

How to measure multidimensional quality of life of persons with disabilities in public policies - a case of Poland

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Abstract

Background

The aim of this paper is to construct the tool that can be used to measure multidimensional quality of life of persons with disabilities in comparison with population without disabilities for the purpose of monitoring of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Methods

The Sen's capability approach was applied to conceptualize the quality of life. We followed guidelines of The Quality of Life Framework developed within the European Statistical System. The QoL scores in each domain (covered by the UNCRPD) were constructed using multiply indicators and multiple causes model (MIMIC). All analysis were based on 2018 EU-SILC data for Poland. We constructed quality of life indicators for population with and without disabilities and compared the differences.

Results

Persons without disability experienced higher QoL as compared to population with disabilities, overall and in various domains. Lower average QoL of persons with disabilities is a result of a lower share of those who experience high QoL. The biggest difference is observed for health and for productive and main activity domains. For material conditions and economic security and physical safety there was a moderate difference recorded. For the leisure and social relations domain there is almost no difference observed. Additionally, we identified diversified impact of particular determinants (such as age, gender, household situation, education, partner status, urbanization, health) on the QoL across domains and analysed populations.

Conclusions

This tool developed in this paper can be calibrated to enable cross-country and in time comparisons between different populations support evidenced-based social policy.

Introduction

Persons with disabilities are getting worldwide attention, yet quantifying this population is still a challenge. Although international bodies introduce disability as a separate topic, developing programmes such as United Nations Disability Statistics Programme or International Disability Alliance (part of world Bank Group), still the coherent data on disability is hardly available. This is mainly due to various operationalization of disability term, therefore estimating total number of persons with disabilities as well as making international comparison is very challenging [1]. For this reasons global statistical databases (e.g. World Bank, United Nations) provide evidence on population of persons with disabilities separately per country with significant discrepancies between them [2].

World Bank is currently estimating, that 15% of world's population experience some kind of disability. It is very rough estimation, though, without further disaggregation of this population. Assessing the form, levels or quality of life of persons with disabilities pose even more challenges.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) set several guidelines that have created new approach towards persons with disabilities, especially with regard to public policy. This approach is based on right of persons with disabilities to enjoy life equally with the rest of the population. The Convention itself obliges countries that signed the document to monitor its implementation (article 31) by collecting appropriate information, including statistical and research data. Voluntary working group - The Washington Group on Disability Statistics - has been set up to define measurement standards and monitor the Convention [3]. These activities did not bring the solutions for gaps in disability data, though.

The guidelines proposed by the Convention refer to direct monitoring of system solutions that are supposed to ensure equal rights in all life spheres for population with disabilities. Useful concept to be employed for this monitoring is a multidimensional quality of life (QoL) [4]. QoL can be considered as a link between general values and rights embodied especially in the UNCRPD with the personal life of the individual [5, 6, 7, 8].

In this paper we are proposing the indirect monitoring of the UNCRPD fulfilment based on the quality of life measurement by developing a statistical tool to measure the level of quality of life of persons with disabilities and compare it to quality of life of persons without disabilities. We do this on a country level and use the example of Poland, where the UNCRPD convention was signed in 2006, although the document is still not implemented. Additionally, Poland is an average case in European Union in terms of disability prevalence, with 25.8% of women (EU – 26.1%) and 22.7% of men (EU – 21.8%) reporting long-standing limitations in usual activities due to health problems [9].

Background

The concept of QoL has appeared in the public discourse in 1960's as an alternative to prevailing social development goals, which was at that time defined as an increase in material living conditions [10]. Although the term is commonly used, there is no single, universally accepted definition of quality of life. The World Health Organization's definition focuses on individuals' perceptions of their position in life and the correspondence with their expectations. Other definitions include satisfaction with needs, objective, and subjective evaluations of different domains of life, agency and meaning of life. It is gaining importance in the area of healthcare and, as such, it is identified as an outcome of the efficacy of the treatment [11]. Hence, the concept is multifaceted, multidimensional, ambiguous, and requires a clear definition before beginning the research.

In this article we apply the individual-referenced definition outlined by Schalock et al. [12], in which they underline that QoL is a multidimensional phenomenon composed of core domains influenced by

personal characteristics and environmental factors. The authors claim that core domains are the same for all people, although they may vary individually in relative value and importance.

