

## Quality of life and provision of social rehabilitation services in elementary school age children with special needs in Riga City

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**Abstract.** Long-term quality of life of children with special needs has not been studied in Latvia, and information on changes of quality of life (QoL) rates during child's development period is insufficient. The aim of the study was to analyze and compare the QoL related self-reports of school age children with special needs, which were repeatedly carried out once a year (2009–2010), with the proxy reports of their parents, as well as to compare the obtained results with Europe normative data on QoL developed by KIDSCREEN research group; to investigate the provision of social rehabilitation services for such families. The study was carried out in Riga municipality 2009–2010. Altogether 34 families with 8–11 years of age children with developmental disabilities participated in the study. Both parents and children filled KIDSCREEN-52 questionnaire, but a survey developed by a group of researchers "Social services" was used to gather information from the parents about the received children and family centered social services in the period between the both quality of life assessments. Results showed statistically significant changes in the latest quality of life self-assessment rates of school-age boys and girls with special needs in time period 2009–2010. Participants of the study – children with developmental disabilities – in both cases reported a lower QoL in comparison with Europe normative data on QoL developed by KIDSCREEN research group.

**Key words:** *quality of life, children with special needs, social rehabilitation services*

Health related quality of life (HRQoL) is often perceived as a versatile structure, which comprises such welfare components as physical, emotional, mental, social, cultural and behavioral, as well as the individual's functioning in accordance with child's or adult's perception (Bowling, 2005). The subjective health assessment is one of the most important parameters in dynamic monitoring of population's health condition.

Generic HRQoL measures can be useful to identify children and adult's health problems or health risks and can help determine the impact of a particular disease or disability on the quality of a person's life. It is worth noting that HRQoL can act as parameter of rehabilitation effectiveness which supplements the objective clinical data (Békési et al., 2011). On the basis of the obtained information about HRQoL of children with developmental disabilities, in order to promote the life quality of children, politicians, social care workers, healthcare and education specialist are able to improve the state or local government organized social rehabilitation services. Accordingly, in order to determine the provision of social care and social services for children with special needs in relation to HRQoL, studies in rehabilitation field are necessary.

Since the Latvian National Development Plan 2007–2013 envisages increasing the country's population, including the QoL of children, with the task of approaching the EU average, the Riga City Council Welfare department has launched a long-term project for the QoL of children with special needs in relation to social rehabilitation services for these children and their families (Latvian National Development Plan, 2006; Svekļe et al., 2010).

The research within the project are based on evidence that children are capable of adequately and reliably assessing their own well-being and functioning, if the survey is developed according to child's age and the level of reference (White-Koning, 2007). Unfortunately, most of the QoL measurements are developed for adult population. Often these measurements are adjusted for information acquisition form children and adolescents. However, it is not correct, because it is essential to include such parameters as family, school, peers, etc. in assessment of children's QoL (Jozefiak, 2008; White-Koning, 2007; Vasiļevska, 2006). Therefore, from 2001 to 2004 a group of European researchers under the guidance of U. Ravens-Sieberer developed a new instrument "KIDSCREEN" for assessing HRQoL and had it approved by 12 countries; altogether 22110 children and adolescents were surveyed, as well as the QoL standards of 8–18 years old European children and adolescents was identified. In addition, measurement versions for parents/caregivers were developed. KIDSCREEN is suitable for acquiring information in both clinical and epidemiological research. Below, a short, more accurate explanation of 10 KIDSCREEN-52 QoL of life dimensions is provided:

- physical well-being (5 questions) – determines physical activity, energy and fitness of a child or adolescent;
- psychological well-being (6 questions) – examines child's or adolescent's psychological satisfaction with life, including positive emotions;
- mood and emotions (7 questions) – indicates the extent to which a child or an adolescent experiences depression or stress;
- self-perception (5 questions) – examines how the respondent perceives his appearance, his body image;
- autonomy (5 questions) – evaluates the respondent's options to spend the spare time and being in society;
- family and home life (6 questions) – evaluates the relationship with parents and the atmosphere at home;
- social support and peers (6 questions) – evaluates the respondent's relationship with other children or adolescents;
- financial resources (3 questions) – evaluates the respondent's perception of their financial situation;
- school environment (6 questions) – determines child's or adolescent's perception and cognitive abilities, and the evaluation of school life;
- social acceptance/Bullying (3 questions) – indicates the extent of child's or adolescent's marginalization among school peers (Ravens-Sieberer, 2005; The KIDSCREEN Group Europe, 2006).

