

# Health-related quality of life of Hungarian children and adolescents with disabilities

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This study presents a comparative analysis of the HRQOL (health related quality of life) of Hungarian children and adolescents with disabilities. This empirical research was carried out during the academic years of 2016/2017, 2017/2018, and 2018/2019. Gathered via the KIDSCREEN-27 questionnaire, the data provide information on the HRQOL of 2,631 children with typical development (TD) (1,411 boys and 1,220 girls, mean age 14.88±2.68 yrs) and 1,056 children with a disability (diagnosed with special educational needs -SEN) (702 boys and 354 girls, mean age 15.72±2.6 yrs). QOL was examined from various aspects. Results in the various subsamples were first compared to Hungarian reference data. Then, an analysis of variance (ANOVA) was performed to detect differences between the subsamples in the five dimensions of QOL. When comparing the QOL of Hungarian children with SEN to Hungarian reference data, we found that only children within an autism spectrum disorder (ASD) had low HROOL in the dimension of social support and peers. The comparison of the T-values characterising the HRQOL of the subsamples showed that children with other psychological developmental disorders (OPDD), those with ASD, and children with hearing impairment (HI) experience significantly poorer HRQOL T-values in several dimensions compared to children with TD or other disabilities. The physical wellbeing of children with OPDD is lower than that of students with TD or a mild intellectual disability (MID). In addition, children with OPDD show significantly lower levels of OOL in the school environment dimension compared to other subsamples (children with physical disabilities /PD/, with MID, or with low vision /LV/). Students with HI or ASD showed lower rates of QOL compared to other subsamples in the dimensions of autonomy and parent relations, social support and peers, and school environment. The lower QOL found in the different dimensions will help experts plan and determine the foci of intervention.

Keywords: Health-related Quality of Life (HQOL), children and adolescents with disabilities, children and adolescents with special educational needs, KIDSCREEN-27

#### Introduction

## The definition and importance of Health Related Quality of Life

The concept of Health-related Quality of Life (HRQOL) has been used in science since the 1950s (Kullmann, 2010), when the social goal of developed countries



shifted from a primary focus on economic growth to increasing the well-being and QOL of citizens. The fields of medical/health sciences, psychology, and social sciences started investigating QOL approximately at the same time (Kovács, 2007; Ercsey, 2010). Consequently, there is no unified definition of QOL (Kullmann, 1993; Kovács, 2007). Sociology characteristically investigates QOL by measuring life satisfaction and happiness (Utasi, 2007) and analyses the social, economic, cultural, and environmental factors that determine QOL (Kovács, 2007). In psychological research, QOL equals happiness. WHO defines Quality of Life as 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment' (WHO, 1997, p. 1).

As the above definition shows, QOL is not related merely to health status: it is also determined by social participation and life satisfaction. It is therefore important and informative to examine QOL among individuals with disabilities (Kullmann, 2010). Schalock's QOL model and definition are widely applied with reference to individuals with disabilities. According to the definition, QOL is a multi-dimensional phenomenon, which includes eight core domains (emotional well-being, physical well-being, material well-being, social inclusion, interpersonal relations, self-determination, rights, personal development), which are all influenced by personal and environmental factors. The various dimensions are assessed by means of culture-sensitive indicators and form the basis for providing personalised support (Schalock et al., 2002, 2011; 2011).

There are several reasons why measuring the QOL of children and adolescents experiencing chronic diseases is important (EISER, 1997), and the same reasons underline the significance of evaluating QOL among children with disabilities. Making health-related decisions may be supported by quantifying the impact of the medical intervention (e.g., that of an amputation versus limb salvage procedures) on the child's QOL. Together with survival statistics, date on QOL may support clinical trials and intervention development. QOL helps reveal children's difficulties and identify children who may need some kind of support (Eiser, 1997).

HRQOL is a subcategory of QOL, used for measuring self-perceived health. It is often applied in effectiveness studies that measure its impact on health (Gu & Chang, 2016) because it not only maps bodily changes, but also self-perceptions related to all physical, psychological, social, and functional changes (Papp et al., 2016).

## Assessing quality of life

A large variety of QOL tools are used by different sciences. There are *three main types of QOL measures: questionnaires, visual analogue rating scales, and observation.* Questionnaires are the most widely used QOL evaluation method (Kullmann, 2010). Some questionnaires survey the factors which influence QOL and therefore help in profiling different problems (QOL profiling). Other

instruments determined QOL with aggregate data (QOL index). There are generic questionnaires which are valid in terms of the whole or the majority of the population and specific questionnaires designed for specific smaller populations (Kullmann, 2010).