On general level we can distinguish two approaches in measurement of quality of life. The first one is connected with measuring QoL for the total population or its particular sub-groups (present mostly on sociological, economic and demographic research). The second one is dedicated strictly to population with particular afflictions, which are usually connected with some kind of disability or disabilities (present mostly in medical and socio-medical research).

In case of the first approach connected with measuring the life quality for total population or its socio-demographic subgroups, the most complex and precise concept of measurement is provided by the final report of the Sponsorship Group 'Measuring Progress, Well-being and Sustainable Development' and Task Force on 'multidimensional measurement of quality of life' [13], which refers to recommendations Report on Measurement of Economic Performance and Social Progress [14]. This approach underlines multidimensional character of QoL, as well as the necessity to combine both subjective and objective measures.

The second concept of quality of life - related to health or activity limitations - originally have been aimed at physical symptoms or mortality [15, 16], but nowadays, it is widely recognized that quality of life is a goal of all healthcare interventions [17]. In disability research it has been suggested that quality of life and participation should be considered the key outcomes [18, 19]. In this approach, quality of life is also considered as a multidimensional construct, which includes physical, mental and social domains [20], however it is studied for particular groups of persons with disabilities, distinguished by the type of disability or impairment. Within this approach, the measurement of QoL is based on the impact of medical procedures on symptoms and the frequency of complications [21, 22, 23, 24, 25, 26, 27, 28]. Subjective assessment of QoL is based on the perception of activity limitation on a person's psychological, emotional health and social functioning [29].

Interesting proposal for measuring QoL, combining the elements of both above mentioned approaches (for the entire population or dedicated to persons with particular type of disability or affliction), is provided by capability approach, developed and refined by Sen [30,31,32,33,34,35,36]. This approach can be successfully implemented, both for measuring QoL of the entire population and for population with disabilities. It is based on the assumption that commodities themselves are not crucial in achieving a high quality of life. It is their properties that enable achievement of desired lifestyles by individuals. According to Nussbaum and Sen [37], capabilities refer to effective possibilities of realising achievements and fulfilling expectations, whereas functionings, that are the "beings and doings" of a person, refer to realised achievements and fulfilled expectations. Graphical illustration of the relationship between commodities, capabilities and functionings, using the key concepts of the capability approach, is demonstrated in Figure 1.

The achieved functionings are the result of personal choice to select from the capabilities available and subject to personal preferences, social pressure and other decision-making mechanisms. Moreover, they

are constrained by personal, social and environmental characteristics [38, 39]. Due to the above-mentioned theoretical considerations, we decided to use the capability approach to measure QoL for both populations: persons with and without disabilities.

Methods

Methodological approach

The proposed methodological approach combines three aspects: (1) measuring QoL within the framework of the capabilities approach; (2) the guidelines of the European Statistical System [13], indicating domains in which the QoL should be measured; (3) the UNCRPD monitoring requirements by focusing on those domains which are explicitly pointed by the UNCRPD.

The domains identified by UNCRPD and used in this study are:

- [material living conditions](#) (art. 28 of the UNCRPD),
- [productive or main activity](#) (art. 27 of the UNCRPD),
- [health](#) (art. 25 of the UNCRPD),
- [education](#) (art. 24 of the UNCRPD),
- [leisure and social interactions](#) (art. 30 of the UNCRPD),
- [economic and physical safety](#) (art. 14, 16, 19 of the UNCRPD).

Moreover, for the sake of comparability and establishing the reference category, the same measurement process was applied to persons with and without disabilities.

In order to operationalize the measurement of quality of life within the framework of capabilities approach (Sen), this paper proposes to apply a MIMIC model that was formulated by Hauser and Goldberger [40], and then popularized by Jöreskog & Goldberger [41], who presented its detailed assumptions as a special case of the structural equation model (SEM) [42, 43]. Krishnakumar [44] pointed at the SEM approach as the most suitable tool for estimating latent capabilities. The MIMIC model allows to explain the level of individual's quality of life and to assess the impact of external determinants (individual's personal, social, and environmental characteristics) on latent capabilities.

