



Social
Research
Institute Inc.

Quality of Life and Costs of Living and Services of Disabled People in Various Residential Arrangements in Hungary

Summary of the final study related to the project „VP/2013/013/0057 New dimension in social protection towards community based living”

**TÁRKI Social Research Institute, Budapest
Budapest, 18 January 2016. január**

The summary was written by

Ágnes Kozma

Project manager:

Anikó Bernát

Principal investigator:

Marianna Kopasz

Survey expert:

Bori Simonovits

Research team:

Marianna Kopasz

Bori Simonovits

Ágnes Kozma

Anikó Bernát

Tamás Verdes

Zsolt Bugarszki

TÁRKI Társadalomkutatási Intézet Zrt.

1112 Budapest, Budaörsi út 45.

Tel.: 309-7676

Fax: 309-7666

Web: www.tarki.hu

E-mail: tarki@tarki.hu

TABLE OF CONTENT

1. Background.....	4
2. Research questions	4
3. Research methods.....	4
3.1. Research design	5
3.2. Participants	5
3.3. Data collection instruments	6
3.4. Recruitment of participants.....	8
4. analysis	10
5. Results	11
5.1. People with intellectual disabilities.....	11
5.2. People with profound intellectual and multiple disabilities	13
5.3. People with autism	14
5.4. People with psychosocial disabilities	16
5.5. Limitations	18
References.....	20

1. BACKGROUND

This reports provides a summary of the methods and findings of the project „New dimension in social protection towards community based living” (VP/2013/013/0057). The research was carried out by TARKI Social Research Institute and funded by the Equal Opportunities of Persons with Disabilities Non-profit Ltd. (Fogyatékos Személyek Esélyegyenlőségéért Közhazsnú Nonprofit Kft. - FSZK) together with Hand in Hand Foundation (Kézenfogva Alapítvány) in Hungary in 2015-2016.

2. RESEARCH QUESTIONS

The study has two closely related objectives: on the one hand it aims to examine and compare the quality of life of adults with disabilities living in residential institutions, smaller group homes and private households (either with their family or independently). On the other hand it also aims to analyse the cost-efficiency of these different residential arrangements in terms of social care provision. The analysis covers those in residential settings – institutions and supported accommodation (i.e. group home) services – included in current deinstitutionalisation policies in Hungary.

The study examines four groups: (1) adults with intellectual disabilities, (2) adults with autism, (3) adults with profound intellectual and multiple disabilities, as well as (4) adults with psychosocial disabilities. All four groups include people with different levels of disabilities – from mild to more severe – defined on the basis of independent living (adaptive behaviour) skills, a key determinant of quality of life.

3. RESEARCH METHODS

The methodology was shaped by previous research as well as the local context in Hungary. It required extensive preparation because there were no existing studies or protocols in Hungary or elsewhere that could have been readily adapted to the current study. Therefore we used existing quality of life instruments and adapted them to the Hungarian situation, and we also developed our own research instruments that met the expectations of the Funder and were feasible within the budget available. This section gives an overview of the main phases of the research as well as the key methodological components, highlighting some of the challenges encountered and ways of addressing them.

3.1. RESEARCH DESIGN

The study started in March 2015, the research methodology and data collection instruments were developed in March and April. These were then reviewed by people with disabilities, family and paid carers as well as social care professionals and they were also piloted extensively with people with disabilities in different residential settings between April and June. The recruitment of participants also started during this phase. Data collection started in July and ran until December, 2015.

The research focuses on four groups of people with disabilities identified by the Funder, namely adults with intellectual disabilities, autism, profound intellectual and multiple disabilities, and psychosocial disabilities. The four groups were examined in three main residential arrangements: large residential institutions, smaller scale group homes, and private households (including those living with their families or independently). Due to the low number of people in supported accommodation settings (in Hungarian: támogatott lakhatás), their quality of life was examined separately in a case study using qualitative interviews with service users, staff and professionals.

Because the aim of the research was to examine the quality of life outcomes and cost-effectiveness across different residential arrangements, we used non-representative sampling and a matched samples design to eliminate bias arising from the different case mix in the different residential arrangements.

