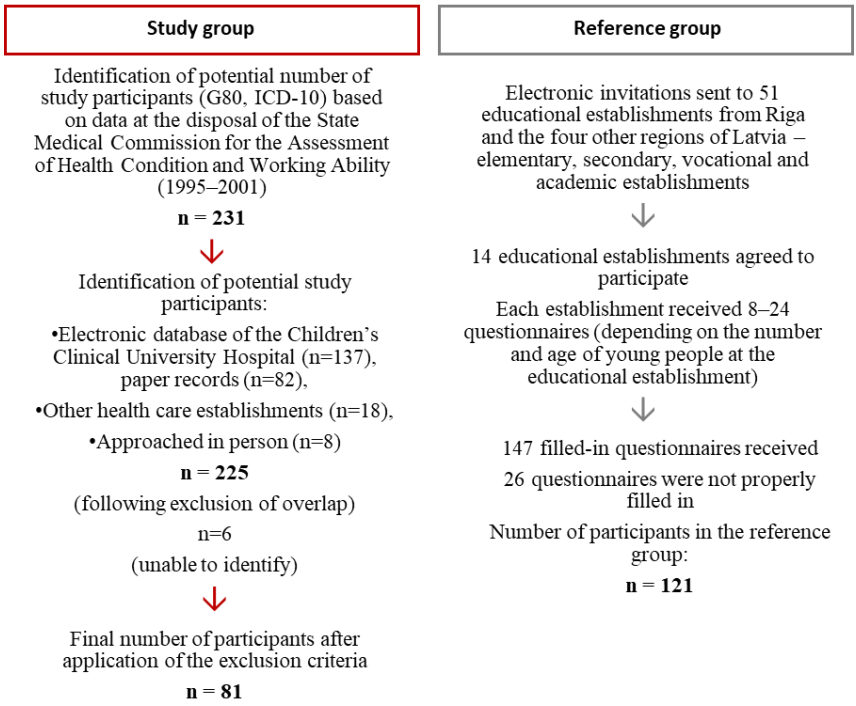


Figure 1.2 **Flowchart for identification and selection of the study group and the reference group**

ICD-10: International Classification of Diseases 10th Revision,
G80: Cerebral palsy.

All participants or their parents had to review the informed consent before completing the questionnaire and the participant's descriptive data were obtained. Young people with cerebral palsy and / or their parents were answered any queries they had on site. The survey was carried out in conditions comfortable for the study participant, predominantly – at their place of residence.

On the other hand, young people in the reference group completed the questionnaire in all cases on their own. After completion of the documentation, the participant placed it in an envelope bearing a pre-attached postage stamp and the return address and sent it to the author of the study.

The survey was conducted between October 2017 and June 2018.

The study was carried out in compliance with the provisions of the Helsinki Declaration (1975[1]) and the legal acts of the Republic of Latvia. The study protocol was authorised by the Ethics Committee of Rīga Stradiņš University (5/18.08.2016.; 5 August 2016) and by the Children's Clinical University Hospital (SP-68/2016, 12 June 2016).

## 1.3 Assessment tools

### 1.3.1 Mini-Mental State Examination (MMSE)

MMSE or the Mini-Mental State Examination is a 12-point questionnaire used for screening individual cognition (Finney, Minagar and Heilman, 2016; Moura et al., 2017), but not for setting a diagnosis – the result serves as an initial indicator of cognitive status and does not account for a specific assessment (Folstein, Folstein and McHugh, 1975). The questions are divided into categories: 1. Orientation, 2. Registration, 3. Attention and calculation, 4. Recall, 5. Language, 6. Repetition, 7. 3-stage command, 8. Comprehension, 9. Writing, 10. Drawing. The maximum number of points is 30. The interpretation of points is as follows: 24–30: none or some / uncertain cognitive impairment, 18–23: mild to moderate cognitive impairment, 0–17: severe cognitive impairment (Velayudhan et al., 2014; Mazzi et al., 2020; Shirley Ryan AbilityLab, 2021).

[1] Revised in 2013.

### 1.3.2 Gross Motor Function Classification System (GMFCS)

The GMFCS or the Gross Motor Function Classification System is a five-level classification system that evaluates the mobility, sitting and transfer capacity of children and adults (McCormick et al., 2007) with cerebral palsy. General heading for each level:

LEVEL I: walks without limitations;

LEVEL II: walks with limitations;

LEVEL III: walks using a hand-held mobility device;

LEVEL IV: self-mobility with limitations; may use powered mobility;

LEVEL V: transported in a manual wheelchair (Palisano et al., 1997).

### 1.3.3 Manual Ability Classification System (MACS)

MACS or the Manual Ability Classification System is a five-level assessment system designed to describe the day-to-day activities of a child or adult (van Meeteren et al., 2010) at home, school and environment using both hands. General heading for each level:

LEVEL I: Handles objects easily and successfully;

LEVEL II: Handles most objects but with somewhat reduced quality and / or speed of achievement;

LEVEL III: Handles objects with difficulty; needs help to prepare and / or modify activities;

LEVEL IV: Handles a limited selection of easily managed objects in adapted situations. Performs parts of activities with effort. Requires continuous support;

LEVEL V: Does not handle objects and has severely limited ability to perform even simple actions (Eliasson et al., 2006).

### 1.3.4 Rotterdam Transition Profile (RTP)

Rotterdam Transition Profile or RTP is an assessment tool that describes the readiness of young people with cerebral palsy to transit to adult life and the degree of autonomy in certain aspects of life (Donkervoort et al., 2009). The tool has two main sections, broken down into specific domains: 1) PARTICIPATION: Education and employment, Finance, Housing, Leisure (social activities), Intimate relationships, Sexuality, Transportation; 2) HEALTH CARE: Care demands, Services and aids, Rehabilitation services. The level of autonomy is assessed by phases – zero to three, respectively:

Phase 0 – no experience;

Phase 1 – dependent on adults;

Phase 2 – experimenting and orientating to the future;

Phase 3 – autonomy.

Based on the conclusions of the instrument validation study (Donkervoort et al., 2009) and the outcomes of other studies (Wiegerink et al., 2010b, Schmidt et al., 2020), the importance of the variability of RTP results was considered for a more in-depth description of RTP results, given the level of gross motor functions (GMFCS) of the participants, thus providing a more detailed description of the degree of autonomy.

Subject to seeing previous permission from the authors, this study used RTP 1.0, version of March 2010. In order to allow RTP to be used in Latvian, RTP was translated into Latvian following the Guidelines on Translation and Adaptation of Instruments World Health Organization (WHO) (WHO, 2016). The reliability indicators for the translated version are presented in Table 1.1.

Table 1.1

**The reliability indicators of RTP's version in Latvian, ICC**

| RTP | Inter-rater reliability*, $r_s$ | Test-retest reliability**, $r_s$ |
|---|---|---|
| Education and employment | 0.56 | 0.91 |
| Finance | 0.47 | 0.63 |
| Housing | 0.55 | 0.84 |
| Leisure (social activities) | 0.24 | 0.93 |
| Intimate relationships | 0.98 | 0.98 |
| Sexuality | 0.94 | 0.99 |
| Transportation | 0.69 | 0.94 |
| Care demands | 0.44 | 0.77 |
| Services and aids | 0.78 | 0.91 |
| Rehabilitation services | 0.80 | 0.99 |

* Raters – two physiotherapists with at least five years of experience working with young people with cerebral palsy. ** Interval between tests of 7–10 days, RTP: Rotterdam Transition Profile, ICC: intraclass correlation coefficient, $r_s$: Spearman's Rho. $p < 0.0001$.

### 1.3.5 Transition Readiness Assessment Questionnaire (TRAQ)

TRAQ or the Transition Readiness Assessment Questionnaire is a valid tool to assess the transition readiness of adolescents and young people with special health care needs to adult health (Sawicki et al., 2011) care. The tool covers 20 items grouped into 5 domains: 1) Managing Medications, 2) Appointment Keeping, 3) Tracking Health Issues, 4) Talking With Providers, 5) Managing Daily Activities. Each question is scored on a scale of 1–5, where '1' is the lowest and '5' is the highest score, describing their skill level for a certain domain as follows:

1 – No, I do not know how;

2 – No, but I want to learn;

3 – No, but I am learning to do this;

4 – Yes, I have started doing this;

5 – Yes, I always do this when I need to.

Each answer is subject to an interpreting definition and is attributed a stage of the change model, namely:

1 – Has no intention of taking action within the next 6 months (Primary idea).

2 – Intends to take action in the next 6 months (Intent).

3 – Intends to take action within the next 30 days and has taken some behavioural steps in this direction (Preparation).

4 – Has changed behaviour for less than 6 months (Action).

5 – Has changed behaviour for more than 6 months (Maintenance) (Sawicki et al., 2011).

The systematic review 2014 named TRAQ as the best validated tool for the assessment of transition readiness, with an additional benefit – neutrality of diagnosis (Zhang, Ho and Kennedy, 2014). The study uses the version translated into Latvian, for which *Mg. Sc. Sal.* L. Baranova, as part of her master's thesis, established overall internal consistency – Cronbach's alpha ($\alpha$) = 0.94, while the subsets demonstrated $0.64 < \alpha < 0.87$ (Baranova, 2016).

Considering the importance of cognitive functions, as highlighted in other sources, on the individual's abilities in health care management and transition (Ali et al., 2013; NICE, 2016; Ally et al., 2018; Leeb et al., 2020), the present Thesis provides an additional review of the importance of differences in TRAQ results based on the participant's MMSE results, thus acquiring in-depth data of the participants' transition readiness level.

### 1.3.6 World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)

WHODAS 2.0 or the World Health Organization Disability Assessment Schedule 2.0 is designed to determine the health and disability of a person. Its comprehensive concept is based on the Activity and Participation components of

the International Classification of Functioning, Disability and Health (ICF). WHODAS 2.0 is intended to be used for both general populations and specific diseases, including mental and neurological diseases. WHODAS 2.0 covers six functioning domains:

1. Cognition – understanding and communicating (concentrating, remembering, problem solving, learning and communicating).
2. Mobility – moving and getting around (standing, moving around inside the home, getting out of the home and walking a long distance).
3. Self-care – attending to one's hygiene, dressing, eating and staying alone.
4. Getting along – interacting with other people.
5. Life activities – domestic responsibilities, leisure, work and school;
6. Participation – joining in community activities, participating in society (WHO, 2010b).