Medicine, psychology and sociology use different QOL definitions and methods. WHO (World Health Organisation) has developed various generic and specific QOL assessments (e.g. WHOQOL, 100; WHOQOL, BREF; WHOQOL-5; WHOQOL - DIS etc.) (Kullmann, 2012). There are numerous QOL evaluations for children as well (Collier et al., 2000; Eiser & Morse, 2000; Wallander et al., 2001; Solans et al., 2008). The majority of these HRQOL questionnaires were developed for children with TD or chronic diseases. Although there are questionnaires adapted for specific populations of children with disabilities, these are mostly available in the language of the countries they were developed in and were adapted and validated for a particular disability group (e.g., Gómez et al., 2016). DISABKIDS is a QOL questionnaire which emerged out of a collaboration among seven European countries and designed for assessing the QOL of children and adolescents with chronic diseases (epilepsy, diabetes, asthma, etc.) and that of with CP (Baars et al., 2005). Since Hungary was not involved in either the development project or the validation of the questionnaire, this evaluation tool is not available in Hungarian. In a systematic review, Solans et al. (2008) found that KIDSCREEN is the only assessment tool that sets HRQOL reference data for children and adolescents from more than ten different countries and was validated for the languages of all these countries.

### The QOL of children and adolescents with disabilities

Although weighing QOL is obviously important, few studies focus on the QOL of children and adolescents, let alone with a specific focus upon those with disabilities. Moreover, all of these studies are rather different in that they concentrate upon different samples of children and adolescents with different kinds of disabilities, different ages and genders while the research tools are also varied. The comparison of the QOL of different samples of children with disabilities is therefore impossible. Most studies compare the QOL of kids with a particular disability to that of the QOL of their peers with TD. The majority of studies find the QOL of children with disabilities lower, while the factors responsible for this lower QOL vary by disability.

Various studies account for the lower QOL of children with ASD in comparison to those with TD or chronic diseases. In a study carried out with KIDSCREEN-52, Clark et al. (2015) found that the QOL mean scores of adolescents with ASD were lower than the reference data. These results were additionally supported by those received in the parental questionnaire (Clark et al., 2015). De Vries and Geurts (2015) found similar results (i.e., a lower QOL compared to the TD children) in their research of physical, psychological, social well-being, and school subdomains of QOL. While IQ and language did not influence QOL, autistic traits and a lower level of executive functions had an obvious negative impact on it. Children who had social communication

difficulties and problems in motivation exhibited lower QOL in the physical dimension, while lower levels of social motivation, poorer cognitive flexibility, and emotional control led to lower scores in the emotional dimensions. In the dimension of school, lower QOL was associated with poorer working memory, and weaker planning and organisation skills (De Vries & Geurts, 2015).

Data collected with the parent version of the KIDSCREEN-27 questionnaire found below average T-values in the dimensions of physical well-being, psychological well-being and social support and peers for children and *adolescents* with ASD or MID, the dimension of social support peers being the lowest of all. Lower ratings for of well-being were predicted by challenging behaviors, autism, age, and speech as the primary mode of communication (Biggs & Carter, 2016). Although various studies point out the poorer QOL of children with ASD, some argue that this lower QOL is not a result of the autism spectrum disorder as a single cause but rather emerges due to other factors: cognitive functions (Chiang & Wineman, 2014) or the level of support need are also influential (Renty & Roeyers, 2006). Arias et al. (2018) investigated the QOL of 1,060 children displaying varving degrees of intellectual disability, a quarter of whom were also diagnosed with ASD. The subjects who had both intellectual disabilities and ASD achieved lower results only in interpersonal relations, social inclusion, and physical well-being. Similar to former studies carried out with adults, Arias et al. (2018) found that both intellectual disabilities and the level of support need had an impact on various QOL dimensions. As for social inclusion, girls showed lower indicators than boys.

The subjective QOL of *children with ID* is poorly investigated (White-Koning et al., 2005). Although various studies explored the QOL of adults with ID (Nota et al., 2007) and that of families raising children with ID (Jin-Ding et al. 2009; Hu et al., 2012), further research is needed to attain a comprehensive understanding of their situation. The few studies related to this population focus primarily on the subjective perception of pain, emotional and behavioral problems, fears, and anxiety (Renwick et al., 2003) and survey children and adolescents with ID and additional disabilities (Arias et al., 2018; Ncube et al., 2018). Sabaz et al. (2001) explored the QOL of children with epilepsy, some of whom were also diagnosed with ID. Their results showed that epilepsy had a negative impact on QOL in both subsamples, but an intellectual disability alone (without epilepsy) also had a negative effect on QOL.