3.2. PARTICIPANTS

To be included in the study individuals must have an official diagnosis. Participants were allocated to one of the four groups based on their primary disability, and in the case of people with profound intellectual and multiple disabilities the presence of an additional disability in addition to a diagnosis of profound/severe intellectual disability. The intended composition of the sample is shown in Table 1.

Table 1 Intended composition of the sample

	Intellectual disabilities	Autism	Profound intellectual and multiple disabilities	Psychosocial disability	Total
Institution	40	40	40	40	160
Group home	40	40	40	40	160
Private household	40	40	40	40	160
Total	120	120	120	120	480

The study covers four very heterogeneous groups of participants. This raises important methodological challenges that can potentially undermine the internal validity of the comparative analysis. Internal heterogeneity was particularly an issue for people with autism and those with psychosocial disabilities, and it was addressed by narrowing the inclusion criteria. For people with autism, those with high-functioning autism (or Asperger Syndrome) found predominantly in private households were excluded on the basis of advice from professionals and to maintain comparability with those living in group home settings who tend to have more severe autism.

People with psychosocial disabilities are an even more heterogeneous group, therefore – on the basis of consultations with professionals and the Funders – this group was narrowed down to people with schizophrenia and those with any other diagnosis (e.g. depression etc.) were excluded from the study. People with schizophrenia make up the largest group of people living in long-stay mental health institutions and also relatively large numbers live in the community either independently or with their family. Therefore, it is important to keep in mind that any findings reported in this study on people with psychosocial disabilities apply exclusively to people with schizophrenia.

Some service providers operate both institutions and group homes. As a general rule these were excluded from the study to make sure that costs could be clearly attributed to a particular residential arrangement and avoid any bias arising from cross-financing of services. However, this rule could not be applied to services for people with psychosocial disabilities because at present all group homes are operated by large institutions.

3.3. DATA COLLECTION INSTRUMENTS

Data on each individual was collected using three questionnaires¹:

- A self-report “client questionnaire” that asks about the respondent’s subjective well-being in eight quality of life domains and some basic socio-demographic characteristics and personal opinion;
- A “carer questionnaire” that can be answered by a carer (paid or unpaid/family carer) who knows the client and their everyday life well. This questionnaire provides information on the living conditions, infrastructure and some aspects of objective quality of life of the individual;
- A “manager/head of household questionnaire” that can be answered by someone who knows the budget and financial situation of the setting where the participant lives (i.e. institution, group home, or private household).

¹ The Hungarian version of the questionnaires can be obtained from TÁRKI Social Research Institute.

The development of questionnaires lasted approximately four months and included extensive piloting with people with disabilities, service providers and family carers. The main challenge was to create questionnaires that are relevant and adequate for all four participant groups in very different residential arrangements.

In the initial phases of the study the research team reviewed different quality of life and life satisfaction questionnaires for people with disabilities developed and used in other countries. We could not identify a single instrument that met the requirements of our study and could have been readily adapted to the Hungarian context. Therefore we relied on a number of existing instruments that all had in common that are based on the internationally accepted conceptualisation of quality of life (QoL) and cover all eight domains (Schalock et al. 2002)²: (1) emotional well-being, (2) material well-being, (3) interpersonal relations, (4) personal development, (5) physical well-being, (6) self-determination, (7) social inclusion, and (8) rights. These QoL domains have been validated both in terms of internal structure and stability by various international studies (see e.g. Verdugo et al. 2005) and in different cultural contexts (Schalock et al. 2005).

The aim to include the views of people with disabilities themselves directly in the study had implications for the design of the “client questionnaire”, particularly the number of questions, the amount of time required to complete the questionnaire, and the wording of the items. Some of the instruments reviewed had up to nine questions per domain. The original version of the Hungarian client questionnaire consisted of a total of 48 items, eight items per domain selected on the basis of their face validity by the research team.

There were major differences between the instruments reviewed in terms of the use of response scales. Some questionnaires had the same response scale for each item (e.g. INICO-FEAPS), while others used different response scales (e.g. POS). Some questionnaires use Likert-type response scales (i.e. responses range from “totally agree” to “totally disagree”), others use frequency scales (i.e. where the extremes are “always” and “never”). The selection of response scale has implications for the use of the questionnaire – whether responses for each item can be added together and used as an index/summary rating. Our original response scale was a four-level frequency scale.