The operationalization of measurement of quality of life under a MIMIC model is based on the assumption, that the freedom of individual choice in capabilities is represented by an unobservable latent variable, which can be estimated as two sets of observable variables:

- the reflective part of the model (measurement sub-model), constructed using a set of selected basic indicators of quality of life (quality of life symptoms), and these variables can be interpreted as

realised functionings, potentially reflecting quality of life.

- the formative part of the model (structural sub-model), constructed on the basis of the individuals' personal, social and environmental exogenous characteristics, which are interpreted as the conversion factors that strengthen or weaken the capabilities and influence the process of transformation of available resources into achieved functioning [44].

The starting point for building the MIMIC model is to define symptoms and determinants of quality of life. The analysis starts by defining the relationships between latent variables (capabilities) and observable variables (quality of life symptoms and determinants), and these relations are presented in Figure 2. The set of symptoms used in the study are presented in the Annex 1.

Persons with and without disabilities can, due to different individual resources, possibilities as well as preferences, maximize their quality of life (realise achievements) in various ways. Furthermore, their personal, social, and environmental characteristics can strengthen or weaken their capabilities in different ways. Considering these differences, we estimate two separate models (for persons with and without disabilities), transforming all symptoms and determinants into stimulants (the higher the variable value, the higher the quality of life).

The minimum value of latent variable reflecting quality of life is the value of this variable for an artificial person who had the lowest values of all symptoms and determinants of quality of life, and the maximum value equals the value for a person with the highest achievable values of all symptoms and determinants of quality of life. Thus, the critical values of the latent variable were determined in a way that allows comparative analysis of quality of life of groups of persons with and without disabilities, while taking into consideration that persons with and without disabilities can maximise their quality of life in different ways, and that their personal, social, and environmental characteristics can strengthen or weaken their capabilities very differently. Having the QoL scores in each domain, it is possible to aggregate them into one single overall QoL score. We used factor analysis as a method of aggregation.

The identification for persons with disabilities was based on the commonly used measure of disability – Global Activity Limitation Indicator (GALI) [45]. This question has three categories: 1) strongly limited in daily activities, 2) limited, but not strongly, 3) not limited at all. All persons who were at least limited (1 and 2) in their activities are defined as those with disabilities, and others – without disabilities.

Data

We use data from EU-SILC survey conducted in 2018 in Poland. All information on the access to the EU-SILC dataset can be found on the URL (<https://ec.europa.eu/eurostat/web/microdata/european-union-statistics-on-income-and-living-conditions>) – access November 2020. This survey is carried out under EU resolution on a sample representative for the Polish population aged 15 years and over. Total sample size for persons with disabilities was 7,666 (59.0% of women) and for persons without disabilities was 25,714

(51.5% of women). Description of the sample, with distinction for two sub-samples, is presented in table 1.

Table 1
Sample description

Characteristics	Persons			
	With disabilities		Without disabilities	
	n	%	n	%
Sex				
Man	3,145	41.03	12,479	48.53
Woman	4,521	58.97	13,235	51.47
Age				
up to 24 years	151	1.97	3304	12.85
25-34	255	3.33	4177	16.24
35-44	430	5.61	4535	17.64
45-54	787	10.27	4189	16.29
55-64	1885	24.59	4557	17.72
65-74	2093	27.30	3431	13.34
75 years and over	2065	26.94	1521	5.92
Level of urbanisation				
Rural area	3,689	48.12	11,925	46.38
Intermediate area	1,771	23.10	6,090	23.68
Densely populated area	2,206	28.78	7,699	29.94
Relationship status				
Single	3,013	39.30	11,439	44.48
Living with a partner	4,653	60.70	14,277	55.52
Household size				
1 person	1,526	19.91	1,925	7.49
2 persons	3,273	42.69	6,980	27.15
3 persons	1,334	17.4	5,795	22.54
4 persons	743	9.69	5,722	22.26
5 and more persons	792	10.33	5,294	20.59
Equivalentised income quartiles				
bottom	2,829	36.90	6,563	25.52

2 nd	2,206	28.78	6,698	26.05
3 rd	1,584	20.66	6,231	24.23
top	1,047	13.66	6,222	24.20
Education level				
primary and below	2259	30.52	3291	16.13
vocational	2639	35.65	6543	32.06
secondary	1711	23.12	5722	28.04
tertiary	794	10.73	4853	23.78
Employment status				
working	1,582	20.63	12,076	53.04
not working	6,086	79.37	13,640	46.96
Self-rated health				
very good	49	0.64	3,855	18.28
good	651	8.49	11,252	53.37
fair	3,515	45.86	5,246	24.88
bad	2,695	35.16	676	3.21
very bad	754	9.84	55	0.26
Total				
	6615	100.00	18684	100.00

Source: own calculations.