Various international studies focus on attention deficit hyperactivity disorder (ADHD), most of which find that ADHD has a similar impact on QOL compared to that related to other mental and physical disorders. An increase in the severity of the disorder causes a parallel decrease of QOL.

Some studies show that *children with HI* have a lower QOL compared to children with TD in some dimensions. In a systematic literature review and metaanalysis of 41 journal articles, Roland et al. (2016) found that the QOL of children with HI was significantly poorer compared to that of their peers with TD, especially in the social dimensions and the school dimension of QOL. In a longitudinal research, an equal QOL of children with HI and TD was found for the ages of four and eleven in the emotional and physical domains. However, the QOL of children who attended segregated schools and that of

children who switched from segregated to mainstream education proved to be lower in the social and school dimensions compared to the QOL of children with TD and their peers with HI who continuously participated in mainstream education. Parallel to getting older, the QOL of both children with HI and TD continuously decreased in the dimension of school environment. This research found no influence stemming from language skills or the severity of HI on the social dimension of QOL (van der Straaten et al., 2020).

Oliveira et al. (2018) surveyed *children and adolescents with VI* and their parents with the KIDSCREEN-52 questionnaire and found high QOL in the dimensions of psychological well-being and parent relations and home life, while low levels of QOL were detected in the domains of social acceptance (bullying) and moods and emotions. The QOL of low-vision children was higher in all dimensions than that forof blind children. Researchers found higher QOL of children with LV than those of blind children in all QOL dimensions; however, differences were statistically not significant. Parents assessed the QOL of their children be lower than the children themselves.

Studies revealing the QOL of children and adolescents with PD and multiple disabilities (MD) account for lower levels of QOL compared to that displayed among TD children. Calley et al. (2012) compared the QOL of children with cerebral palsy (CP) (spastic diplegia) aged 5-12 years to the QOL of children with TD of the same age. The children's QOL was assessed with the parent version of Cerebral Palsy Quality of Life questionnaire (CP-QoL). The research found greater QOL of children with TD in the domains of functioning, and participation and physical health. Lower levels of QOL of children with PD were found by Wojtkowski et al (2017) as well. The parent questionnaires detected lower QOL of children with motor disabilities compared to TD controls, both in terms of physical and psychosocial health. According to the study, the ability to achieve independent walking correlates with psychological functions, general behaviour, and mental health.

Surveying special populations with generic QOL questionnaires is also the focus of some research studies. Tompke and Ferro (2021) found that the KIDSCREEN questionnaire was valid for usage among children with mental disorders. Young et al. (2007) tested the KIDSCREEN questionnaire's validity among twenty-eight children with CP and found that factors relevant to the life of the population were well-reflected by the questionnaire. In many instances the children's priorities directly corresponded to the dimensions and concepts contained within KIDSCREEN. There are however various domains of everyday life which are relevant for children with PD and have an impact on their QOL but are not included in the questionnaire. These comprise for example relationships with family members other than parents; inclusion and fairness; home life and neighbourhood; pain and discomfort; environmental accommodation of needs; and recreational resources other than finances, and time (Young et al., 2007). When analysing the relevant results of the questionnaire, the above weaknesses must be taken into consideration.

In Hungary, the KIDSCREEN questionnaire was used for assessing the QOL of children with chronic diseases (Papp et al., 2016). When reviewing the

literature, we found no Hungarian study that examines the QOL of children with disabilities. Furthermore, we found no international research that provides a comprehensive assessment of the QOL of children and adolescent populations with different disabilities using the same assessment tool.

#### Aim of the research

The aim of our research is to examine the HQOL of Hungarian children and adolescents with TD and disabilities, including children with

- mild intellectual disability (MID),
- other psychological developmental disorder (OPDD), which in Hungary includes a severe learning disability, attention deficit disorder and behavioural dysregulation
- autism spectrum disorder (ASD),
- visual impairment (VI, include blindness /B/ and low vision /LV/),
- hearing impairment (HI) and
- physical disability (PD).

Our aim was to compare the results to Hungarian reference data (The Kidscreen Group Europe, 2016) and detect differences between subsamples in each dimension of HQOL. The overall goal of the research is to reveal whether any population with a particular disability requires special attention due to a low QOL in any dimension.