This study aimed to analyze and to compare self-reports of HRQoL of these children with proxy reports of their parents collected twice in 2009-2010 as well with European normative data developed by the KIDSCREEN research group; to investigate provision of social rehabilitation services for elementary school age children with special needs in Riga City.

**Place of study:** Riga Social Service 2009–2010.

### **Participants**

Participants: 34 families with children 8–11 years old with developmental disabilities were involved in the study according to the following criteria: family has a child with special needs, family has received social assistance from Riga City municipality. The analysis material of this research comprised surveys filled in 2009 by 34 parents and 27 children, and surveys filled in 2010 by 26 parents and 20 children. Due to unknown reasons 8 parents did not participate in the second survey. Due to functional restrictions not all children were able to complete the self-assessment: 7 children with special needs did not participate in the first survey and 6 – in the second.

**Table 1.** Characteristics of participants of study.

Information about children		Information about parents (caregivers)	
Gender: 18 girls and 16 boys			
Age			
Years	n	Years	n
8	3	20–30	4
9	12	31–40	13
10	12	41–50	15
11	7	61–70	2
Level of education			
Ordinary school	13	Basic	3
Special school	16	Secondary school	7
Home education	2	Secondary/Professional	11
Not attending school	3	University	13
Functional limitations		Employment	
Motor disorders	6	Employed	10
Cognitive disorders	3	Unemployed	3
Multiple disorders	25	Household work and family care	9
		Retired	2
		No information	10

Measures: HRQoL measures were obtained using the KIDSCREEN-52 questionnaire in Latvian – both children and parents filled the questionnaires in the presence of an ergo therapist. Translation of the KIDSCREEN tool, after coordinating it with the KIDSCREEN research group, in Latvian was conducted in 2008 by rehabilitation center “We are beside”. Survey “Social Services” was used to gather information from the parents about social services during the period 2009 to year 2010.

### Data analysis

QoL indicators, that were obtained using the KIDSCREEN questionnaires, were statistically processed, according to guidelines developed by KIDSCREEN research group. The internal consistency of dimensions was measured by Cronbach’s alpha. For the analysis of social service data descriptive statistical methods were used and the following indicators were analyzed: mean, frequency, percentages. All statistical analysis were performed using the SPSS program version 17.0 for Windows, the significance level was set at  $p < 0.05$ .