The domains consist of questions where the respondent is asked to describe its level of difficulty within the last 30 days, performing certain tasks or activities or engaging in routine situations. The level of difficulty is scored on a scale of 1–5, where: 1 – no difficulty, 2 – mild, 3 – moderate, 4 – severe, 5 – extreme. If the question is not relevant for the last 30 days, it is not answered and is marked as 'not applicable'. The results were reflected by simple scoring and by giving average values. At the end of the WHODAS 2.0, the respondent must indicate the number of days, overall, for how many days were these difficulties present, for how many days he / she was totally unable and for how many days he / she had to cut back or reduce his / her usual activities or work because of any health condition. The study was based on the WHODAS 2.0 full (36-item) self-assessment version in Latvian. The schedule in Latvian was translated by Dr. Med. G. Bērziņa (Bērziņa, 2018). The reliability of the

translated version has been checked within this study. Subsequently, the test-retest reliability (an interval of 7–10 days between tests) for the total result of WHODAS 2.0 was $r_s = 0.99$ ($p < 0.01$), for the domains $0.96 < r_s < 0.99$ ($p < 0.01$). Internal consistency (Cronbach's alpha) for the total result of WHODAS 2.0 was $\alpha = 0.84$, for the domains – Cognition $\alpha = 0.79$, Mobility $\alpha = 0.71$, Self-care $\alpha = 0.85$, Getting along $\alpha = 0.72$, Life activities $\alpha = 0.87$, and Participation $\alpha = 0.79$.

To elaborate on the secondary results, the study looked at the importance of the difference of the WHODAS 2.0 results in terms of the gross motor functions (GMFCS) of the participating young people with cerebral palsy.

## 1.4 Type of cerebral palsy, related disorders, contextual factors

Additional descriptive data for young people with cerebral palsy found in the study is depicted in Table 1.2. Type of the cerebral palsy is determined by the medical records of the participants. Average household income was assumed to be EUR 1,017.60 per month (Official statistics portal, 2017).

Table 1.2

**Descriptive data of young people with cerebral palsy and explanation of such data**

| Descriptive data | Explanation |
|---|---|
| Sex* | F / M |
| Age (years)* | 16 / 17 / 18 / 19 / 20 / 21 |
| Place of residence* | Riga, Riga district / other city / village, rural area |
| Type of cerebral palsy, ICD-10 | G80.0 / G80.1 / G80.2 / G80.3 / G80.4 / G80.8 / G80.9 |
| Severe visual, hearing or speech disorders | Yes / No |
| Epilepsy | Yes / No |
| Need for an assistant | No / Required only for transportation / Required for transportation and other purposes |

Table 1.2 continued

| Descriptive data | Explanation |
|---|---|
| Level of education of the parents*** | Elementary / secondary / secondary vocational / incomplete higher education / higher education (bachelor's degree) / postgraduate (master's degree)/ doctorate |
| Grew up in a family with two parents | No / Yes |
| Number of siblings | ≤ 1 / > 1 |
| Monthly average household income, EUR*** | Up to 1,017.60 / approximately 1,017.60** / above 1,017.60 |

* Data obtained for both the study group and the reference group. ** Index of 2016. *** Data obtained for both the researched and the reference group, but for the reference group reflected in the full version of the doctoral thesis. ICD-10: International Classification of Diseases 10th Revision, G80.0 Spastic quadriplegic cerebral palsy; G80.1 Spastic diplegic cerebral palsy; G80.2 Spastic hemiplegic cerebral palsy; G80.3 Athetoid cerebral palsy; G80.4 Ataxic cerebral palsy; G80.8 Other cerebral palsy; G80.9 Cerebral palsy, unspecified.

## 1.5 Statistical analysis

The statistical analysis of data was carried out using the SPSS software (IBM SPSS Statistics, v. 23.0, Chicago, IL, USA). The normal distribution of the measurements of the study data set was subject to the Shapiro-Wilk test. Since normal distribution was not found, non-parametric methods for the statistical processing of data were used. The quantitative data was analysed using median (Me) and interquartile range (IQR). The Mann-Whitney U test was used to compare average values of range data between two independent groups, the Spearman's Rho ($r_s$) method was used for the correlation of the interval, ordinal, and dichotomous data, while Pearson's chi-squared test and Fisher's Exact were used for rank data. Interpretation of correlation coefficients: up to |±0.19| very weak, |±0.20|–|±0.39| weak, |±0.40|–|±0.59| moderate, |±0.60|–|±0.79| strong, |±0.80|–|±0.999| very strong (Statstutor, 2018). The adjusted residual was used at the cross-tabulations – when assessing parameters with several subgroups. The adjusted residual was deemed significant with a value greater than |±1.96|.

For analytical data processing, the statistical significance probability value is assumed to be $p \leq 0.05$. Provided a specific influencing factor exists, an odds ratio (OR) > 1 stands for a higher probability of autonomy or transition readiness to adult health care, while an OR < 1 means the probability is lower. For each of the potentially influencing factors, binary logistic regression was applied to determine the unique impact on the autonomy of the participant or on the transition readiness to adult health care (single-factor model). For the secondary analysis, factors were placed in the multivariate model to determine the most important factor, with Wald and $p \leq 0.05$ being the selection criteria (multi-factor model). To create the binary logistic regression model, the dependent variables were divided into two distinct parts:

- RTP: (a) Phase 0–2 (totally or partially dependent), (b) Phase 3 (autonomy);
- TRAQ (Me): (a) $\leq 3.00$ points (task is currently not performed), (b) $\geq 3.01$ points (a task carried out to a certain degree).

For easier view and to distinguish the results by topics, the relationship between the results of the WHODAS 2.0 and the potential impact on RTP and TRAQ results are presented in separate tables.

Tables, graphs and charts were created in Microsoft Office Excel (2010) and Microsoft Office Word (2010) (Redmond, WA, USA).

# 2 Results

## 2.1 Descriptive data of the young people involved in the study

Table 2.1 includes descriptive data of the young people with cerebral palsy.

Table 2.1

**Descriptive data of young people with cerebral palsy (n = 81)**

| Descriptive data | Explanation | | |
|---|---|---|---|
| Age in years, Me (IQR) | 18 (20–17) | | |
| Sex, n (%) | | | |
| Male | 41 (51) | | |
| Female | 40 (49) | | |
| Income level, n (%) | | | |
| Below average | 50 (62) | | |
| Average | 18 (22) | | |
| Above average | 13 (16) | | |
| Type of cerebral palsy, n (%) | | MMSE, n (%) | |
| Spastic quadriplegia, G80.0 | 27 (33) | 30 points | 17 (21) |
| Spastic diplegia, G80.1 | 24 (30) | 29 points | 23 (28) |
| Hemiplegia, G80.2 | 17 (21) | 28 points | 8 (10) |
| Dyskinesia, G80.3 | 5 (6) | 27 points | 11 (14) |
| Other | 8 (10) | ≤ 26 points | 22 (27) |
| GMFCS, n (%) | | MACS, n (%) | |
| Level I | 36 (44) | Level I | 23 (28) |
| Level II | 24 (30) | Level II | 34 (42) |
| Level III | 13 (16) | Level III | 16 (20) |
| Level IV | 8 (10) | Level IV | 8 (10) |
| Level V | 0 (0) | Level V | 0 (0) |
| Severe speech impairment, n (%) | no 68 (84) yes 13 (16) | | |
| Severe visual impairment, n (%) | no 74 (91) yes 7 (9) | | |
| Severe hearing impairment, n (%) | no 80 (99) yes 1 (1) | | |
| Epilepsy, n (%) | no 73 (90) yes 8 (10) | | |

Table 2.1 continued

| Descriptive data | Explanation |
|---|---|
| Need for an assistant, n (%) | |
| No | 39 (48) |
| Only for transportation | 25 (31) |
| For transportation and other | 17 (21) |
| Place of residence, n ( %) | |
| Riga, Greater Riga area | 30 (37) |
| Another town | 30 (37) |
| Village, rural territory | 21 (26) |
| Parent education level, n ( %) | |
| Elementary | father 6 (6) mother 6 (7) |
| Secondary | father 12 (15) mother 12 (15) |
| Secondary vocational | father 34 (42) mother 27 (33) |
| Incomplete higher education | father 2 (3) mother 3 (4) |
| Higher education (bachelor's degree) | father 14 (17) mother 25 (31) |
| Postgraduate (master's degree) | father 2 (3) mother 2 (3) |
| Doctorate | father 0 (0) mother 0 (0) |
| Unable to determine | father 11 (14) mother 6 (7) |
| Grew up in a family with two parents, n ( %) | no 23 (28) yes 58 (72) |
| Number of siblings > 1, n ( %) | no 54 (67) yes 27 (33) |

n: number, Me: median, IQR: interquartile range, MMSE: Mini-Mental State Examination, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System.

Descriptive data of the young people of the reference group are presented in Table 2.2.

Table 2.2

**Descriptive data of the reference group (n = 121)**

| Descriptive data | Explanation |
|---|---|
| Age in years, Me (IQR)* | 18 (19–17) |
| Sex, n (%)* | |
| Male | 71 (59) |
| Female | 50 (41) |

Table 2.2 continued

| Descriptive data | Explanation |
|---|---|
| Place of residence, n (%) | |
| Riga, Greater Riga area | 26 (22) |
| Another town | 75 (62) |
| Village, rural territory | 20 (16) |

n: number, Me: median, IQR: IQR: interquartile range. *Significance of statistical difference with study group: age p = 0.30, sex p = 0.20.

## 2.2 The degree of autonomy of young people with cerebral palsy in participation and health care domains – the results of the RTP instrument

The results of RTP are shown in Figure 2.1.

The chart shows the results of the participants in three categories: (1) up to 18 years of age (n = 27), (2) 18 years of age and older (n = 54), (3) total result for the entire group (n = 81).

Figure 2.1 **The degree of autonomy of young people with cerebral palsy in participation and health care domains**

Phase 0 – no experience, Phase 1 – dependent on adults, Phase 2 – experimenting and orientating to the future, Phase 3 – autonomy. * between age groups $p \leq 0.05$.

## 2.3 The degree of readiness of young people with cerebral to transit to adult health care — the results of the TRAQ instrument

The average TRAQ result by groups – with a lower MMSE 24–28 points and MMSE 29–30 points –, as well as all participants included in the study, is shown in Table 2.3.