#### Materials and methods

## Study sample

Our research was carried out in two phases. During the spring of the academic year of 2016/17 and autumn of 2017/18, 1,124 students with SEN (MID, APD, ASD, VI, HI, PD) in 42 schools were examined within the framework of the project, EFOP-3.2.8-16-2016-00001. In spring 2018/2019, 2,651 children with TD were surveyed in 44 schools as a part of the project, EFOP-3.2.10-16-2016-0000, in a randomised, regionally and nationally representative sample of age, gender, and type of school. Similar to children with TD, the sampling of their peers with MID and children with other psychological developmental disorder was randomised and the sample was representative nationally, regionally, and based upon school type. Students with other disabilities were examined in their respective segregated institutions.

Participation was voluntary. In the case of minors, a parental consent form was signed. Students had the right to refrain from participation at any time during the assessment procedure.

Participation was limited to students who were diagnosed with a specific disability, had no additional disabilities, and were officially claimed to be students with SEN.

Only fully complete questionnaires were included in the research. Finally, 2,631 children with TD (1,411 boys and 1,220 girls, mean age 14.88±2.68 yrs)

and 1,056 children with SEN (702 boys and 354 girls, mean age: 15.72±2.6 yrs) filled in the questionnaire. A detailed description of the sample can be found in *Table 1*.

**Table 1**Description of the study sample

total			Sample		Decimal age (year, Mean±SD)			
		Boys	girls	total	boys	girls		
	MID	429	277	152	15.75±2.75	15.82±2.82	15.6±2.62	
	OPDD	440	301	139	15.7±2.44	15.88±2.4	15.31±2.48	
	ASD	33	30	3	15.09±2.84	15.06±2.92	15.35±2.35	
	VI	55	31	24	14.96±2.51	15.26±2.55	14.58±2.46	
SEN	VI-B	29	17	12	16.14±2.63	16.27±2.73	15.95±2.58	
	VI-LV	VI-LV 26		12	13.65±1.59	14.04±1.7	13.2±1.37	
	HI	56	35	21	18.16±2.38	18.21±2.31	18.08±2.55	
	PD	43	28	15	13.51±2.07	14.05±2.12	12.5±1.6	
	All	1056	702	354	15.72±2.67	15.84±2.67	15.43±2.66	
Т	TDC		1411	1220	14.88±2.68	15.02±2.68	14.72±2.68	

SEN = special educational needs MID = mild intellectual disability, OPDD = other psychological developmental disorder, ASD = autism spectrum disorder, VI= visual impairment VI-B = Blindness, VI-LV = low vision, HI = Hearing impairment, PD = physical disability TDC = typically developing children

#### Methods

In the research, the HRQOL of children was evaluated with the KIDSCREEN-27 questionnaire (Kidscreen Group Europe, 2016). A generic health-related QOL questionnaire, KIDSCREEN has been validated both for healthy children and children ages eight to eighteen with chronic diseases. It was developed as part of a collaboration among thirteen European countries (Hungary included), therefore results may be interpreted in line with national and international standards.

*KIDSCREEN-27 assesses five HRQOL dimensions:* physical well-being, psychological well-being, autonomy and parent relations, social support and peers, and school environment.

 The dimension of physical well-being investigates the child's physical activity, energy, and fitness and examines whether the child feels unwell, and to what extent he or she complains of poor health. Low QOL in this

- dimension may refer to physical exhaustion, poor physical fitness or low energy levels. High QOL in this dimension shows that the child or adolescent is full of energy, active, and characterised by proper health and physical fitness.
- The dimension of psychological well-being maps the level of positive feelings and life satisfaction, and those of loneliness and sadness. Low QOL in this dimension displays low levels of life satisfaction and points to sadness or low self-esteem. High QOL in this dimension demonstrates happiness, high life satisfaction, and positive feelings.
- The dimension of autonomy and parent relations investigates the interactions of the child or adolescent with his or her parents (caretaker/s), and examines how much the child or adolescent feels to be loved and supported by the family. This dimension also detects the level of autonomy the child feels to have and perceived financial opportunities. Low QOL in this dimension refers to the child's feelings of being limited, lacking in attention, and appreciation, and the feeling that life is determined by finances. High QOL in this dimension indicates good child-parent relations, a feeling of age-appropriate liberty, and a feeling of financial safety.
- The dimension of social support and peers explores peer relations, the quality of interactions, and perceived levels of being supported. Low QOL in this dimension indicates that the child or adolescent feels to be segregated and not accepted by his or her peers. On the contrary, high QOL in this dimension shows that the child feels accepted and included.
- The dimension of school environment focuses on cognitive skills, learning, and concentration and explores feelings related to school and teachers.
  Low QOL in this dimension signals that the child does not like school, while high QOL in this dimension refers to positive feelings.