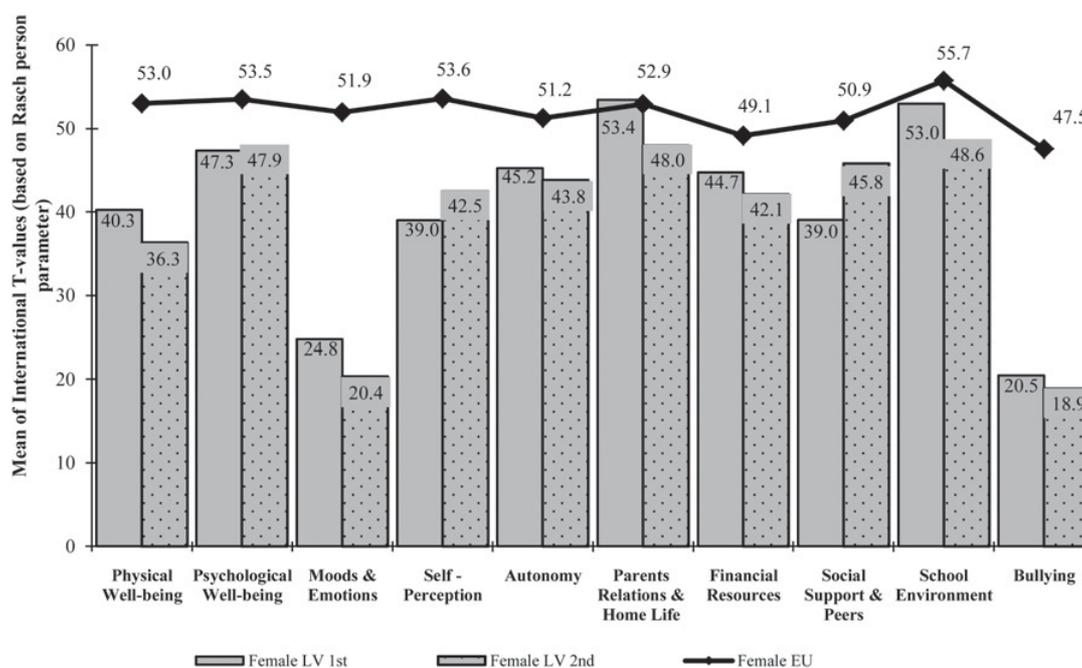
### Results

#### *Characteristics of participants*

Table 1 comprises the characteristics of the 34 participants of the study – children and their parents.

#### *Quality of life self-assessment*

Participants of the study – boys and girls – in both evaluations marked lower QoL rates in comparison with the European normative data of children’s QoL assessment developed by KIDSCREEN research group (age group 8–11 years) (Ravens-Sieberer et al., 2005) (Figure 1, 2). The greatest differences were among assessments according to two dimensions: *Mood and emotions* and *Bullying*.



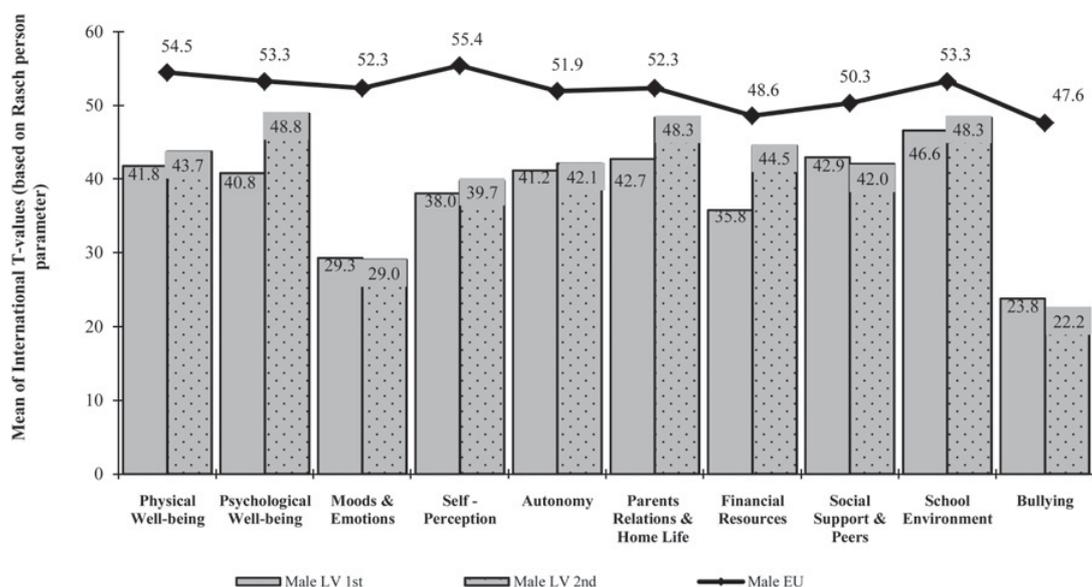
**Figure 1.** Latvian female data (children 8–11 aged) in 2009–2010 in comparison with European normdata KIDSCREEN-52.