Table 2.3

**Median TRAQ indicators depending on MMSE points**

| TRAQ domains | 24–28 p., MMSE Me (IQR) | 29–30 p., MMSE Me (IQR) | All Me (IQR) | p-value* |
|---|---|---|---|---|
| Managing Medications | 2.8 (3.5–2.3) | 4.0 (5.0–3.5) | 3.5 (4.3–2.5) | < 0.001 |
| Appointment Keeping | 2.6 (3.0–2.0) | 3.4 (4.3–2.6) | 2.9 (3.9–2.2) | < 0.001 |
| Tracking Health Issues | 2.8 (3.4–2.3) | 3.8 (4.3–2.8) | 3.3 (4.0–2.5) | 0.001 |
| Talking With Providers | 4.5 (5.0–4.0) | 5.0 (5.0–4.5) | 5.0 (5.0–4.0) | 0.001 |
| Managing Daily Activities | 4.0 (4.7–4.0) | 5.0 (5.0–4.3) | 4.7 (5.0–4.0) | 0.004 |
| Overall TRAQ result | 3.0 (3.6–2.6) | 3.8 (4.5–3.3) | 3.5 (4.2–2.9) | < 0.001 |

* The importance of the differences in median values (Me) between groups (24–28 points vs. 29–30 points), Me: median, IQR: interquartile range, TRAQ: Transition Readiness Assessment Questionnaire, MMSE: Mini-Mental State Examination. Stage of the TRAQ Change Model: 1 – Primary idea, 2 – Intent, 3 – Preparation, 4 – Action, 5 – Maintenance.

## 2.4 The level of health and disability of young people with cerebral palsy – the results of the WHODAS 2.0 instrument

Table 2.4 shows the level of health and disability of young people with cerebral palsy, depending on the gross motor functions, as well as the total level of disability and health, regardless of the gross motor functions.

Table 2.4

**Median results of WHODAS 2.0 domains for young people with cerebral palsy, depending on the GMFCS level (I–II vs. III–IV)**

| GMFCS | WHODAS 2.0, Me (IQR) | | | | | | |
|---|---|---|---|---|---|---|---|
| | Cognition | Mobility | Self-care | Getting along | Life activities | Participation | Total |
| I–II | 1.8 (2.5–1.4) | 1.6 (2.4–1.4) | 1.5 (2.0–1.0) | 1.4 (2.0–1.0) | 1.9 (2.5–1.4) | 2.2 (2.5–1.6) | 1.7 (2.2–1.3) |
| III–IV | 1.7 (2.2–1.3) | 3.8 (4.6–2.9) | 3.0 (4.1–2.5) | 1.4 (1.8–0.9) | 2.4 (3.0–1.7) | 2.6 (3.1–2.4) | 2.5. (2.7–2.1) |
| p-value | 0.40 | < 0.01 | < 0.01 | 0.42 | 0.05 | < 0.01 | < 0.01 |
| All | 1.8 (2.3–1.3) | 2.2 (2.8–1.4) | 1.8 (2.9–1.0) | 1.4 (1.8–1.0) | 2.1 (2.6–1.5) | 2.3 (2.8–1.8) | 2.0 (2.5–1.5) |

Me: median, IQR: interquartile range, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System. Level I–II: n = 60, Level III–IV: n = 21. Interpretation of the WHODAS 2.0 level of difficulty: 1 – no difficulty, 2 – mild, 3 – moderate, 4 – severe, 5 – extreme or cannot do.

## 2.5 Comparison of the WHODAS 2.0 instrument results for young people with cerebral palsy with the reference group

The comparative median results of WHODAS 2.0 domains and the overall or total result among young people with cerebral palsy (n = 81) and the reference group (n = 121) are depicted in Figure 2.2.

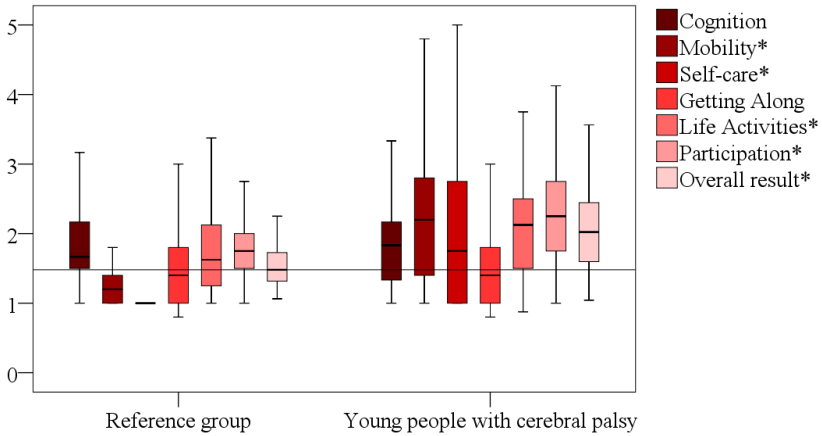


Figure 2.2 **Comparison of the WHODAS 2.0 results of young people with cerebral palsy with the reference group**

* Statistically significant differences between groups. The reference line is drawn through the median value of the reference group of the overall WHODAS 2.0 result (Me 1.5). WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, interpretation of the WHODAS 2.0 level of difficulty: 1 – no difficulty, 2 – mild, 3 – moderate, 4 – severe, 5 – extreme or cannot do.

Table 2.5 indicates the average number of days in the past 30 days when young people with cerebral palsy and young people from the reference group faced difficulties in carrying out the activities mentioned in the WHODAS 2.0, the number of days they were totally unable and the number of days, not counting the days that they were totally unable, they did cut back or reduce their usual activities or work because of any health condition.

Table 2.5

**Results of the final WHODAS 2.0 questions**

| In the past 30 days | Number of days, Me (IQR) |
|---|---|
| Overall, how many days were these difficulties present*?** | |
| Young people with cerebral palsy | 20 (30–8) |
| Reference group | 4 (8–2) |

Table 2.5 continued

| In the past 30 days | Number of days, Me (IQR) |
|---|---|
| For how many days were you totally unable to carry out your usual activities or work because of any health condition?** | |
| Young people with cerebral palsy | 0 (0–0) |
| Reference group | 0 (2–0) |
| Not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?** | |
| Young people with cerebral palsy | 4 (8–2) |
| Reference group | 1 (3–0) |

* When performing WHODAS 2.0 activities. ** Statistically significant differences in results between groups, Me: median, IQR: IQR: interquartile range, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0.

## 2.6 Factors affecting the level of autonomy of young people with cerebral palsy in the context of participation and health care

Table 2.6 shows the correlation of the level of autonomy with the WHODAS 2.0 domains and the total result.

Table 2.6

**Correlation between RTP domains and WHODAS 2.0**

| RTP domains | WHODAS 2.0 domains | | | | | | |
|---|---|---|---|---|---|---|---|
| | Cognition | Mobility | Self-care | Getting along | Life activities | Participation | Total result |
| Education and employment | −0.12 | **−0.24** | −0.22 | 0.05 | 0.14 | − | −0.16 |
| Finance | −0.13 | −0.15 | **−0.30** | −0.01 | −0.14 | − | **−0.23** |
| Housing | **−0.36** | **−0.25** | **−0.42** | −0.20 | **−0.34** | − | **−0.41** |
| Leisure (social activities) | **−0.48** | **−0.34** | **−0.27** | −0.19 | **−0.30** | − | **−0.40** |

Table 2.6 continued

| RTP domains | WHODAS 2.0 domains | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Cognition** | **Mobility** | **Self-care** | **Getting along** | **Life activities** | **Participation** | **Total result** |
| Intimate relationships | **−0.29** | **−0.34** | **−0.44** | −0.10 | **−0.28** | – | **−0.41** |
| Sexuality | **−0.35** | **−0.30** | **−0.46** | −0.19 | **−0.33** | – | **−0.44** |
| Transportation | **−0.35** | **−0.64** | **−0.75** | **−0.22** | **−0.45** | – | **−0.71** |
| Care demands | **−0.44** | **−0.28** | **−0.37** | −0.20 | −0.15 | **−0.28** | **−0.37** |
| Services and aids | **−0.41** | **−0.32** | **−0.38** | −0.21 | **−0.27** | **−0.31** | **−0.41** |
| Rehabilitation services | −0.09 | −0.03 | −0.17 | −0.03 | −0.12 | −0.13 | −0.13 |

RTP: Rotterdam Transition Profile, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0. Due to the similarity in topics, the WHODAS 2.0 domain Participation was not included in the correlation analysis with RTP's first seven domains. Correlations with statistical significance are highlighted in bold.

In order to establish the potential relationship of the correlative factors to the level of autonomy in RTP's domains, a single-factor binary logistics regression analysis was carried out. Domains with at least moderate correlation were included (Table 2.7).

Table 2.7

**Single-factor binary logistic regression model for RTP domains and WHODAS 2.0**

| **RTP*** | **WHODAS 2.0** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Cognition** | | **Mobility** | **Self-care** | | **Life activities** | **Total result** | |
| RTP3 | – | | – | NS | | – | OR | 95 % CI |
| | | | | | | | 0.03 | 0.0-0.6 |
| RTP4 | OR | 95 % CI | – | – | | – | OR | 95 % CI |
| | 0.1 | 0.1–0.4 | | | | | 0.2 | 0.1–0.5 |
| RTP5 | – | | – | OR | 95 % CI | – | OR | 95 % CI |
| | | | | 0.1 | 0.0–0.6 | | 0.1 | 0.0–0.5 |

Table 2.7 continued

| RTP* | WHODAS 2.0 | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Cognition | | Mobility | | Self-care | | Life activities | | Total result | |
| RTP6 | – | | – | | OR | 95 % CI | – | | OR | 95 % CI |
| | | | | | 0.2 | 0.0–0.7 | | | 0.1 | 0.0–0.6 |
| RTP7 | – | | OR | 95 % CI | OR | 95 % CI | OR | 95 % CI | OR | 95 % CI |
| | | | 0.2 | 0.1–0.4 | 0.1 | 0.0–0.2 | 0.2 | 0.1–0.4 | 0.02 | 0.0–0.1 |
| RTP8 | OR | 95 % CI | – | | – | | – | | – | |
| | 0.02 | 0.0–0.2 | | | | | | | | |
| RTP9 | OR | 95 % CI | – | | – | | – | | OR | 95 % CI |
| | 0.1 | 0.0–0.5 | | | | | | | 0.1 | 0.0–0.5 |

* RTP is dichotomized into a binary variable: (1) Phase 0–2, (2) Phase 3. RTP3: Housing, RTP4: Leisure (social activities), RTP5: Intimate relationships, RTP6: Sexuality, RTP7: Transportation, RTP8: Care demands, RTP9: Services and aids. OR: odds ratio, CI: confidence interval, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, RTP: Rotterdam Transition Profile, NS: not significant $p > 0.05$.