Respondents filled in a paper and pencil questionnaire anonymously and autonomously. When necessary, children or adolescents with MID or ASD received support in understanding the statements. For blind children, the questionnaire was read aloud and filled in by the researcher in a two-person situation.

The data were analysed in accordance with the instructions found in the KIDSCREEN manual (Kidscreen Group Europe, 2016) and by means of the IBM SPSS 26 statistical software. Raw QOL in this dimension of the different dimensions were converted into T-values. The T-values of each dimension were analysed. The T-values of the subsamples were compared to the T-values of Hungarian reference data. Data were also analysed for gender. The Kidscreen Group Europe recommends that data within a half-standard deviation from the mean T-values be regarded as average; lower values should be taken as low, higher values as high Quality of Life with respect to the given dimension. Then, mean T-values characterising the QOL of each subsample were compared with ANOVA.

#### Results

# Testing the indicators of reliability (internal consistency) of KIDSCREEN-27

Since KIDSCREEN was developed for assessing the HQOL of children and adolescents with chronic diseases and not for that of respondents with disabilities, indicators of reliability were tested for each subsample and the internal consistency of groups of questions was calculated before data analysis. Cronbach's Alpha scores for each subsample and group of questions and the number of respondents by subsample are shown in *Table 2*.

**Table 2**Cronbach's Alpha scores showing internal consistency for each subsample and group of questions

		QOL dimensions										
Sub- jects	Physical well- being		Psychological well-being		Autonomy & parent relations		Social support & peers		School envi- ronment			
	Cr-α	N	Cr-α	N	Cr-α	N	Cr-α	N	Cr-α	N		
TDC	0.816	2428	0.831	2361	0.790	2370	0. 828	2411	0.796	2398		
MID	0.734	329	0.700	314	0.774	323	0.770	325	0.704	319		
OPDD	0.748	370	0.788	354	0.792	364	0.820	366	0.751	364		
ASD	0.888	25	0.751	27	0.848	26	0.889	26	0.874	28		
В	0.737	20	0.715	21	0.767	20	0.303	21	0.499	21		
LV	0.747	26	0.778	25	0.518	25	0.835	26	0.801	26		
HI	0.686	28	0.673	28	0.688	28	0.865	28	0.809	28		
PD	0.601	30	0.768	31	0.713	31	0.807	31	0.713	29		

 $Cr-\alpha$  = Cronbach's Alpha, TDC = typically developing children, MID = mild intellectual disability, OPDD = other psychological developmental disorder, ASD = autism spectrum disorder, B = Blindness, LV = low vision, HI = Hearing impairment, PD = physical disability

Cronbach's- $\alpha$  displays good internal consistency in the case of children and adolescents with MID, OPDD, and ASD (Cronbach's- $\alpha \ge 0.700$ ) which means that the reliability of the questionnaire is high in all dimensions of HQOL. In the following cases, however, Cronbach's- $\alpha$  scores were low (Cronbach's- $\alpha \ge 0.700$ ):

- children and adolescents with HI in the dimension of physical well-being (Cronbach's- $\alpha$ =0.686), psychological well-being (Cronbach's- $\alpha$ =0.673) and autonomy and parent relations (Cronbach's- $\alpha$ =0.688);
- children with PD in the dimesnion of physical well-being (Cronbach's- $\alpha$ =0.601);
- children and adolescents with LV in the dimension of autonomy and parent relations (Cronbach's- $\alpha$ =0.518);

– blind children in the dimension of social support and peers (Cronbach's- $\alpha$  =0,303), and school environment (Cronbach's- $\alpha$ =0.499). Due to low Cronbach's- $\alpha$  values, the reliability of the results in the dimensions listed above may be questionable.

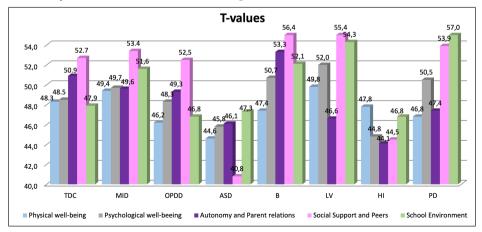
# The QOL of children and adolescents with disabilities compared to Hungarian reference data

When comparing the T-values of each dimension to the Hungarian reference data (see *Table 3*) while using aggregate results of boys and girls (*Figure 1*), only the subsample of *children with ASD in the dimension of social support and peers had low QOL*. Blind children had slightly higher T-values compared to the average reference data in the dimension of social support and peers. Children with LV displayed slightly higher T-values while *children with PD had much higher T-values compared to reference data (thereby had high QOL) in the dimension of school environment*. Respondents with TD performed average in every dimension of QOL, compared to the Hungarian reference data.