It should be noted that the boys' QoL self-assessments were different in comparison with the self-assessments of girls involved in the study. By analyzing the self-assessments of children, which were repeated in a year, it was deduced that the girls involved in the study had reduced the QoL rates in seven of ten KIDSCREEN dimensions – the greatest fall was noticed in the following dimensions (statistically reliable differences): *Relationship with parents* (53.4–48.0) and *School environment* (53.0–48.6). In the second self-assessment the girls evaluated the QoL higher in three of ten dimensions; the greatest changes were noticed in *Social support* (39.0–45.8) (Figure 1).

However, if the self-assessments of boys, which were repeated in a year, are compared, it was observed that the boys in both surveys indicated higher QoL rates in the following dimensions: *Physical well-being*, *Mood and emotions*, and *Bullying*, and in the second survey a distinctive rise was noticed in the rates of *Psychological well-being* (40.8 and 48.8) and *Relationship with parents* (42.7–48.3) (Figure 2).

When comparing the 2009 and 2010 survey data, in the second year statistically reliable changes in QoL rates of children with special needs were detected (Figures 1, 2, 3). In both surveys parents' evaluation of their child with special needs was distinctly different (rates from 15.7 to 55.8). Similarly to the children, the parents' highest average rate was in dimension – *Parents relations/home life* (55.8), the second – *School environment* (53.3). However, the lowest evaluations, similarly to the children's responses, was in *Social acceptance/Bullying* (15.7) and *Mood and emotions* (18.1) (Figure 3).

Already in 2009 a distinctive difference in opinions of children and parents about the QoL was discovered in the following dimensions: *Social support*, *Self perception*, *Mood and emotions*, *Financial recourses*. Also, after a year the children's with special needs self-assessment of QoL was different from their parent's evaluation – the children were more likely to indicate higher QoL rates than their parents: it was determined that in the second survey children evaluated the QoL higher according to six dimensions in the first survey and according to eight dimensions out of 10 mentioned in KIDSCREEN-52 questionnaire. By analyzing the 2010 survey data, a difference in opinions between



**Figure 2.** Latvian male data (children 8–11 aged) in 2009–2010 in comparison with European normdata KIDSCREEN-52.

QoL evaluation of children and parents is present in the following dimensions: *Social support* and *Social acceptance/Bullying*.