The description of results refers to life domains. Presentation of results in each life domain is divided in two parts: the measurement part (in brackets we provide factor loadings) and structural parts (where we point the significance of each determinant in particular domains). In the text we present the path diagrams which can serve as graphical illustration of the results. All detailed results are presented in the Annex 2.

Results

Overall quality of life

The average quality of life scores are presented in Table 2. Persons without disabilities enjoy on average higher overall QoL than persons with disabilities (0.65 vs 0.50). The biggest difference in favor of persons without disabilities is observed for health (0.32) and for productive and main activity (0.26) domains. It is connected with health status of persons with disabilities, being influenced by their older age structure, which consists mostly of persons over 55 years old. Health problems and older age result in lower activity of persons with disabilities, especially on the labour market. For material conditions and economic security and physical safety there was a moderate difference recorded. This can be attributed to the stable sources on income (although not very high), connected with pension or disability allowances. For the leisure and social relations domain there is almost no difference.

Table 2

QoL scores by domains

QoL domain	Persons with disabilities	Persons without disabilities	Difference
Overall QoL*	0.50	0.65	0.15***
Material conditions	0.47	0.59	0.12***
Productive and main activity	0.23	0.49	0.26***
Economic security and physical safety	0.57	0.70	0.13***
Health	0.39	0.71	0.32***
Leisure and social relations	0.62	0.63	0,01***

*Aggregation method: factor analysis

*** Results statistically significant, $p=0.000$

Source: own calculations.

Population with disabilities is less homogenous in terms of overall QoL and its distribution is more skewed toward left tail, which suggests that disability might be a factor which not only negatively affects quality of life on average, but also can be associated with outlying observations in the left tail of the distribution, which correspond to persons with severely decreased quality of life.

Quality of life in different domains

In most of the domains the distribution's right tail is significantly heavier for persons without disabilities (see Figure 3). This suggests, that lower average quality of life of persons with disabilities is a result of a

lower share of those who experience high and very high QoL. The share of people with low QoL is similar in both groups, however, persons with disabilities relatively rarely achieve high levels of QoL.

Generally the QoL in each domain is reflected by the similar set of variables (see Annex 2), although there can be observed some differences. In case of material conditions domain crucial for QoL for persons with disabilities is material deprivation and subjective assessment of material conditions rather than objective indicators. In case of persons without disabilities both subjective and objective indicators are crucial of QoL in this domain.

The QoL in productive and main activity domain is reflected first of all by indicators connected with labour market participation: economic activity and working last week both for persons with and without disabilities. Such indicators as low income job, job satisfaction, low work intensity or long-term unemployment reflects QoL score in that domain in small extend for both analysed populations.

The QoL in the domain of economic security and physical safety is mostly reflected in the ability to face unexpected expenses, both for analyzed populations. Also being indebted reflects the QoL in this domain for both types of populations, although in weaker way.

For persons with and without disabilities the QoL in the health domain is reflected mainly in the health self-assessment. For persons without disabilities crucial role can be attributed also to long term illness, whereas for persons with disabilities this indicator reflects QoL in this domain in much smaller degree. Also unmet medical needs can be considered as a symptom of the QoL for persons without disabilities in this domain, but of a much weaker strength.

In the domain of leisure and social relations crucial role for persons without disabilities can be assigned to the frequency of meeting together with friends. Other symptoms, such as leisure activities, possibility to receive non-material help from others, loneliness, satisfaction with relations and satisfaction with leisure reflect the QoL in this domain to smaller extent. Whereas for persons with disabilities the most stronger symptoms of the QoL in this domain are loneliness and satisfaction with relations, followed by the frequency of meeting together with friends. Leisure activities and satisfaction with leisure reflects the QoL for persons with disabilities in a smaller degree. The least symptomatic nature for persons with disabilities in this domain can be assigned to possibilities to receive non material help for others.