**Table 3**T-values meaning average HQOL by dimensions based on Hungarian reference data (The Kidscreen Group Europe 2016)

	Physical well-being	Psycho- logical well- beeing	Autonomy & Parent relations	social sup- port & peers	School Environment
T-value (means of Hungarian children)	42.37 – 51.77	42.84 – 53.22	43.,15 – 53.90	45.7 – 56.32	42.92 – 53.48

**Figure 1** *T-values of QOL dimensions in the subsamples* 



TDC = Typically developing children MID = mild intellectual disability, OPDD = other psychological developmental disorder, ASD = autism spectrum disorder, B = Blindness, LV = low vision, HI = Hearing impairment, PD = physical disability

# Characteristics of the QOL of boys and girls in the subsamples, comparison with Hungarian reference data

When comparing the answers of boys and girls separately (see *Table 4 and 5*), the HQOL of both genders with TD is average in comparison with reference data. The ranking of T-values in the different QOL dimensions is almost the same as that found in the ranking of the reference data.

No low QOL were found in the results of children and adolescents with MID. The lowest T-values were found for boys with MID in the dimension of autonomy and parent relations, for girls with MID in the dimension of physical well-being. Boys and girls with MID and with OPDD (like their peers with TD) scored highest QOL in the dimension of social support and peers. For both boys and girls with OPDD, the lowest T-values were found in the dimension of physical well-being, but all QOL indicators of children with OPDD are average compared to Hungarian reference data.

As regards boys with ASD, QOL were low in the dimension of social support and peers. T-values in the dimension of school environment were the highest. Although the sample of girls (N=3) was too small for drawing comprehensive conclusions, it is worth noting that they had low QOL in the dimension of physical well-being and their T-values were above average in the dimension of autonomy and parent relations compared to reference data.

As for blind subjects, boys' T-values were above average in the dimension of social support and peers while girls exhibited high QOL in autonomy and parent relations. Boys' T-values were lowest in psychological well-being compared to girls' lowest T-values in physical well-being, while their T-values in both cases appeared in the average zone.

Children with LV (both boys and girls) performed above average QOL T-values in the dimension of school environment, while T-values of boys were even higher in the social support and peers dimension. Boys and girls had their lowest T-values in autonomy and parent relations, but these were still in the average zone.

Boys and girls with HI had low QOL in two dimensions: boys in autonomy and parent relations and social support and peers, girls in social support and peers and in school environment. Boys scored the highest T-values in the dimension of school environment, while girls in physical well-being. However, even these higher values belonged in the average zone.

The QOL of boys and girls with PD was equally high in the school environment dimension, and their QOL in this dimension was above average. Above average values were found in the dimension of social support and peers for boys with PD. While for both boys and girls, T-values were lowest in the dimension of physical well-being, these values were however average.

**Table 4** *T-values meaning average HQOL by dimensions and by genders based on Hungarian reference data (The Kidscreen Group Europe. 2016)* 

Hungarian reference data (Kidscreen Group Europe)	Hungarian boys (T-values)	Hungarian girls (T-values)
Physical well-being	44.08 - 53.68	41.26 - 50.32
Psychological well-being	43.96 - 54.52	42.09 - 52.24
Autonomy & parent relations	44.37 - 54.97	42.36 - 53.14
Social Support & Peers	44.76 – 55.91	46,37 – 56.56
School Environment	42.13 - 52.87	43.50 - 53.91

**Table 5**T-values of the subsamples in the different dimensions of QOL, and their discrepancy with Hungarian reference data

		TDC	MID	OPDD	ASD	В	LV	HI	PD
Physical well-	Boys	49.,5	50.5	47.3	45.1	50.7	49.5	47.1	48.5
being	Girls	46.9	47.6	44.0	40.5	42.5	50.2	49.3	43.4
Psychological	Boys	50.0	50.6	50.2	46.0	50.4	54.1	43.9	53.2
well-beeing	Girls	46.8	48.1	44.4	44.8	51.3	49.6	46.5	44.9
Autonomy &	Boys	51.9	49.9	50.4	44.5	50.9	47.6	42.6	48.9
Parent relations	Girls	49.9	49.1	47.2	59.0	57.0	45.5	47.3	44.3
Social support	Boys	52.6	53.8	52.7	39.8	57.1	56,9	44.2	56.1
& peers	Girls	52.8	52.8	52.1	48.3	55.3	53.7	45.1	49.3
School	Boys	48.0	51.3	47.4	46.7	51.2	54.5	48.5	56.7
Environment	Girls	47.8	52.2	45.6	53.1	53.5	54.1	43.2	57.6