Single-factor binary logistic regression found that the WHODAS 2.0 domain Cognition has an impact on RTP domains Leisure (social activities), i.e. OR = 0.1; 95 % CI = 0.1–0.4, Care demands (OR = 0.02; 95 % CI = 0.0–0.2) and Services and aids (OR = 0.1; 95 % CI = 0.0–0.5). The WHODAS 2.0 domain Mobility was found to have an impact on the level of autonomy in the Transportation domain (OR = 0.2; 95 % CI = 0.1–0.4). The WHODAS 2.0 domain Self-care was found to have an impact on the domain Intimate relationships (OR = 0.1; 95 % CI = 0.0–0.6), Sexuality (OR = 0.2; 95 % CI = 0.0–0.7) and Transportation (OR = 0.1; 95 % CI = 0.0–0.2). The domain Life activities has an impact on the level of autonomy in the domain Transportation (OR = 0.2; 95 % CI = 0.1–0.4). The total WHODAS 2.0 result demonstrated an impact on all RTP domains, with the exception of Care demands. The further analysis of RTP's effects examined the correlation between the levels of functioning of young people with cerebral palsy, related disorders and contextual factors with each RTP domain (Table 2.8).

Table 2.8

**The correlation of RTP domains with the level of functionality, related disorders and contextual factors**

| RTP | Age | MMSE | GMFCS | MACS | Severe vision impairment | Severe speech impairment | Need for an assistant | The level of education of the mother | The level of education of the father | Number of siblings > 1 |
|---|---|---|---|---|---|---|---|---|---|---|
| RTP1 | **0.28** | **0.27** | **−0.27** | **−0.33** | −0.02 | −0.10 | **−0.44** | −0.19 | −0.20 | 0.04 |
| RTP2 | **0.43** | 0.17 | −0.12 | −0.21 | −0.16 | −0.15 | −0.21 | −0.14 | −0.06 | 0.16 |
| RTP3 | **0.29** | **0.43** | −0.18 | **−0.32** | −0.14 | −0.20 | **−0.31** | −0.14 | 0.02 | **0.38** |
| RTP4 | **0.26** | **0.35** | **−0.28** | −0.13 | **−0.23** | −0.03 | **−0.30** | −0.02 | −0.11 | 0.04 |
| RTP5 | 0.10 | **0.27** | **−0.41** | **−0.28** | **−0.25** | −0.11 | **−0.45** | **−0.37** | **−0.28** | 0.21 |
| RTP6 | **0.24** | **0.35** | **−0.36** | **−0.35** | **−0.23** | **−0.22** | **−0.44** | **−0.26** | −0.23 | 0.18 |
| RTP7 | 0.18 | **0.48** | **−0.64** | **−0.54** | −0.14 | −0.22 | **−0.76** | **−0.24** | −0.02 | 0.18 |
| RTP8 | 0.19 | **0.35** | **−0.28** | **−0.29** | −0.18 | −0.09 | **−0.32** | −0.13 | −0.08 | 0.07 |
| RTP9 | **0.35** | **0.46** | **−0.28** | **−0.30** | −0.14 | −0.16 | **−0.39** | −0.17 | −0.17 | 0.20 |
| RTP10 | **0.69** | 0.04 | −0.09 | −0.16 | −0.10 | −0.19 | −0.12 | −0.10 | 0.03 | 0.17 |

The table does not include factors such as gender, severe hearing impairment, epilepsy, place of residence, income level and growing up in a single-parent or two-parent family, as all correlations values $p > 0.05$. RTP: Rotterdam Transition Profile. RTP1: Education and employment, RTP2: Finance, RTP3: Housing, RTP4: Leisure (social activities), RTP5: Intimate relationships, RTP6: Sexuality, RTP7: Transportation, RTP8: Care demands, RTP9: Services and aids, RTP10: Rehabilitation services, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System, MMSE: Mini-Mental State Examination. Correlations with statistical significance are highlighted in bold.

Further, the single-factor logistic binary regression analysis (Table 2.9) was carried out to establish the relationship between the potential influencing factors (with correlations at least moderate) and the level of autonomy with RTP domains.

Table 2.9

**A single-factor logistic binary regression model with RTP domains and impact on the level of functionality, related disorders and contextual factors**

| RTP | Age | | MMSE | | GMFCS | | MACS | | Need for an assistant | |
|---|---|---|---|---|---|---|---|---|---|---|
| RTP2 | OR | 95 % CI | – | | – | | – | | – | |
| | 2.1 | 1.3–3.3 | | | | | | | | |
| RTP3 | – | | OR | 95 % CI | – | | – | | – | |
| | | | 3.0* | 1.0–9.0 | | | | | | |
| RTP5 | – | | – | | NS | | – | | OR | 95 % CI |
| | | | | | | | | | 0.2 | 0.1–0.9 |
| RTP6 | – | | – | | – | | – | | OR | 95 % CI |
| | | | | | | | | | 0.2 | 0.0–0.7 |
| RTP7 | – | | OR | 95 % CI | OR | 95 % CI | OR | 95 % CI | OR | 95 % CI |
| | | | 1.9 | 1.3–2.6 | 0.2 | 0.1–0.5 | 0.2 | 0.1–0.5 | 0.04 | 0.0–0.2 |
| RTP9 | – | | OR | 95 % CI | – | | – | | – | |
| | | | 3.2 | 1.6–6.8 | | | | | | |
| RTP10 | OR | 95 % CI | – | | – | | – | | – | |
| | 2.1 | 1.4–3.2 | | | | | | | | |

RTP: Rotterdam Transition Profile, RTP2: Finance, RTP3: Housing, RTP5: Intimate relationships, RTP6: Sexuality, RTP7: Transportation, RTP9: Services and aids, RTP10: Rehabilitation services, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System, MMSE: Mini-Mental State Examination. OR: odds ratio, CI: confidence interval, NS: not significant $p > 0.05$, * $p = 0.056$.

The age of the participants showed an effect on autonomy in the RTP domains: Finance (OR = 2.1; 95 % CI = 1.3–3.3) and Rehabilitation services (OR = 2.1; 95 % CI 1.4–3.2). The result of the MMSE has been found to have an effect on autonomy in the domains Transport (OR = 1.9; 95 % CI = 1.3–2.6) and Services and aids (OR = 3.2; 95 % CI = 1.6–6.8). Gross motor functions (GMFCS) and manual abilities (MACS) have shown an effect on autonomy in the domain Transportation (OR = 0.2; 95 % CI = 0.1–0.5 and OR = 0.2; 95 % CI = 0.1–0.5), while the need for assistant – has an effect on autonomy in the domain Intimate relationship (OR = 0.2; 95 % CI = 0.1–0.9), Sexuality

(OR = 0.2; 95 % CI = 0.0–0.7) and Transportation (OR = 0.04; 95 % CI = 0.0–0.2).

## 2.7 Factors affecting the readiness of young people with cerebral to transit to adult health care

In order to determine the extent to which each potential factor is related to transition readiness to adult health care, the TRAQ cumulative median (Me) was divided into two groups: ≤ 3.00 points and ≥ 3.01 points (Table 2.10).

Table 2.10

**The importance of factors related to the degree of transition readiness to adult health care**

| Factors | p-value | Adj.res. | TRAQ | |
|---|---|---|---|---|
| | | | **≤ 3.00** | **≥ 3.01** |
| Sex, n (%) | 0.41 | – | – | – |
| Age, 16–21 years (IQR) | 0.44 | – | – | – |
| GMFCS, LEVEL I–IV (IQR) | < 0.001 | – | 2 (3–2) | 1 (2–1) |
| MACS, LEVEL I–IV (IQR) | < 0.01 | – | 3 (3–2) | 2 (2–1) |
| MMSE, 24–30 points (IQR) | < 0.001 | – | 26 (28–25) | 29 (30–27) |
| Severe speech impairment, n (%) | < 0.01 | – | – | – |
| no | – | – | 16 (20) | 51 (64) |
| yes | – | – | 8 (10) | 5 (6) |
| Severe vision impairment | 0.93 | – | – | – |
| Severe hearing impairment | 0.13 | – | – | – |
| Epilepsy | 0.63 | – | – | – |
| Need for an assistant, n (%) | < 0.001 | > 1.96¥ | – | – |
| no | – | – | 2 (3)* | 36 (45)* |
| only for transportation | – | – | 16 (20)* | 9 (11)* |
| for transportation and other | – | – | 6 (7) | 11 (14) |

Table 2.10 continued

| Factors | p-value | Adj.res. | TRAQ | |
|---|---|---|---|---|
| | | | ≤ 3.00 | ≥ 3.01 |
| Place of residence | 0.88 | – | – | – |
| Income level, n ( %) | 0.14 | < 1.96§ | – | – |
| below average | – | – | 17 (21) | 32 (40) |
| average | – | – | 6 (8) | 12 (15) |
| above average | – | – | 1 (1)** | 12 (15)** |
| Level of education of the parents | – | – | – | – |
| mother | 0.26 | – | – | – |
| father | 0.82 | – | – | – |
| Grew up in a family with two parents | 0.96 | – | – | – |
| Number of siblings > 1 | 0.92 | – | – | – |
| RTP, Phases 0–3 (IQR) | – | – | – | – |
| Education and employment | 0.02 | – | 1 (2–0) | 2 (2–1) |
| Finance, n ( %) | 0.13 | > 1.96§ | – | – |
| Phase 0 | – | – | 0 (0) | 1 (1) |
| Phase 1 | – | – | 17 (21) | 30 (38) |
| Phase 2 | – | – | 6 (8) | 12 (15) |
| Phase 3 | – | – | 1 (1)* | 13 (16)* |
| Housing | 0.01 | – | *** | 1 (2–1) |
| Leisure (social activities) | < 0.001 | – | 2 (2–1) | 3 (3–2) |
| Intimate relationships | < 0.01 | – | 0 (0–0) | 1 (2–0) |
| Sexuality | < 0.001 | – | 0 (0–0) | 0 (2–0) |
| Transportation | < 0.001 | – | 1 (1–1) | 3 (3–1) |
| Care demands | < 0.01 | – | 2 (2–1) | 2 (2–2) |
| Services and aids | 0.001 | – | 1 (1–1) | 2 (3–1) |
| Rehabilitation services | 0.12 | – | – | – |

Adj. res.: adjusted residual, IQR: interquartile range, TRAQ: Transition Readiness Assessment Questionnaire, RTP: Rotterdam Transition Profile, interpretation of RTP phases: Phase 0 – no experience, Phase 1 – dependent on adults, Phase 2 – experimenting and orientating to the future, Phase 3 – autonomy. Stage of the TRAQ Change Model: 1 – Primary idea, 2 – Intent, 3 – Preparation, 4 – Action, 5 – Maintenance. Pearson's chi-squared test was used, if data: ¥ depicted for easier view, § p-value insignificant but in some categories adj. res. > 1.96. * adj. res. > 1.96, ** adj. res. = 1.9, *** constant if TRAQ ≤ 3.00.