The inclusion of pre-screening is sometimes recommended in self-report questionnaires for people with intellectual disabilities (Emerson et al. 2013). However, this was not feasible in this study – due to data collection arrangements – nevertheless a practice item was incorporated into the questionnaire that provided participants the opportunity to practice the use of the response scale before answering the QoL questions and highlighted any major difficulties in responding that the interviewer could note on the questionnaire.

² These were: (1) Ask Me!, (2) INICO-FEAPS Scale: Comprehensive Quality of Life Assessment of People with Intellectual and Development Disabilities, (3) Personal Outcomes Scale (van Loon et al. 2009).

The carer and manager/head of household questionnaires were developed alongside the client questionnaire, however were much less challenging in terms of their design. They were based on input from service providers (e.g. funding sources, availability of information on expenditures etc.) as well as existing instruments on household expenditures/costs.

All three instruments were piloted with the target group and revised on the basis of feedback. The first version of the client questionnaire was piloted with seven individuals from the four participant groups in different residential settings, including private households. Based on feedback, the number of QoL questions was drastically reduced from 48 to 16. The questions that we retained were selected on the basis of ease of use by the target group and face validity. The four-item response scale was replaced by a simple three-level scale (yes, no, so-so). The revised instrument was tested again with two individuals with intellectual disabilities living in an institution. Following feedback, the wording of the questionnaire was further simplified. The third and final version was tested again in all three residential arrangements with five individuals.

Client and carer questionnaires were administered face-to-face by professional interviewers from TÁRKI. All interviewers had to take part in a training session where the instruments were presented as well as some information on the target groups, particularly issues around communication and the interview situation. During the interview, participants with disabilities were given the opportunity to ask someone they know well and trust to be present and where necessary facilitate communication.

For people with profound intellectual and multiple disabilities who cannot respond to a self-report questionnaire, a carer who knows them well (the same person who responded to the carer questionnaire) provided proxy responses.

3.4. RECRUITMENT OF PARTICIPANTS

Given that there is no comprehensive database of people with disabilities that could have been used as the sampling frame of the study, participants were identified and recruited through various channels and using a range of methods. The study had the endorsement of government agencies (e.g. Ministry of Human Resources, Directorate for Child Protection and Social Care) that provided letters of support to facilitate recruitment.

The sample of eligible residential institutions and group homes (see Section 2.2 on Sampling) was drawn up using stratified sampling, taking into account the location and the client profile of the institution (i.e. types of service users catered for). From this list, services were selected randomly and asked to take part in the study. A total of 22 institutions and 49 group homes were invited to take part in the study, out of which 19 institutions and 35 group homes agreed to be involved in the research. Once consent from management was

obtained, services were contacted to find out about the distribution of service users by type and severity of disability to help planning individual sampling and they also received the management questionnaire electronically. When the management questionnaire was returned – this sometimes took a long time and reminders had to be sent – services were contacted to recruit individual participants (service users and carers) and arrange site visits.

Originally, the intention was to examine all four participant groups in all three residential arrangements (see Table 1); however it was not possible to identify a sufficient number of people with a formal diagnosis of autism in institutions. This was not entirely unexpected; Turnpenny (2011) found no service user with a diagnosis of autism in a random sample of 60 people living in institutions. Autism is a relatively new diagnostic category in Hungary – introduced in 2003 – and thus more common among children and young people. Although there are adults with autism living in institutions, the majority of them remain undiagnosed (Petri & Vályi 2009).

Another difficulty during recruitment arose from the fact that the distribution of the four participant groups differs across the three residential arrangements. It has already been highlighted that the number of people with a diagnosis of autism is very low in institutions, thus – despite our best efforts – we could not recruit enough participants from this type of setting and it had to be excluded from the analysis. (i.e. people with autism in institutions). Another challenge was to identify and recruit older age groups living in private households in all four participant groups, as well as younger participants (aged under 30 years) in mental health institutions.