TDC= tipically developing children MID= mild intellectual disability, OPDD=other psychological developmental disorder, ASD= autism spectrum disorder, B=Blindness, LV= low vision, HI= Hearing impairement, PD= physical disability; high shadow cell = low QOL compered to Hungarian reference data, dark shadow cell = high QOL compered to Hungarian reference data

# Differences in HQOL of children and adolescents with TD and with different disabilities based on ANOVA, differences between means of T-values

When comparing the average T-values of children with disability in all the dimensions to the T-values of children with TD, *psychological well-being was* 

the only dimension in which ANOVA detected no differences in any subsample of children with disabilities and children with TD.

In comparison to children with TD, children with OPDD achieved lower values in the dimension of physical well-being (p=0,002), children with HI in the dimensions of autonomy and parent relations (p=0,004) and social support and peers (p=0,002), and children with ASD in the dimension of social support and peers (p<0,001).

In the dimension of school environment, children with MID (p<0,001), low-vision (p=0,018) and PD (p<0,001) achieved higher QOL based on T-values compared to subjects with TD.

# Differences in HQOL of children and adolescents with different disabilities based on ANOVA, differences between means of T-values

Comparing the T-values of children with different disabilities in the different dimensions of QOL, the T-values of children with OPDD in the dimension of physical well-being are significantly lower than those of children with MID (p<0,01). Although the post-hoc tests of ANOVA showed no significant differences among the subsamples in the dimension of physical well-being, the low T-values of children with HI and the high T-values of low-vision subjects must be noted.

Similarly to psychological well-being, children with HI had the lowest QOL among the subsamples in the dimension of autonomy and parent relations (T-value =44.1) as well. Blind subjects achieved the highest T-value (53.3) in this dimension. The difference of the two subsamples in this dimension was significant (p=0.022).

Children with ASD and their peers with HI achieved significantly lower QOL T-values in the dimension of social support and peers than all other subsamples (see Table 6).

**Table 6**Differences of average T-values in the dimensions of social support and peers. Results of the post-hoc test of ANOVA

Kind of disability					95% Confidence Interval	
1	2	Mean Difference	Std. Error	Sig.	Lower Bound	Upper Bound
	MID	-12.60022*	2.22249	0.000	-19.3408	-5.8597
	OPDD	-11.66612*	2.21325	0.000	-18.,3786	-4.9536
ASD	В	-15.,60128*	3.19938	0.000	-25.,3046	-5.8979
ASD	LV	-14.,59347*	3.02442	0.,000	-23.7662	-5.4208
	HI	-3.70689	2.96992	0.917	-12,.7143	5.3005
	PD	-13.11003*	2.89990	0.000	-21.9051	-4.3150

	MID	-8.89333*	2.14773	0.001	-15.4071	-2.3795
	OPDD	-7.95923*	2.13817	0.005	-14.4440	-1.4744
HI	ASD	3.70689	2.96992	0.917	-5.3005	12.7143
п	В	-11.89439*	3.14792	0.004	-21.4416	-2.3471
	LV	-10.88658*	2.96992	0.,006	-19.8940	-1.8792
	PD	-9.40314*	2.84302	0.021	-18.0257	-0.7806

In the dimension of school environment, children and adolescents with PD were found to have significantly higher QOL not only than children with TD (p<0,01), but also their peers with OPDD (p<0,01), and children with HI (p=0,02). In this dimension, lowest T-values were found among children with OPDD and children with HI (T-value =46,8 in both subsamples). QOL T-values of children with OPDD were significantly lower than those of children with PD (p<0,001), MID (p<0,001) and LV (p=0,004). In the dimension of school environment, the QOL of children with HI was significantly different only compared to the QOL of children with PD (p=0,002).

#### Discussion and conclusions

As a result of our study, we have data regarding the HQOL of 1,056 Hungarian children and adolescents with disabilities and 2,631 children and adolescents with TD. Results for each dimension were compared to the Hungarian reference data (The Kidscreen Group Europe, 2016) and mean T-values of the subsamples by dimensions were also compared with ANOVA.