Factors showing the strongest correlation were identified in the correlation analysis and factors with $r_s \geq |\pm 0.40|$ (Table 2.11) were selected in the further logistic binary regression.

Table 2.11

**The related factor correlations and the single-factor logistic binary regression with the TRAQ result**

| Factors | Spearman's Rho | Wald | Predictive, % | OR (95 % CI) |
|---|---|---|---|---|
| GMFCS | −0.41 | 9.98 | 73 | 0.43 (0.26–0.73) |
| MACS | −0.36 | – | – | – |
| MMSE | 0.53 | 17.50 | 79 | 2.18 (1.51–3.13) |
| Severe speech impairment | −0.30 | – | – | – |
| Need for an assistant | −0.40 | 9.26 | 64 | 0.36 (0.19–0.70) |
| Education and employment | 0.26 | – | – | – |
| Housing | 0.30 | – | – | – |
| Leisure (social activities) | 0.43 | 12.39 | 73 | 3.19 (1.67–6.09) |
| Intimate relationships | 0.36 | – | – | – |
| Sexuality | 0.39 | – | – | – |
| Transportation | 0.52 | 15.92 | 75 | 5.16 (2.31–11.56) |
| Care demands | 0.34 | – | – | – |
| Services and aids | 0.36 | – | – | – |

OR: odds ratio, CI: confidence interval, TRAQ: Transition Readiness Assessment Questionnaire, MMSE: Mini-Mental State Examination, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System. All correlations are statistically significant.

For the multi-factor logistic binary regression model, factors with a Wald value > 10.00 were selected (Table 2.12). Crucial influencing factors on the MMSE were: cognition of the participant (OR 2.11; 95 % CI 1.37–3.25) and the level of autonomy in the domain Transportation (OR 2.98; 95 % CI 1.25–7.10).

Table 2.12

**Multi-factor logistic binary regression model for the TRAQ result and the influencing factors**

| Factors | Wald | p-value | OR (95 % CI) |
|---|---|---|---|
| Transportation | 6.05 | < 0.01 | 2.98 (1.25–7.10) |
| MMSE | 11.48 | < 0.001 | 2.11 (1.37–3.25) |
| Leisure (social activities) | 3.00 | 0.08 | 2.05 (0.91–4.60) |

OR: odds ratio, CI: confidence interval, TRAQ: Transition Readiness Assessment Questionnaire, MMSE: Mini-Mental State Examination. The model classified accurately 84 % of cases.

A correlation analysis was carried out to determine the correlation of WHODAS 2.0 domains and the total result with the transition readiness to adult health care in TRAQ domains and the overall result (Table 2.13).

Table 2.13

**TRAQ correlation with WHODAS 2.0**

| TRAQ domains | WHODAS 2.0 domains | | | | | | |
|---|---|---|---|---|---|---|---|
| | Cognition | Mobility | Self-care | Getting along | Life activities | Participation | Total result |
| Managing Medications | **−0.47** | **−0.30** | **−0.54** | **−0.34** | **−0.44** | **−0.33** | **−0.53** |
| Appointment Keeping | **−0.43** | **−0.33** | **−0.53** | **−0.28** | **−0.42** | **−0.34** | **−0.52** |
| Tracking Health Issues | **−0.39** | −0.21 | **−0.36** | −0.13 | **−0.26** | −0.10 | **−0.32** |
| Talking With Providers | **−0.36** | −0.07 | **−0.26** | **−0.41** | **−0.27** | −0.16 | **−0.31** |
| Managing Daily Activities | **−0.40** | **−0.51** | **−0.60** | **−0.37** | **−0.49** | **−0.53** | **−0.68** |
| Overall TRAQ result | **−0.50** | **−0.34** | **−0.56** | **−0.33** | **−0.45** | **−0.34** | **−0.56** |

WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, TRAQ: Transition Readiness Assessment Questionnaire. Correlations with statistical significance are highlighted in bold.

For a further single-factor logistic binary regression, correlations with $r_s \geq |\pm 0.40|$ were put forward (see Table 2.14).

Table 2.14

**TRAQ and WHODAS 2.0 single-factor binary logistics regression model**

| TRAQ | WHODAS 2.0 | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Cognition** | **Mobility** | **Self-care** | **Getting along** | **Life activities** | **Participation** | **Total result** |
| T1 | OR<br>95 % CI<br>0.3<br>0.2–0.8 | – | OR<br>95 % CI<br>0.4<br>0.2–0.6 | – | OR<br>95 % CI<br>0.4<br>0.2–0.7 | – | OR<br>95 % CI<br>0.2<br>0.1–0.5 |
| T2 | OR<br>95 % CI<br>0.2<br>0.1–0.5 | – | OR<br>95 % CI<br>0.4<br>0.2–0.7 | – | OR<br>95 % CI<br>0.4<br>0.2–0.7 | – | OR<br>95 % CI<br>0.2<br>0.1–0.5 |
| T4 | – | – | – | OR<br>95 % CI<br>0.1<br>0.0–0.5 | – | – | – |
| T5 | NS | OR<br>95 % CI<br>0.4<br>0.2–0.7 | OR<br>95 % CI<br>0.2<br>0.1–0.4 | – | OR<br>95 % CI<br>0.2<br>0.1–0.5 | OR<br>95 % CI<br>0.2<br>0.1–0.7 | OR<br>95 % CI<br>0.04<br>0.0–0.3 |
| TΣ | OR<br>95 % CI<br>0.2<br>0.1–0.4 | – | OR<br>95 % CI<br>0.4<br>0.2–0.6 | – | OR<br>95 % CI<br>0.3<br>0.1–0.5 | – | OR<br>95 % CI<br>0.1<br>0.0–0.3 |

OR: odds ratio, CI: confidence interval, TRAQ: Transition Readiness Assessment Questionnaire, T1: Managing Medications, T2: Appointment Keeping, T4: Talking With Providers, T5: Managing Daily Activities, TΣ: Overall result, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0, NS: not significant $p > 0.05$.

As regards the transition readiness to adult life, the domain Managing Medications was found to be related to Cognition (OR = 0.3; 95 % CI = 0.2–0.8) (interpretation – a drop by one point in Cognition (Median (Me))

reduces the odds of being ready to manage medications by 70 %), Self-care (OR = 0.4; 95 % CI 0.2–0.6), Life activities (OR = 0.4; 95 % CI 0.2–0.7) and to the total WHODAS 2.0 (OR = 0.2; 95 % CI 0.1–0.5). The domain Appointment Keeping was found to be related to the domains Cognition (OR = 0.2; 95 % CI = 0.1–0.5), Self-care (OR = 0.4; 95 % CI = 0.2–0.7), Life activities (OR = 0.4; 95 % CI = 0.2–0.7) and the total WHODAS 2.0 result (OR = 0.2; 95 % CI = 0.1–0.5). Talking With Providers was found to be related to Getting along (OR = 0.1; 95 % CI = 0.0–0.5), while Managing Daily Activities was found to be related with the domains Mobility (OR = 0.4; 95 % CI = 0.2–0.7), Self-care (OR = 0.2; 95 % CI = 0.1–0.4), Life activities (OR = 0.2; 95 % CI = 0.1–0.5), Participation (OR = 0.2; 95 % CI = 0.1–0.7) and the total WHODAS 2.0 result (OR = 0.04; 95 % CI = 0.0–0.3). Whereas, the overall TRAQ result was found to be related to the domains Cognition (OR = 0.2; 95 % CI = 0.1–0.4), Self-care (OR = 0.4; 95 % CI = 0.2–0.6), Life activities (OR = 0.3; 95 % CI = 0.1–0.5) and the total WHODAS 2.0 result (OR = 0.1; 95 % CI = 0.0–0.3).

A multi-factor logistic binary regression model, as shown in Table 2.15, was established with each TRAQ domain demonstrating more than one significant relation to the WHODAS 2.0 domains and the total result.

Table 2.15

**Multi-factor logistic binary regression model of the TRAQ result and the WHODAS 2.0**

| **WHODAS 2.0** | **TRAQ** | | |
|---|---|---|---|
| | **Wald** | **p-value** | **OR (95 % CI)** |
| | Managing Medications | | |
| Cognition | 4.11 | **0.04** | 0.27 (0.08–0.96) |
| Self-care | 6.17 | **0.01** | 0.23 (0.07–0.73) |
| Life activities | 0.83 | 0.36 | 0.58 (0.18–1.90) |
| Total result | 1.60 | 0.21 | 6.24 (0.36–106.87) |

Table 2.15 continued

| WHODAS 2.0 | TRAQ | | |
|---|---|---|---|
| | **Wald** | **p-value** | **OR (95 % CI)** |
| The model accurately classified 74 % of cases | | | |
| Appointment Keeping | | | |
| Cognition | 7.47 | **0.01** | 0.12 (0.03–0.55) |
| Self-care | 4.03 | **0.05** | 0.27 (0.08–0.97) |
| Life activities | 1.19 | 0.28 | 0.49 (0.14–1.76) |
| Total result | 1.94 | 0.16 | 8.25 (0.42–160.69) |
| The model accurately classified 74 % of cases | | | |
| Managing Daily Activities | | | |
| Mobility | 0.20 | 0.66 | 1.23 (0.49–3.10) |
| Self-care | 4.02 | **0.05** | 0.21 (0.05–0.97) |
| Participation | 0.11 | 0.74 | 0.68 (0.07–6.95) |
| Total result | 0.22 | 0.64 | 0.40 (0.01–19.45) |
| The model accurately classified 94 % of cases | | | |
| Overall TRAQ result | | | |
| Cognition | 3.27 | 0.07 | 0.28 (0.07–1.11) |
| Self-care | 0.52 | 0.47 | 0.65 (1.20–2.11) |
| Life activities | 0.03 | 0.85 | 1.12 (0.33–3.86) |
| Total result | 0.95 | 0.33 | 0.22 (0.01–4.72) |
| The model accurately classified 78 % of cases | | | |

OR: odds ratio, CI: confidence interval, TRAQ: Transition Readiness Assessment Questionnaire, WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0.