Determinants of quality of life

Interesting part of the results are the patterns of the influence of the determinants of the QoL score across domains. Being a men positively influence QoL in material living conditions, productive and main activity, economic security and physical safety and in health domain, but for health only in case of persons without disabilities. Being a women favors QoL in leisure and social relations domain and in case of persons with disabilities also in health domain. So when it comes to domains connected with economic and material situation being a men favors the QoL score, whereas being a women increases the QoL

scores in social relations and leisure. In the literature we can find evidence that gender influence the QoL, however the impact differs with age, but also with income and cultural context [e.g. 46, 47]. The results of the interdependencies between age, gender and QoL depend on the particular measurement tool of the QoL used.

The diversified impact of age on the QoL was observed. For material living conditions and economic security and physical safety domain we can observe a positive impact of age on the QoL, stronger for persons with disabilities than for persons without disabilities. Whereas for productive and main activity, health and social relations the impact is opposite for both analyzed populations. Those results reflects the life course perspective and ageing process that deteriorates health and decrease different life activities, highlighting the need to take proper preventive actions [48, 49].

Household situation is also crucial for the QoL in different domains. Generally possessing a partner positively influence the QoL in all domains, with the exception of health domain for persons without disabilities. Moreover, for persons with disabilities bigger households facilitate the QoL in material living conditions, productive and main activity, economic security and physical safety domain, whereas negative influence of the household size was recorded in domains of health (with a very small effect) and social relations. Presence of other household members in case of persons with disabilities improve material and economic situation by providing additional income sources and enabling more engagement on the labour market leading also to improving the QoL. The negative impact in social relations domains can be associated with the fact that a need of contact with other persons is fulfilled within the households [50, 51].

The impact of education is important determinant of the QoL score in all domains, for persons with disabilities the pattern of influence for all educational levels across all domains is positive – the higher the level of education the higher the QoL. For persons without disabilities the general impact is also positive (even stronger than for persons with disabilities, although the pattern of influence by different educational levels across domains is more diversified [52, 53].

In case of urbanization degree the pattern of influence is diversified. For persons with disabilities the less urbanized area of living the higher the QoL in material living conditions, economic security and physical safety, social relations and leisure domain, in the rest of domains the influence was statistically insignificant. It can be connected with stronger family and community relations on rural areas, where the creation of the support network around persons with disabilities is easier [54, 55]. In case persons without disabilities living on less urbanized areas favors the QoL in material living conditions and health domains, whereas in productive and main activity and social relations domains the direction of influence is opposite.

Discussion

The paper made two crucial contributions: methodological and analytical. The first one is connected with establishing a tool to monitor implementation of the UNCRPD or more generally to monitor the QoL of

persons with disabilities, which can be calibrated to monitoring purposes of public policies towards population with disabilities, also for cross country comparisons. The second contribution refers to the comparison of the level of QoL between persons with and without disabilities in Poland, with the application of the above-mentioned tool. In this analytical part of the study, we used symptoms and determinants of the QoL in five life domains, indicated by the UNCRPD: material living conditions, productive and main activity, economic security and physical safety, health, leisure and social interactions. Hence, this study presents the possibilities of the tool as an important element of the evidence based policy towards persons with disabilities [56].

The tool presented here allows direct comparisons (in scores) of overall and domain QoL for persons with and without disabilities. The applied MIMIC approach enable simultaneous modelling of symptoms and determinant of QoL in each domain. Not surprisingly, persons without disability experienced higher quality of life as compared population with disabilities. Moreover, population with disabilities is more heterogenous, which is in line with the evidence of other researchers, who separately analysed the situation of persons with a particular type of disability or impairment [26, 27, 28, 57, 58, 59, 60].

The tool developed in this article enables comparisons between population with and without disabilities in the domains covered by the UNCRPD. Also at the European level there is a lack of proper indicators for measuring the QoL for persons with disabilities in comparison to persons without disabilities. For example, Social Scoreboard of European Pillar of Social Rights does not include any indicator covering persons with disabilities (<https://composite-indicators.jrc.ec.europa.eu/social-scoreboard/>). The proposed tool fulfills the gap in this area.

The tool itself has a big potential for comparability on different levels:

- Track changes over time,
- Compare various groups in the same period of time,
- Compare the same group in various countries/regions.