The recruitment of those living in private households was especially challenging and resource-intensive. Day service providers and advocacy organisations were asked (e.g. ÉFOÉSZ, AOSZ) to circulate a call for participants in their networks. Potential participants from waiting lists of participating service providers were also contacted. Overall, the recruitment of participants in private households lasted until November 2015 and 473 families indicated their willingness to take part in the study, out of whom 293 met inclusion criteria. People with psychosocial disabilities were recruited exclusively via day service providers.

Participation in the study was voluntary and anonymous.

4. ANALYSIS

Data on quality of life and costs were analysed by participant group. In accordance with the original study design, matched sub-samples were used. In three participant groups sub-samples were matched on the basis of adaptive behaviour (i.e. the collection of practical and social skills used in everyday life) that is considered a key determinant of quality of life for people with intellectual disabilities (Mansell 1996). The intellectual disabilities and autism sub-samples were matched by case and the profound intellectual and multiple disabilities sub-sample was matched on the basis of the average score on the adaptive behaviour item list. The sub-sample of people with psychosocial disabilities was matched on the basis of their average age. Table 2 indicates the total number of participants in the final sample.

Table 2 Composition of the achieved sample

	Intellectual disabilities	Autism	Profound intellectual and multiple disabilities	Psychosocial disability	Total
<i>prior to matching</i>					
total	130	82	112	138	462
<i>after matching</i>					
Institution	33	-	31	35	99
Group home	33	30	31	35	130
Private household	33	30	31	35	130
Total	99	60	93	105	359

Adaptive behaviour was measured using a simple list of nine items related to everyday skills (such as using the toilet, getting dressed, getting out and about etc.), and for each item carers were asked to indicate whether the participant was independent or needed any help.

A combined quality of life score was created using answer on the 16-item quality of life questionnaire. To create the combined score, positive answers were recorded as 1 and negative or „in-between” answers were recorded as zero. Scores were then added to obtain the combined score, therefore its value ranges between 16 and 0, higher scores representing better quality of life. Considering the extremely limited timeframe of the study, it was not possible to validate and examine the psychometric properties of the combined score.

As a general rule, we used information reported by people with disabilities for the 16-item quality of life questionnaire and the combined quality of life score. Where this was not possible due to non-response, the missing answer was filled in with a response from the proxy questionnaire. This did not exceed 10% for the majority of items for people with intellectual disabilities and 25% for people with autism, however it was considerably higher for people with profound intellectual and multiple disabilities. Substituting missing answers

was not necessary for people with psychosocial disabilities who could self-report quality of life information.

Other information (i.e. on medication, illnesses, number of people sharing facilities etc.) was gained from proxy respondents.

5. RESULTS

This section gives a brief overview of the main findings by participant group.

5.1. PEOPLE WITH INTELLECTUAL DISABILITIES

The main characteristics of this subsample are summarised in Table 3. This was a relatively able group of people, with the majority of them requiring no or little help in most areas of everyday life.

Table 3: Distribution of the sample by residential arrangement, age group and level of adaptive behaviour (N)

	Age	Independent in up to 4 areas	Independent in 5-7 areas	Independent in 8-9 areas	total
Institution	18-39 years	4	4	12	20
	40-60 years	5	7	0	12
	Total	9	12	12	33
Group home	18-39 years	7	6	8	21
	40-59 years	2	6	4	12
	Total	9	12	12	33
Family home	18-39 years	5	8	7	20
	40-59 years	4	4	5	13
	Total	9	12	12	33
Total	18-39 years	16	18	27	61
	40-59 years	11	18	9	37
		27	36	36	99

For people with intellectual disabilities we found significant differences between the three residential arrangements in terms of the combined quality of life score (Table 4). People living in group homes, and to a lesser extent institutions, had better quality of life scores than those living at home. Particularly, people living in residential settings scored higher than those living with family carers on two quality of life domains: rights and self-determination. Furthermore, the share of those who were in a relationship or in a co-habiting partnership was significantly higher in residential settings, while people who lived in the family had a more extensive relationship with their extended family. An obvious explanation for the observed difference in quality of life scores might be the status of adults with intellectual disabilities within the family, namely the fact that many of them are treated quasi as children and controlled by family carers. Another notable issue is the large standard deviation of combined quality of life scores and the relatively large share of participants reporting very poor quality of life, especially in families: 10% of the total sample had a score of 4 or less on the combined quality of life indicator.