Significant impacts on the TRAQ result in the domain Managing Medications in the multi-factor logistic binary regression model were identified for domains Self-care, OR = 0.23 (95 % CI = 0.07–0.73) and Cognition, OR = 0.27 (95 %, CI = 0.08–0.96). Key drivers in the transition readiness to adult health care for Appointment Keeping were found to be the following

domains: Cognition, OR = 0.12 (95 % CI = 0.03–0.55) and Self-care, OR = 0.27 (95 % CI = 0.08–0.97). The only significant influencing factor of the TRAQ domain Managing Daily Activities is the domain Self-care, OR = 0.21 (95 % CI = 0.05–0.97).

# 3 Discussion

## 3.1 Comparison the WHODAS 2.0 results for young people with cerebral palsy and the reference group

A comparison between young people with cerebral palsy and the reference group in terms of median values of WHODAS 2.0 domain results showed that there was a statistically significant difference in results in almost all domains, namely mobility, self-care, life activities and participation. Although improving mobility and self-care is more often deemed a task related to the rehabilitation of children (Öhrvall et al., 2010, Phipps and Roberts, 2012), as has been shown by van der Slot et al. – also adults with cerebral palsy struggle with mobility and self-care, affecting at least 60 % of the study participants (van der Slot et al., 2010). Similar results to the present study were also revealed by Donkervoort et al.; their study found that young people with cerebral palsy compared to general population are lagging behind in achieving full autonomy in the transition to adult life in housing activities, 36 % vs. 26 % respectively (Donkervoort et al., 2009). The results of the present study also highlight the significant difference in the level of difficulty in participation between the study group and the reference group. This leads to a discussion on the role of the transition process in reducing the burdens in terms of involvement in community activities and general society.

## 3.2 An analytical comparison of RTP results with other studies

This study showed that there is a statistically significant difference between the level of autonomy in RTP domains such as Education and Employment, Finance, Leisure (social activities), Sexuality and Rehabilitation services between young people with cerebral palsy who are minors and adults – the older the participant became, the more autonomy he / she achieved. It has been previously shown that age is a significant factor in terms of the level of

autonomy for certain participation aspects (Donkervoort et al., 2009, Schmid et al., 2020). By 18 years of age, individuals obtain almost full legal rights; however, this study showed that even adults with cerebral palsy are not fully autonomous in certain domains.

Less than a tenth of the adult participants were in phase 3 in the education and employment domain (having "paid job, volunteer work") and nearly half of them were still in phase 1 in the finance domain (dependent on adults for "pocket money, clothing allowance"). Other studies also report that young adults with cerebral palsy demonstrate low rates of employment and management of their finances (Roebroeck et al., 2009, Rutkowski and Riehle, 2009, van der Slot et al., 2010, Verhoef et al., 2014). As discovered by Verhoef et al., in the age range of 20–24 years, young adults with cerebral palsy in Netherlands have lower employment rates and higher unemployment rates than the general population (Verhoef et al., 2014).

Around 2/3 of adult-aged participants in the housing domain were still in phase 1 ("living with parents, not responsible for household activities") and little more than half were in phase 3 ("young adult goes out in the evening with peers") in the leisure (social activities) domain. Van der Slot et al. came to similar conclusions – at least 60 % of adults with cerebral palsy experienced difficulties with recreation and housing (van der Slot et al., 2010). Such findings lead to considering not only the possible external, but also internal factors within home setting, which the adult-aged individual cannot overcome with ease.

The most severe inexperience for adult-aged participants with cerebral palsy was in the domains of intimate relationships and sexuality with 56 % ("no experience with dating") and 59 % ("no experience with French kissing"), respectively. Wiegerink et al. (Wiegerink et al., 2011) found that in the age range of 20–24 years, 45 % of young adults with cerebral palsy feel emotionally inhibited to initiate sexual contact, and for 90 % of participants, sexuality was not discussed during the rehabilitation courses. Other research studies also

emphasize the lack of experience and autonomy regarding intimate relationships and sexuality (Roebroeck et al., 2009, Wiegerink et al., 2010a, Wiegerink et al., 2010b). These findings highlight a specific issue of the transition age compared to other age groups, the subject of intimate relationships and sexuality, which is topical for young people with cerebral stroke when transition to adult age, and should therefore be included in the content of health programmes.

The present study shows that in the transportation domain, more than one-third were still in phase 1 ("parents or caregivers transport the young adult") and less than half or 44 % had reached full autonomy. Also Palisano et al. had found in their unique study that most young people (aged 17–20) with cerebral palsy are dependent on other persons in terms of transportation (Palisano et al., 2009). There are almost ten years between the study by Palisano et al. and the latest study, and despite various environmental solutions for disabled persons, there are still possible restrictions on autonomy in transport organisation for young adults with cerebral palsy living in Latvia.

The study reveals that only a fifth of young people with cerebral palsy have reached autonomy in the care demands domain, namely, "young adult formulate care demands him / herself". However, it should be borne in mind that the transition period may last up to 25 years of age (Willis and McDonagh, 2018), which gives hope that the level of autonomy among young people in the study group may increase, while health professionals should back up the success of this.

As for services and aids, almost half of young people with cerebral palsy in the age group 18–21, were still in phase 1 of the transition process ("parents apply for services and aids"). For comparison – in a study carried out in the Netherlands, 18 % of young people with cerebral palsy aged 18–22 were in phase 1 in the domain services and aids and 50 % were in phase 2, i.e. "young adult learns the procedures to apply for services & aids" (Donkervoort et al., 2009). It should be noted that the study carried out in the Netherlands included young

people who did not attend educational establishments for people with cognitive impairment; thus, most probably the participants did not have cognitive impairments. This aspect raises the discussion that the percentage of participants in the present study in this domain may be linked to the cognitive issues of the participants.

The results of sixteen- to seventeen-year-old young people with cerebral palsy showed that none of them were consulted in a rehabilitation centre for adults, while half of the young people aged 18–21 had received rehabilitation in paediatric centres or were consulted in adult rehabilitation, and only 39 % of adult-aged young people were consulted in adult rehabilitation. As for these results, the findings of the present study are similar to the Dutch study: 32 % of young people with cerebral palsy aged 18–22 (normal intelligence) were consulted in adult rehabilitation. The results of the present study indicate a break in the receipt of rehabilitation services for half of the young people with cerebral palsy involved in the study. It should also be noted that sources underline the discontinuation of care as one of the adverse consequences in the lack of structured transition programmes in health care (Ramos et al., 2017, Szymanski et al., 2017).

## 3.3 Analysis of RTP and WHODAS 2.0 correlations and single-factor binary logistics regression

The analysis of the strongest correlations shows that RTP domain Housing had the strongest correlation with the WHODAS 2.0 domain Self-care. Similar results are also seen for RTP domains Intimate relationships, Sexuality and Transportation, which built moderate to strong correlation with the WHODAS 2.0 domain Self-care. Given this link and knowing that adults with CP experienced difficulties with self-care (van der Slot et al., 2010), it can be assumed that the customised transition rehabilitation programmes should pay

particular attention to the assessment and, if possible, improvement of self-care skills (including through aids, environmental modification, training) to a level that could have a positive impact on participation-related aspects of life.

RTP domain Transportation made a strong correlation with the WHODAS 2.0 domain Mobility and a moderate correlation with the domain Life activities. Similar was discovered by Donkervoort et al. in their study that better gross motor functions are linked to a higher degree of autonomy within the RTP domain Transportation (Donkervoort et al., 2009), but the degree of autonomy in Leisure (social activities) is not significantly linked to higher level of GMFCS (Schmidt et al., 2020). In contrast, a U.S. study found that transportation related challenges were more common for persons with more severe disabilities. Nearly half of the respondents reported that the reason they cancelled a meeting / appointment was transportation-related (24.6 % inadequate public transportation, 8.8 % lack of access to public transportation, 15.2 % lack of specialised transportation) and most respondents noted that the limited access to transportation reduce their opportunities for social involvement (Bascom and Christensen, 2017).

The domains Health care and Services and aids showed a moderate correlation with the WHODAS 2.0 domain Cognition. In the present study, the domain of cognition was also found to be among the most important influencing factors in the TRAQ results or the transition readiness to adult health care. The importance of cognitive functions in tracking health issues has been emphasised studies by other authors from the Great Britain (Ali, Scior et al., 2013) and Canada (Ally et al., 2018).

The RTP domain Rehabilitation services did not have any significant correlation with the WHODAS 2.0 domains or the total WHODAS 2.0 result. This could be explained by the fact that RTP domain of rehabilitation services is more likely to be related to the patient's age than to the level of difficulty in performing certain tasks or activities, which was also confirmed in the correlation

results of this study. However, an adverse trend shall be highlighted: irrespective of functional difficulties, there is a gap in the receipt of rehabilitation services.

The summary of the single-factor logistic binary regression shows that the degree of autonomy is affected as follows:

- Housing is affected by the total WHODAS 2.0 result or by the overall level of health and disability of a young person with cerebral palsy,
- Leisure (social activities) – by cognition and the total level of health and disability,
- Intimate relationships and Sexuality – by the self-care level and the total level of health and disability,
- Transportation – by the mobility and self-care level, difficulties in life activities and the total level of health and disability,
- Care demands – by cognition,
- Services and aids – by cognition and the total level of health and disability.

## 3.4 An analysis of the correlation between RTP and the level of functioning, related disorders and contextual factors and the single-factor logistic regression analysis thereof

According to the analysis, there is a correlation between the need for assistance and the autonomy of young people with cerebral palsy in most of the participation domains in the context of participation as regards transition to adult life. The results can be translated in two ways: First, an apparently logical translation – the higher the autonomy, the less the need for assistance. It has to be noted that the term ‘autonomy’ shall be distinguished in its essence from ‘independence’. Independence is the ability to live without the help of others or without their influence, while autonomy – the ability to make independent

decisions without control of others. Consequently, there is a possibility that a person with a high level of autonomy will still need an assistant (Mâsse et al., 2012). And, second, the results lead to the conclusion: Ensuring adequate assistance services is essential to facilitate the transition of young people with cerebral palsy to adult life in the context of participation. A study carried out in the Netherlands assessing 56 adults (mean age: 36.4 years) with a spastic bilateral cerebral palsy (73 % GMFCS I–II) showed that informal caregiver assistance was used by 16 % and professional household assistance by 32 %; 45 % of the adults with cerebral palsy had difficulty with personal care, 45 % experienced difficulties in personal care and 60 % of the participants had difficulty in recreational activities (van der Slot et al., 2010). A study carried out in Sweden showed that 43 % of young people with cerebral palsy aged 20–22 (54 % GMFCS I–II) needed support from family members in daily activities (e.g. eating, dressing, washing, and toilet visits), who, according to the authors, is a major obstacle in transitioning to an independent life (Jacobson et al., 2019).