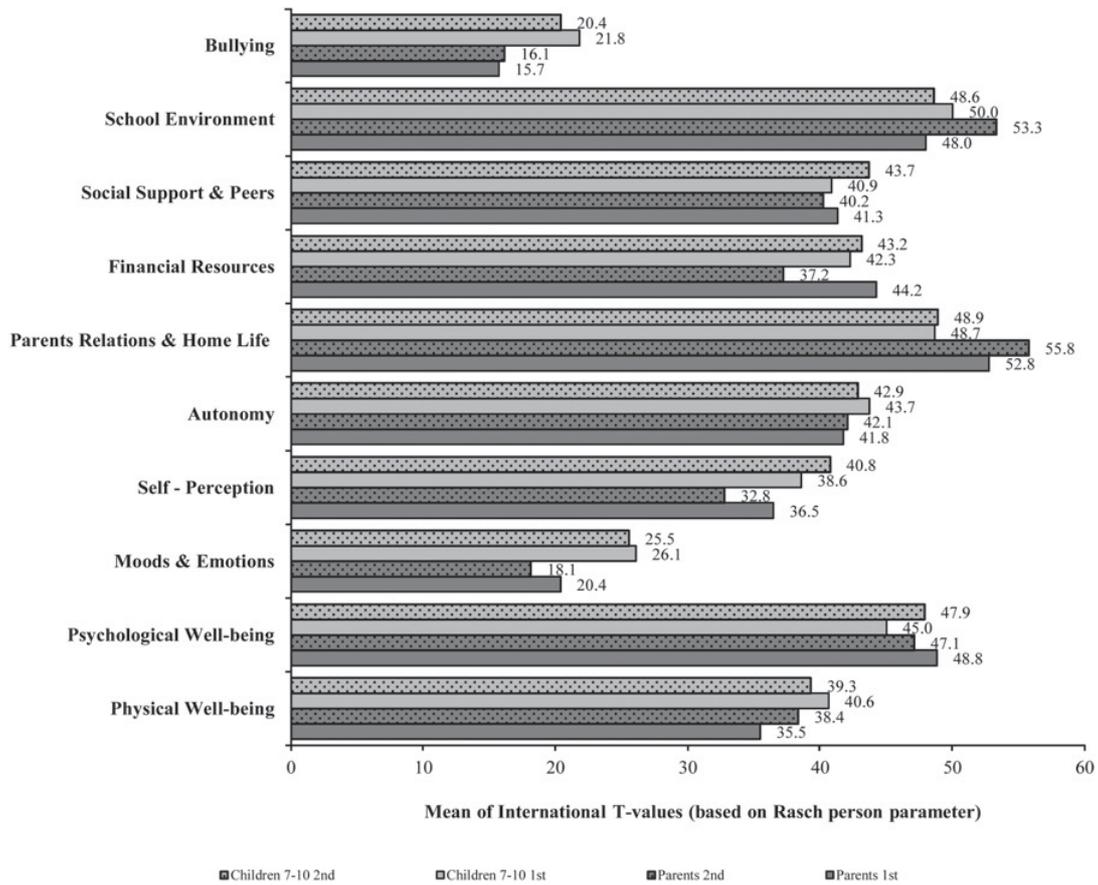
Good internal consistency (Cronbach alpha) was detected in the following KIDSCREEN dimensions of children’s self-assessments (2009-2010): *Mood and emotions* (0.84), *Parents relations/home life* (0.91), *School environment and studies* (0.84), *Autonomy* (0.73), and in the following dimensions of parent’s evaluations: *Parents relations/home life* (0.89), *School environment* (0.73), *Bullying* (0.77), *Financial resources* (0.74).

#### *Provision of social rehabilitation services*

The ten social services, which were most often mentioned by the families involved in the study, are the following: provision of technical aids, day center services, some rehabilitation services (Table 2). According to the results of the study, almost 50% of the respondents use the services offer by the municipality, particularly, those related to environmental adaptation (provision of technical aids and housing adaptation), as well as specialized transportation services. Only two families have used services that are focused on family’s unburdening, namely, home care and respite time, although specialist had recommended these services to other families as well.

#### **Discussion**

Only in recent years there have been several studies to identify changes in both healthy and children with special needs long-term QoL (Josefiak et al., 2009; Rajmil, 2009; Villalonga-Olives et al., 2010; Békési et al., 2011). Time period, after which the QoL was measured repeatedly in the particular studies, depends – from a 4-month study carried out in Hungary (Békési et al., 2011) till a 3-year study carried out in Spain (Rajmil, 2009; Villalonga-Olives et al., 2010). Norwegian researchers even after a short period of 6 months detected changes in QoL rates of healthy school age children; greater changes and decline in rates was observed with older children (Josefiak et al., 2009). Similar results of this study



**Figure 3.** Comparison of Latvian children data (8–11 aged) and their parents’ proxy reports according KIDSCREEN-52 over a one year period (2009–2010).

**Table 2.** Services provided by Social service offices of Riga municipality.

	Care at home	Personal assistant	Day care center	Support groups	Education of parents	Technical aids	Home adaptation	Respite care	Special transport	Rehabilitation
Received services	1		7	1	-	16	3	1	7	12
Prescribed and unreceived services	3	5	3	3	1	2	2	-	1	6
Services needed at education institution	-	4	1	3	2	2	-	-	6	3

illustrate credible changes in QoL rates in the evaluation carried out after a year; it should be noted that the self-assessment of the girls involved in the study was lower and the changes were detected in several dimensions. In the past few years numerous studies have been conducted to compare the children’s self-assessment of QoL with the parents’/caregivers’ one. (Arnaud, 2008; White-Koning, 2007; Erhart et al., 2009; Ellert et al., 2011). In various reviews it is determined that parents of healthy children