The results of this QOL assessment partially confirm the results of other research in this field, thereby indicating that the QOL of children and youth with disabilities is lower than that of their peers with TD (Sabaz et al., 2001, Calley et al., 2012; De Vries & Geurts, 2015; Clark et al., 2015; Biggs & Carter, 2016; Wojtkowski et al., 2017).

When comparing the QOL of children with a disability to the Hungarian reference data, only respondents with ASD exhibited low QOL in the dimension of social support and peers. This result contradicts the findings of several studies that found a lower quality of life in children with autism spectrum disorder in several dimensions (De Vries & Geurts, 2015; Biggs & Carter, 2016). Our findings underscore that the respondents with ASD feel segregated and do not feel accepted by their peers. As for blind children, a slightly high QOL appeared in the dimension of social support and peers. In the dimension of school environment, children with LV and PD displayed high QOL based on T-values compered with Hungarian reference data. (Values of children with LV was only slightly higher than the reference values). Contrary to the research findings of Calley et al. (2012) and Wojtkowsi et al. (2017), children with PD are not characterised by low QOL in any dimension based on the results of our research.

When analysing data for boys and girls separately, below average QOL was detected among children with ASD and those with HI. QOL of Boys with ASD

was low in the dimension of social support and peers, while QOL of girls with ASD was low in the dimension of physical well-being. Boys with HI has low QOL in dimensions of autonomy and parent relations and social support and peers. Girls with HI exhibited low QOL in social support and peers and school environment dimensions. These findings regarding HI girls were confirmed by Roland et al. (2016). In all other subsamples the QOL was mostly the same as the Hungarian reference data, above average QOL was found in the following dimensions:

- Girls with ASD in autonomy and parent relations;
- Blind boys in social support and peers, blind girls in autonomy and parent relations;
- Low-vision boys in social support and peers and school environment, girls in school environment;
- Boys with PD in social support and peers and school environment, girls with PD in school environment.

Comparing the average of T-values of the subsamples with ANOVA, we find that children with OPDD, ASD and HI show significantly lower QOL in various dimensions compared to subjects with TD or other disabilities. The physical well-being of children with OPDD is lower than that of children with TD and MID. This result may refer to the subjective feeling of physical exhaustion and low energy levels of the subsample. Participation in proper amounts and quality of physical activity is an important factor in the QOL of these children. When comparing children with OPDD to other subsamples (children with PD, MID, LV), we found significantly lower T-values in the dimension of school environment. Low QOL in this dimension shows that the child does not like school and has negative feelings about it. The result is not surprising, since the majority of the subjects in this subsample were diagnosed with specific learning disorders or ADHD. If they are not taught with proper methods, the children often face failure in learning, meaning that prevention of negative school experiences is crucial in improving their QOL.

Children with HI and ASD achieved significantly lower T-values than their peers in various dimensions (autonomy and parent relations, social support and peers, school environment). Low QOL values in the dimension of social support and peers have to be highlighted, because both of the aforementioned subsamples (HI, ASD) had significantly lower T-values compared to all other subsamples. Among this group of children, these results refer to feelings of isolation and the perception of not being accepted. The real social inclusion of children and adolescents with HI and ASD is therefore crucial in improving their overall QOL. When we compare subsamples with disabilities to children with TD, in the dimension of autonomy and parent relations only children with HI achieved significantly lower QOL T-values. Results show that in the families of children with HI, complex and comprehensive interventions are necessary in particular.

The psychological well-being dimension of QOL was the only dimension in which no differences were detected between the subsamples based upon

the results of ANOVA. This shows that children and youth with disability and their peers with TD experience equal levels of happiness and life satisfaction, sadness and loneliness are not characteristic in either subsample.

We can conclude that not all subsamples of children with disabilities experience lower levels of QOL than their peers. HRQOL of children with MID, VI (blind or low-vision), and PD are equal to that of their TD peers in every dimensions. Children with PDD, ASD and HI are characterised by lower QOL in various dimensions. These particular results may guide the planning and implementation of intervention and find the foci of it.

#### Limitations

Sampling was representative (national, regional, type of school) only for children and adolescents with TD, MID, and OPDD. In the other subsamples, sampling was randomised and students attended mostly segregated educational institutions. The use of different sampling methods may influence final findings. In some subsamples (especially when data were analysed with respect to gender and age) the number of respondents was low. KIDSCREEN-27 was not validated for different populations of children with disabilities, but its usability with individuals with disability was proven by various international research studies and the internal consistency of the questionnaire was carried out in this research, too.

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