For the cognitive function or MMSE result of the respondents, three correlations of moderate strength were identified with the RTP domains of participation – housing and transportation – and health care domain – services and aids. The results of other authors also show that cognition plays a crucial role in promoting participation in young people with long-term neurological development disorders (Mâsse et al., 2012, Jacobson et al., 2019). It should be noted that a study carried out in Great Britain showed that reduced cognition unfolds as a discriminatory factor in the receipt of health services and requires a specific approach in transition programmes (Ali et al., 2013).

RTP domain Transportation, made a moderate correlation with GMFCS and MACS. A longitudinal study carried out in the Netherlands showed that the lower the gross motor function, the lower the capacity of a young person with cerebral palsy to organise transport (Schmidt et al., 2020). This once again

emphasises the need to address accessibility and suitability of transport for young people with various functional disabilities.

The RTP domain Intimate relationships, demonstrated a moderate correlation with GMFCS and weak correlation with MACS, while the sexuality had weak correlation with both GMFCS and MACS. A study carried out in the Netherlands concluded that the level of gross motor function was associated significantly with intercourse experience, but not with romantic relationships (Wiegerink et al., 2010b). The most recent study in Sweden revealed that intimate relationships between young people with cerebral palsy (after adjusting for intellectual disability) is not related to GMFCS or MACS, but only to communication level (Jacobson et al., 2019). In the present study, similar was found: respondents with severe speech impairment demonstrated the strongest correlation with RTP's domain Sexuality ($r_s$ −0.22, $p \leq 0.05$). This finding shows that transition programmes, in particular for young people with more severe functional disabilities, should include counselling on sexual functioning, while intimate relationships, keeping in mind these might be distant relationships, should focus on seeking appropriate communication and / or technical aids.

The age of the participants demonstrated a moderate correlation with RTP's domain Finance and a strong correlation with the domain Rehabilitation services. Differing outcomes have been found in other studies focussing on the transition process: age of the respondent demonstrated moderate correlations with RTP's domains Education and employment, Intimate relationships, and Transportation (Donkervoort et al., 2009), and older young people are more sexually experienced (Wiegerink et al. 2010a). In the present study, the correlation of age with the above domains was weak or insignificant. Referring to the results of the above-mentioned Dutch study, it may be assumed that even 10 years ago the autonomy in several domains tended to increase with the increasing age of a patient; while as for the participants of the present study, considering the established restricting factors, the increase of autonomy in

participation runs at a slower pace. It should be noted that young people with no cognitive impairment participated in the studies referred to.

Translation of the single-factor logistic binary regression results:

- The older a young person with a cerebral palsy, the higher the autonomy in the domains of finance and rehabilitation services;
- Lower cognition is linked to lower autonomy in the transportation and services and aids domains;
- The lower the gross motor functions and manual abilities by young people with cerebral palsy, the lower the autonomy in the transportation domain;
- The higher the need for an assistant, the lower autonomy in the domains Intimate relationships, Sexuality and Transportation.

## 3.5 An analytical comparison of TRAQ results with other studies

The study found that there is a statistically significant difference between transition readiness to adult health care in all domains between young people with MMSE = 24 to 28 points and young people with MMSE = 29 to 30 points. However, in the 2019 publication of this study, in which young people were subdivided by age groups, 16–17 and 18–21 respectively, a significant difference in results between these groups was only observed in two domains: Managing Medications and Appointment Keeping, as well as the overall TRAQ result (Rožkalne, Mukāns and Vētra, 2019). This indicates that age affects the transition readiness to adult health care less than the cognition level. The result is in line with one of the basic principles of the transitional life stage: Transition is not a one-time event, but a long-term process that can last for several years (Ansell and Chamberlain, 1998; Donkervoort et al., 2009; NICE, 2016, Schmidt et al., 2020). The median of the overall TRAQ result, depending on the

participants' MMSE score, showed that young people with cerebral palsy with lower cognition level are in Stage 3 of the model (intends to take action within the next 30 days and has taken some behavioural steps in this direction (Preparation)), young people with a maximum or close-to-a-maximum MMSE score are Stage 4 (has changed behaviour for less than 6 months (Action)). This points to the need of particularly addressing young people with potential cognitive disorders and requires a more detailed assessment of their transition readiness to adult health care.

In general, the participants demonstrated the lowest score in the domain of appointment keeping. Also, a study by Chan et al. on measuring transition readiness of adolescents with Type 1 diabetes (14–19 years old) showed the lowest results for appointment keeping, namely 2.8 (SD ± 1.1) (Chan et al., 2019). This indicates that these skills are the most crucial that should be improved in terms of the transition process, aiming to achieve the most optimal potential. Young people with cerebral palsy need a clear understanding of tracking health care issues and conditions facilitating this should be established (Bagatell et al., 2017).

## 3.6 Correlation analysis of the TRAQ results and the level of functioning, related disorders, contextual factors with the RTP domains, and multi-factor logistic binary regression

The correlation with the overall TRAQ median result indicates that the gross motor functions have a negative moderate correlation and the cognition has a positive moderate correlation with the overall transition readiness to adult health care. The study of Leeb et al. indicated that adolescents with diagnosed mental, behavioural, and developmental disorders are more affected by poorly planned transition process and only 19.5 % of these adolescents (15–17 years) had received transition planning guidance (Leeb et al., 2020).

Higher need for an assistant demonstrated a negative correlation of moderate intensity with lower transition readiness to adult health care, indicating that for young people with more severe functional disorders, a successful transition to adult health care may be subject to receiving assistant services to an appropriate extent.

Moderate correlation and, at the same time, the strongest among the domains of RTP, was found between the RTP participation domains Leisure (social activities) and Transportation and the overall transition readiness to adult health care. It should be noted that the facilitation of participation for patients with cerebral palsy is among the key objectives of their rehabilitation (Imms and Adair, 2017; Bromham et al., 2019; Hanes et al., 2019). Whereas, the role of transportation in the context of transition to adult health care points to both the need for specific skills and knowledge and the provision of adequate infrastructure.

Based on a multi-factor logistic binary regression model, a factor of a significant value and the highest Ward indicator that affects the transition readiness to adult health care is the MMSE result. This leads to the following findings:

- Young people with reduced cognitive functions are more likely to have a lower transition readiness to adult health care,
- The cognitive level of young people is the key aspect to be considered in the transition process,
- The content of the programme should be adapted to it, including, as repeatedly emphasized in scientific literature, to reach the maximum potential of young people.

## 3.7 Analysis of TRAQ and WHODAS 2.0 correlations and multi-factor binary logistics regression

The TRAQ domains of Managing Medications and Appointment Keeping demonstrated significant correlations with all WHODAS 2.0 domains and the total result, but at least moderate correlations were demonstrated with the domains cognition, self-care, life activities and the total WHODAS 2.0 result. Indeed, Chan et al. have studied the practical barriers to medication adherence, and one of the issues with which correlation was found was insufficient capability – knowledge and skills (Chan et al., 2020). The correlation of self-care functions with keeping appointments leads to considering approaches of making appointments that are suitable for young people (e.g. a phone call vs. SMS vs. e-mail), taking into account his functional capabilities and the ability of health care institutions to provide such a service.

The TRAQ domain – Tracking Health Issues – made the least significant correlation with one of the WHODAS 2.0 domains or the total result, of which two strongest correlations were demonstrated with the domains of cognition and self-care. Lower self-care capabilities are known to be correlated with poorer gross motor functions (Leeuw et al., 2021), which, seen in combination with the results of this study, indicate that young people with higher health risks in the future (lower levels of physical and cognitive function) are less aware of their health condition, and therefore, they should be particularly prepared for the transition to adult health care.

The domain Talking With Providers made the only correlation of moderate intensity with the WHODAS 2.0 domain ‘Getting along’. Pointing to the fact that attention should be paid to the existing communication model with a young person visiting healthcare professionals – whether a young person is actively involved in discussions, decision-making and whether the involvement

of parents at an appropriate age and maturity is gradually reduced, which would be an approach in line with the guidelines (NICE, 2016, NICE, 2017).

The TRAQ domain Managing Daily Activities is strongest related to the total WHODAS 2.0 result. This domain includes activities like cooking, housekeeping, and visiting local stores for grocery shopping or visiting pharmacies. It should be noted that, in the context of the transition, autonomous living includes also the ability to carry out both activities of daily living and the ability to use healthcare-related services (Donkervoort et al., 2009, Willis and McDonagh, 2018). Thus, in the transition to adult health care, the ability to carry out activities of daily living should be assessed and facilitated.

The overall TRAQ result is strongest related to the WHODAS 2.0 domains Self-care and the total WHODAS 2.0 result. It should be noted that the promotion of self-care skills for people with cerebral palsy is one of the rehabilitation objectives not only during childhood (Öhrvall et al., 2010, Kim, Kang and Jang, 2017), but also adolescence stage, because the need for self-care changes as the child grows older, (Nieuwenhuijsen et al., 2009, Bromham et al., 2019) and therefore should be included in the programmes designed to promote transition to adult health care.

The results of multi-factor logistic binary regression models of TRAQ domains may be interpreted as follows:

- In order to promote the transition readiness of young people with cerebral palsy to adult health care, cognitive functions and self-care skills are key factors to be considered,
- To achieve a complete understanding of the transition to adult health care, not only an analysis of the overall TRAQ results is required but also an analysis of each TRAQ domain,
- To promote transition to adult health care, the fact that each domain has different influencing factors shall be taken into account.

## 3.8 Analysis of the design, methodology and limitations of the study

Since the study involved young people with some / uncertain cognitive impairment along with young people whose mother tongue was not Latvian, mistakes in filling out the questionnaires cannot be ruled out.

The content of the RTP and TRAQ questionnaires covers two subjects of the transition process described in the literature review: the transition in the context of participation and transition in health care, providing descriptive information on the actual situation in the transition process. An advantage was the broad and multi-faceted nature of data and results; however, for future studies, qualitative data collection in the form of focus groups or interviews would be desirable.