Table 4 People with intellectual disabilities: combined quality of life score by residential arrangement and adaptive behaviour

	N	Mean	Standard deviation
Total	98	10.1	3.7
Residential arrangement			
Institution	33	10.1	4.0
Group home	33	11.5	2.8
Family home	32	8.7	3.9
F value (sign)	5.08 (0.008)**		
Adaptive behaviour			
Independent in up to 4 areas	27	7.1	4.3
Independent in 5-7 areas	36	10.8	2.8
Independent in 8-9 areas	36	11.5	2.9
F value (szign)	14.92 (0.000)***		

* indicates correlations that are significant according to the F-test ($p < 0.05$)

** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.01$)

*** - indicates correlations that are significant according to the F-test ($p < 0.001$)

**** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.0001$)

The above findings are qualified by the fact that in a number of other key areas people in residential settings had a clearly worse quality of life. The use of psychoactive medication should be noted as one such area where people in institutions had more favourable outcomes. They were significantly more likely to take psychoactive medication: 85% of people without a diagnosis of epilepsy or mental illness were taking such drugs in institutions compared to 46% in group homes and 31% in family homes.

Overcrowding – which has implications for emotional, physical and material well-being – was more common in institutions than in group homes or family homes. One in four people with intellectual disability in institutions was sharing a room with at least three others, while 72% of those living with their family had their own room.

People in residential settings were also more likely to be under any form of guardianship than those living with their family.

In a number of areas (e.g. employment, friendships etc.), however, there were no significant differences in the quality of life of people with intellectual disabilities in different residential arrangements. There was no relationship between quality of life and age group or quality of life and gender.

5.2. PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

Group-level matching was used to create comparable sub-samples of people with profound intellectual and multiple disabilities. Table 5 provides an overview of the main *characteristics of the sample*.

Table 5 Distribution of participants with profound intellectual and multiple disabilities by level of adaptive behaviour, residential arrangement, gender and age (N, mean, SD, Min, Max)

Residential arrangement					
Type	N	Mean	SD	Minimum	Maximum
Institution	31	2.94	2.29	0	7
Group home	31	2.81	2.44	0	7
Family home	31	2.39	2.12	0	7
Gender					
Male	47	2.57	2.18	0	7
Female	46	2.85	2.38	0	7
	93	2.71	2.28	0	7
Age group					
18-34 years	53	2.43	2.22	0	7
35-57 years	40	3.08	2.32	0	7
Total	93	2.71	2.28	0	7

In this group there was no statistically significant relationship between the combined quality of life score and residential arrangement (see Table 6). Although those living with their families had less favourable outcomes in some areas associated with physical well-being. In

particular, they were less likely to do any physical activity (i.e. exercise, gardening etc.) or attend dental health checks than those living in residential care settings.

Table 6 People with profound intellectual and multiple disabilities: combined quality of life score by residential arrangement and adaptive behaviour

	N	Mean	SD
Total	93	8.3	3.3
Residential arrangement			
Institution	31	8.9	3.0
Group home	31	7.8	3.0
Family home	31	8.2	3.9
F-test (sign)		0.832 (0.438)	
Adaptive behaviour			
Independent in up to 2 areas	47	6.8	2.8
Independent in 3-7 areas	46	9.9	3.1
F-test (sign)		25.676 (0.000)****	

* indicates correlations that are significant according to the F-test ($p < 0.05$)

** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.01$)

*** - indicates correlations that are significant according to the F-test ($p < 0.001$)

**** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.0001$)

We also found significant differences between people with profound intellectual and multiple disabilities living in different residential arrangements in terms of the use of psychoactive medication and living conditions (overcrowding). The use of psychoactive drugs and overcrowding was more common in institutions. People living with their families were less likely to be under guardianship than those in residential care.

In a number of areas (e.g. employment, friendships etc.) there were no significant differences in the quality of life of people with intellectual disabilities in different residential arrangements, however many people experienced poor outcomes. For example only 20% of the total sample was working, just over half had friends and only two individuals were in a relationship. There was no relationship between quality of life and age group or quality of life and gender.

5.3. PEOPLE WITH AUTISM

As it has been mentioned previously, not enough people with autism could be recruited in institutions, therefore the comparison of quality of life outcomes is limited to those living in group homes and in the family home. The characteristics of the sample is summarised in Table 7.