tend to evaluate their children's QoL higher (White-Koning, 2007). And on the contrary, that parents of children with special needs evaluate their children's QoL lower (White-Koning, 2007), which is confirmed by the results of this study – it was deduced that children with special needs evaluated their QoL higher according to six dimensions in the first survey and according to eight dimensions out of ten mentioned in the KIDSCREEN-52 questionnaire after a year. The diverse opinion of parents about the QoL of their children with special needs is useful for rehabilitation specialists as supplementary information to help planning suitable social rehabilitation services for these families (Erhart et al., 2009).

In literature it is stressed that in social studies the attention is much more paid to research of social workers' practice, methods of social rehabilitation services, but less to the analysis of the received social rehabilitation services, the parents' and children's evaluation of the received services and their impact on the results of rehabilitation (Kuronen et al., 2010). Riga City municipality offers day care center services, home care, palliative care services, respite services (it is a provision of short-term social care in an institution up to 30 days a year), housing adaptations, specialized vehicles service, attendant-assistant services (ensures assistant to a specific object), consultation of occupational therapist to assess the necessity of technical aid for the child, as well as finances the necessary rehabilitation services (for example, hippotherapy, watertherapy) for low-income families.

Only two families have used the service *Home care* and *Respite care*. During the survey it was determined that parents do not entrust childcare to people from care services, because they are not feeling safe and believe that the care at home or at an institution will not be carried out sufficiently expert.

The results of the survey show that five respondents have been advised to use the attendant-assistant service, but the respondents have not received it. In these cases the attendant-assistant for the child was necessary in the education environment, but unfortunately the municipality does not provide such service at present. Three of the respondents pointed out that they have not received the home care service, because in order to receive the service the income of the family is assessed, and, according to the assessment, the aforementioned respondents had to make a co-payment, which the parents refused to do. Furthermore, the day care center service was not received by the clients whose place of residence is located far from the service reception site. The parents often do not receive the support group service, because at the moment the support groups are organized only in several regions of Riga City.

Riga City municipality does not finance those services that are provided from the state's budget; therefore, six families were not admitted to receive financing for a rehabilitation course, which is financed from the state's budget. Unfortunately, at the moment the state budget funds for rehabilitation are not enough, subsequently, there are queues forming to receive these state financed services.

Questionnaire results indicate that families require services that are available at the educational institution attended by the child: attendant-assistant, support-educational groups for parents, as well as rehabilitation services, thereby facilitating parents' daily routine. According to the authors, the results indicate on one positive tendency – the parents are willing to receive support and knowledge about childcare and rehabilitation issues in support-educational groups.

## Conclusions

If the 2009 and 2010 survey data is compared, it can be deduced that statistically credible changes in the rates of QoL of children with special needs have taken place; in the second evaluation children, becoming older, rate the QoL lower. Participants of the study – children with developmental disabilities residing in Riga aged from 8 to 10 years – in both evaluations indicated a lower QoL assessment in all ten QoL dimensions of the questionnaire, if compared with the European normative data of children's QoL assessment developed by the KIDSCREEN research group.

In the second survey the QoL self report of children with special needs was different from the one provided by their parents – the children indicate higher QoL rates than their parents. When comparing the two surveys of QoL assessments – children's self reports and the parent's assessment in 2009 – a distinct difference in opinions was discovered in the following dimensions: *social support, self perception, mood and emotions, financial resources*, and in 2010: *social support and bullying*.

The families involved in the study most often used the following social services: provision of technical aid, day care center service, some rehabilitation services. The parents consider that the services provided by Riga city municipality for children with special needs or the whole family are necessary, but not always they correspond to the needs of the child with special needs or their families.

The results of the study indicate that it is necessary to find opportunities to raise the QoL of Riga residing elementary school aged children with developmental disabilities, for example, by changing the social rehabilitation system in Riga City and provide services more suitable for the needs of these children and families and child and family centred.

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