The WHODAS 2.0 questionnaire, which was completed by both young people with cerebral palsy and their peers from the reference group, was used to determine the significant difference. Useful outcomes are referred to the domains, for which the differences were not found, and for those, in which the differences were the greatest. However, in order to carry out an in-depth assessment of the course of transition and to set individual, patient-centred targets, it seems important not only to identify the difficulties of maintaining a friendship (WHODAS 2.0, Getting Along, question D4.2), but also asking questions like: "*How many* friends do you have?", *"What* are your relationships with friends?", "*How often* do you meet friends?", "*What are the obstacles* to maintaining friendship?". Besides, perhaps the study would have a greater contribution to the analysis of the transition process if not only the level of disability but also the subjects related to the transition to adult life were compared between the study and the reference group.

Single and / or multi-factor logistic binary regression was applied to identify the factors affecting transition to adult life. The odds ratio of it indicates the impact of the change in the independent variable on the dependent variable, namely, whether the independent variable has positive or negative impacts on the transition process. For example, the impact of self-care capabilities (WHODAS 2.0) on Managing Medications (TRAQ) – OR = 0.4, 95 % CI 0.2–0.6; meaning, a drop by one point in self-care capabilities (median (Me)) is likely to worsen Managing Medications by 60 %. Thus, the interpretation of the study results is of direct relevance to the practical work with young people who are in transition to adult life.

The study limitations could be the exclusion of other important potentially influencing factors such as the psycho-emotional state of young people, and its impact on autonomy in participation and transition readiness to adult life, or, also, the parents' opinion of the transition process. These aspects have been studied elsewhere (Magill-Evans et al., 2005, Maggs et al., 2011, Dang et al., 2015, Bagatell et al., 2017, Nazareth et al., 2018, Smith et al., 2018) and would be worth considering for further research also in the Latvian population.

# Conclusions

1. The largest proportion of young people with cerebral palsy in transition age, who had some / uncertain cognitive impairment or none, included in the study have no experience in the participation domains Intimate relationships and Sexuality, they depend on their parents in the domains of Education and Employment, Finance, Housing and Transportation, and the participation domain Leisure (social activities) is the only domain where the largest proportion of young people with cerebral palsy have achieved full autonomy.
2. In the health care domains Care demands and Rehabilitation services, the largest proportion of young people with cerebral palsy are in phase 2 of autonomy, i.e. parents and young adults formulate demands together, but they receive consultations neither of paediatric, nor adult rehabilitation care; and as for Services and Aids, the majority of young people remain fully dependent on their parents.
3. As for transition readiness to adult health care by the participating young people with cerebral palsy, the average outcome lies between the Preparation and the Action stage.
4. The most frequent and strongest correlation to certain domains related to autonomy in participation and health care were formed with the level of difficulty in self-care and cognition. Abilities in self-care more often affects participation domains, while cognition – health care domains. Important factors influencing the autonomy in certain domains of participation and health care were found to be the following: the level of difficulty in mobility and life activities, the age of young people, gross motor functions, manual abilities and the degree of necessity of an assistant.
5. The study results demonstrate that key factors influencing the transition readiness by young people with cerebral palsy to adult health care are the

level of gross motor functions, cognition, the need for an assistant, the degree of autonomy in the domains of Leisure (social activities) and Transportation, and the level of difficulty in self-care activities, of which the most important factors are the level of cognition and self-care capabilities.

6. Compared to young people in the reference group, the level of difficulty by young people with cerebral palsy in terms of participation in social life is largely significantly higher, and the total level of difficulty for young people with cerebral palsy in terms of functioning and inabilities is significantly higher than that of their peers in the reference group, including the fact that young people with cerebral palsy, in performing a variety of tasks and activities, faced difficulties much more often.

## Proposals

**For promoting participation and autonomy in health care:**

- Address participation aspects such as education and employment, financial independence, independent living, domestic obligations, recreational and social activities, transportation (mobility) opportunities, and improving the autonomy of intimacy and sexuality issues, and preparations for the transition to adult life should start at least two years before reaching the age of majority;
- On the basis of the study results, autonomy in participation and healthcare domains is most often linked to self-care capabilities and cognition, pointing to the need for targeted evaluation of functionality during the transition process;
- Mobility, ability to undertake life activities, age, gross motor functions, manual abilities and the need for an assistant are important factors and have a link to certain domains of autonomy in participation and health care and the potential degree of facilitating the level of autonomy for young people. Considering this, experts should be able to set real aims of the transition process and undertake meaningful and reasoned negotiations with both young people and their relatives.

**For promoting the readiness for transition from paediatric to adult health care:**

- Based on the study results, the issues the providers should most focus on when working with a young person in transition age in terms of transition readiness are keeping appointments and tracking health issues;

- When discussing health issues with a young person with cerebral palsy, a health care provider must consider the level of cognition of such patient and explain this in a way that is comprehensible and acceptable to the patient;
- The impact of self-care capabilities on transition readiness to adult health care indicates the need for health care providers to assess the level of self-care in young people and their direct impact on transition readiness issues, aiming at achieving the maximum potential of young people;
- It is essential to address the issues of physical accessibility, the provision of transport and, where appropriate, the involvement of an assistant to secure the transition to adult health care in a more successful way;
- Other factors that the involved providers and experts need to take into account in order to set meaningful targets and provide a service suitable for the young people are the level of gross motor functions and severe speech impairment.
- Young people with a cerebral palsy should be ensured continuity in the reception of health care, including rehabilitation, services.

# Publications and reports on the subject of the Doctoral Thesis

## Publications included in international databases:

1. **Rožkalne, Z.**, Mukāns, M. and Vētra, A. 2019. Readiness of independency in health care management for young adults with cerebral palsy. SHS Web of Conferences 68, 02008. Available from: https://doi.org/10.1051/shsconf/20196802008

2. **Rožkalne, Z.**, Mukāns, M. and Vētra, A. 2019. Transition-Age Young Adults with Cerebral Palsy: Level of Participation and the Influencing Factors. Medicina (Kaunas). 55(11): 737. Available from: doi: 10.3390/medicina55110737

## Poster presentations at international and local scientific conferences:

1. Rožkalne, Z., Vētra, A. 2018. Jauniešu ar cerebrālo trieku fiziskā funkcionālā līmeņa saistība ar gatavību pārejai uz neatkarīgu pieaugušā dzīvi. (English: The relationship between the physical functional level of young people with cerebral palsy and their transition readiness to independent adult life.) Rīga Stradiņš University. *Scientific conference of 2018* (Riga, Latvia, March 22–23, 2018). Theses. Riga: RSU, 2018. XXIV, 120.

2. Rožkalne, Z., Vētra, A. 2018. Transition process for youth with cerebral palsy associated with independent functioning in daily living and healthcare system: research proposal. *30th European Academy of Childhood Disability conference "Together we are stronger"*, Tbilisi, Georgia, 28–31 May 2018. Available from: https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.13790

3. Rožkalne, Z., Vētra, A. 2018. Reliability of the Latvian translation of the Rotterdam Transition Profile (RTP). *12th World Congress of the International Society of Physical and Rehabilitation Medicine*. Paris, France, 8–12 July 2018; Available from: https://simul-europe.com/2018/isprm/posters

4. Rožkalne, Z., Vētra, A. 2019. Inter-rater, test-retest and internal consistency reliability for Latvian version of WHODAS 2.0. Rīga Stradiņš University. International Conference on Medical and Health Care Sciences *Knowledge for Use in Practice* (Riga, 1–3 April 2019): Abstracts. Riga: RSU, XLVII, 676.

5. Rožkalne, Z., Vētra, A. 2019. Dalības izvērtējums jauniešiem ar cerebrālo trieku, salīdzinot ar jauniešiem bez funkcionāliem traucējumiem. (English: Assessment of participation of young people with cerebral palsy compared to young people without functional disabilities.) *Third Latvian National Conference of Physiotherapists*. Riga, Latvia. 7 September 2019.

6. Rožkalne, Z., Mukāns, M., Vētra, A. 2019. Comparison of difficulties in activities of daily living for young adults with cerebral palsy and young adults without functional limitations. *First Latvian National Congress of Rehabilitation Medicine*. Rīga Stradiņš University. 19–20 September 2019. Congress agenda: https://www.rsu.lv/sites/default/files/imce/Dokumenti/programmas/programma-PLNRK_18092019.pdf

7. Rožkalne, Z., Vētra, A. 2019. Transition level to adult life for youth with cerebral palsy compering to able-bodied peers. *Advances in Health Care Sciences Conferences "Getting Research into Practice"*, Stockholm, Sweden, 13–14 November 2019.

8. Rožkalne, Z., Mukāns, M., Vētra A. 2021. Impact of level in health and disability on independency in healthcare transition for young adults with cerebral palsy. *33rd European Academy of childhood Disability conference "Childhood Disability in a Changing World"*. Zoom platform, 20 May, 27 May, 3 June, 10 June 2021. Available from: https://onlinelibrary.wiley.com/doi/10.1111/dmcn.14882

9. Rožkalne, Z., Vētra, A. 2021. Jauniešu ar cerebrālo trieku autonomija dalībā un jauniešu vecums un funkcionēšanas līmenis. (English: The autonomy of young people with cerebral palsy in participation and the age and level of functioning of young people.) *Second Latvian National Congress of Rehabilitation Medicine*. Rīga Stradiņš University. Riga, Latvia. 25–27 November 2021.

## Oral presentations at international and local scientific conferences:

1. Rožkalne, Z., Mukāns, M., Vētra, A. 2018. Readiness of independency in health care management for young adults with cerebral palsy. *7th International interdisciplinary Scientific Conference "Society. Health. Welfare"*, Riga, Latvia. 10–12 October 2018. Available from: https://www.shs-conferences.org/articles/shsconf/abs/2019/09/contents/contents.html

2. Rožkalne, Z., Mukāns, M., Vētra, A. 2019. Level of disability and participation and the readiness of transition to adulthood for youth with cerebral palsy", *31st Annual Meeting of the European Academy of Childhood Disability "Innovation for participation"*. Paris, France, 23–25 May 2019. Available from: https://onlinelibrary.wiley.com/doi/10.1111/dmcn.14244

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*"There is no greater disability in society than the inability to see a person as more."*

/Robert M. Hensel/

*"Your present circumstances don't determine where you can go; they merely determine where you start."*

/Nido Qubein/