Table 7: Distribution of participants with autism by adaptive behaviour and residential setting, gender and age group (N)

	Independent in up to 4 areas	Independent in 5-9 areas	Total
Residential arrangement			
Group home	14	16	30
Family home	14	16	30
Total	28	32	60
Gender			
Male	19	21	40
Female	9	11	20
Total	28	32	60
Age group			
18-30 years	20	15	35
31-53 years	8	17	25
Total	28	32	60

Among adults with autism there was no significant relationship between the combined quality of life score and residential arrangement. Or differently, people with autism who live in a group home and people who live at home with their family have a similar quality of life (as measured by the combined quality of life indicator) (See Table 8).

Table 8 People with autism: combined quality of life score by residential arrangement and adaptive behaviour

	N	Mean	SD
Total	60	9.22	3.66
Residential arrangement			
Group home	30	9.6	3.51
Family home	30	8.8	3.83
F-test (sign)		0.773 (0.383)	
Adaptive behaviour			
Independent in up to 2 areas	28	7.1	3.46
Independent in 3-7 areas	32	11.0	2.80
F-test (sign)		23.121 (0.000)****	

* indicates correlations that are significant according to the F-test ($p < 0.05$)

** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.01$)

*** - indicates correlations that are significant according to the F-test ($p < 0.001$)

**** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.0001$)

People with autism living in group homes had marginally (but statistically not significant) better access to leisure activities, more intimate relationships, better knowledge of their

rights and worried less. People living with their family had more relationships with people in the local community (e.g. neighbours) and in their extended family. They were also more likely to have access to the Internet.

5.4. PEOPLE WITH PSYCHOSOCIAL DISABILITIES

As it has been highlighted previously, within the group of people with psychosocial disabilities, our analysis focused on those with a diagnosis of schizophrenia and used sub-samples matched on average age in the three residential settings. Originally, the intention was to use a matched-cases design based on age at diagnosis, however due to a high number of missing answers and issues around the reliability of information, the decision was made to use age as the main variable for matching. The characteristics of the sample with psychosocial disabilities is shown in Table 9 and Table 10.

Table 9 Distribution of people with psychosocial disabilities by residential arrangement, gender and age group (N)

		30-47 years	48-65 years	total
Institution	Male	12	6	18
	Female	9	8	17
	total	21	14	35
Group home	Male	6	11	17
	Female	3	15	18
	total	9	26	35
Family home	Male	18	4	22
	Female	6	7	13
	Total	24	11	35
Total	Male	36	21	57
	Female	18	30	48
	total	54	51	105

Table 10 Average age at psychiatric diagnosis by age group and residential arrangement

Res. arrangement	Age groups	N	Mean age	SD
Institution	30-42	9	24.5	7.5
	43-55	15	27.2	7.0
	56-65	10	29.9	7.5
	total	34	27.3	7.4
Group home	30-42	5	22.3	2.9
	43-55	13	21.6	2.9
	56-65	11	28.0	6.6
	total	29	21.7	7.9
Family home	30-42	17	25.1	4.5
	43-55	11	24.8	8.4
	56-65	4	39.3	5.7
	total	32	26.8	7.7
Total	Institution	34	27.2	7.5
	Group home	29	24.0	7.3
	Family home	32	26.8	7.7
	total	95	26.0	7.6

In this group, those living in group homes had the best quality of life (as measured by the combined score) and those living in institutions had the worst quality of life. The quality of life of people living in a private household was comparable to those in group home settings (see Table 11).

Table 11 People with psychosocial disabilities: combined quality of life score by residential arrangement and age group

	N	Mean	SD
Total	105	10.0	3.1
Residential arrangement			
Institution	35	8.9	3.2
Group home	35	11.0	2.8
Family home	35	10.1	3.0
F-test (szign)		4.205 (0.018)*	
Age group			
30-42 years	35	9.5	3.4
43-55 years	41	10.3	3.2
56-65 years	29	10.3	2.6
F test (sign)		0.851 (0.43)	

* indicates correlations that are significant according to the F-test ($p < 0.05$)

** - indicates correlations that are significant according to the F-test összefüggések ($p < 0.01$)

*** - indicates correlations that are significant according to the F-test ($p < 0.001$)

****- indicates correlations that are significant according to the F-test összefüggések ($p < 0.0001$)

People living in group homes enjoyed a relatively better quality of life in a number of areas compared to those in other settings: they had higher levels of social participation (access to leisure activities), reported more social and intimate relationships, were more aware of their rights, had more freedom to manage their own money (make decisions about how to spend their money), better physical well-being and personal-development.

It is worth highlighting that living conditions were by far the worst among people with psychosocial disabilities in institutions (see Table 12).

Table 12 Number of people with psychosocial disabilities sharing different facilities

Setting	Mean	Median	Minimum	Maximum	N
Bedroom					
Institution	4.0	4	1	8	35
Group home	2.5	2	1	6	35
Family home	1.4	1	1	4	12
Total	3.0	2	1	8	82
Bathroom					
Institution	22.2	25	2	60	35
Group home	6.5	5	1	10	35
Family home	2.3	2	1	5	12
Total	12.6	6	1	63	82

5.5. LIMITATIONS

When interpreting the results the following limitations must be taken into account:

- Internal validity: the 16-item quality of life questionnaire was not validated. In particular, we did not examine the properties of the questionnaire in groups of people with different levels of disability (due to the very short time available for the study). It is obvious that some questions are less relevant and applicable for people with more severe intellectual disabilities (such as the use of internet, talking to friends about feelings etc.). Therefore scores on individual quality of life items and the combined quality of life scores are not comparable across participant groups. Furthermore, the questionnaire focuses on some quality of life areas that are relatively easy to measure using a questionnaire and structured interviews and disregards others, that are equally important for quality of life but require different methods to explore them (for example the quality of interpersonal relationships etc.). These might provide a different picture on the quality of life in different residential arrangements.
- As a general rule information reported by the participants with disabilities was used to analyse quality of life, however, the validity and reliability of self-report was not examined

systematically. Although questionnaires were piloted extensively in the four participant groups, individual variations can occur in the ability to self-report, particularly among those with more severe cognitive limitations.

- Proxy respondents: we used different groups as proxy respondents in the different residential settings (i.e. paid carers and family carers) and we could not take into account any potential differences between their responses. In the literature it is sometimes highlighted that paid carers as proxies tend to rate quality of life higher than family carers, although others argue that this is only the case when paid carers know the individual less well (Rand & Caiels 2015). In the present study this might have been an issue among paid carers in institutions, or, to a lesser extent, in group homes. A jelen kutatásban ez elsősorban intézeti helyettes válaszadók között merülhetett föl, bár lakóotthoni segítők esetében sem kizárható.

- Selection bias: although the study did not aim to use a representative sample, we must take into account that institutions and group homes that agreed to take part were systematically and significantly different from those who did not want to take part in research. Similarly, it is unclear to what extent families that were recruited via parents' associations and advocacy organisations represent "typical" families.

- Generalisability (external validity): on the one hand the relatively low number of participants (approximately 100 people in each participant group) and the sampling method (non-probability) do not allow the generalisability of the findings. This means that the findings cannot be compared across participant groups – even though data were collected using the same methods and instruments. Another limitation is that the findings presented in this study cannot be generalised to other groups of people with disabilities because the composition of matched samples differs (in various aspects) from the composition of the population.

REFERENCES

- Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and developmental disabilities, 51*(5), 333-348.
- Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.
- Petri, G. & Vályi, R. (2009). Autizmus – Tény – Képek. Autisták Országos Szövetsége - Jelenkutató Alapítvány.
- Rand, S., & Caiels, J. (2015). *Using Proxies to assess Quality of Life: A Review of the Issues and Challenges*. Discussion Paper 2899. QORU: Personal Social Services Research Unit, University of Kent, Canterbury
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American journal of mental retardation: AJMR, 110*(4), 298-311.
- Turnpenny, A. (2011). *Deinstitutionalisation and Community-based Care for Adults with Intellectual Disabilities in Hungary: Policy Change, Challenges and Outcomes*. Tizard Centre, University of Kent. Unpublished PhD dissertation.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of intellectual disability research, 49*(10), 707-717.