The stability of the EU-SILC database, which was used to calculate the model in this article and its comparability between waves poses the possibility to measure changes over time.[1] After proper calibration, the tool can be applied to compare the quality of life of persons with disabilities to any other group. Finally, the proposed tool could be used to compare QoL for persons with disabilities in different countries, with the ability e.g. to prepare the ranking of countries.

The broad possibilities of the proposed tool in comparing the QoL across different population groups make the developed tool universal, also for public policy purposes. The QoL scores calculated on the basis of the developed tool should be considered as the long-term outcome of the public policy towards persons with disabilities rather than direct output [61]. The monitoring can be successfully implemented in particular periods of time, depending on the timeliness of data collection.

Limitations and further research

In the article we have conducted only the first measurement of the multidimensional QoL in a comparative (persons with vs. without disabilities). To monitor the progress the further measurements are needed, not only for Poland, but also for other European countries. It is possible due to the EU-SILC database used in this paper.

Abbreviations

QoL – Quality of Life

UNCPRD - The UN Convention on the Rights of Persons with Disabilities

EU-SILC - The European Union Statistics on Income and Living Conditions survey

ADL - Activities of Daily Living limitation

MIMIC - Multiple Indicator Multiple Causes model

SD - Standard Deviation,

CV – Coefficient of Variation

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

The dataset analyzed during the current study is available on request via Eurostat following the rules presented on the website, <https://ec.europa.eu/eurostat/web/microdata>

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

IG planned the study and was a major contributor in writing the manuscript. RA analyzed and interpreted the data and was a second contributor in writing the manuscript. JZ planned and executed statistical analysis and wrote methods section. TP planned the statistical analysis. All authors read and approved the final manuscript.

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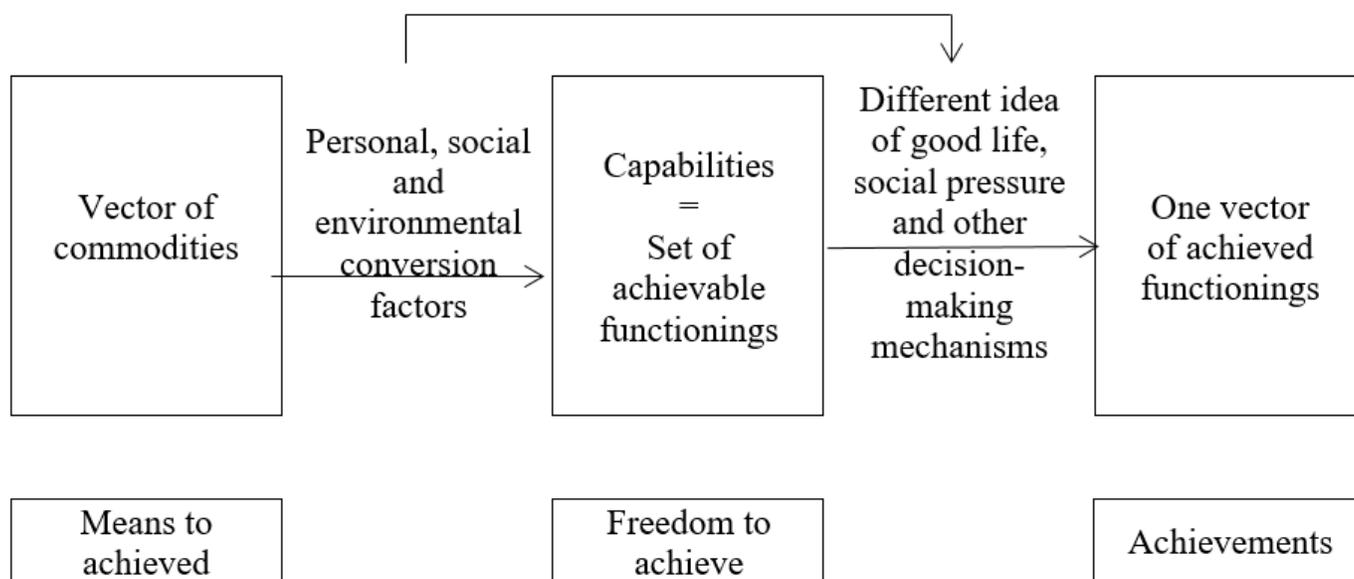
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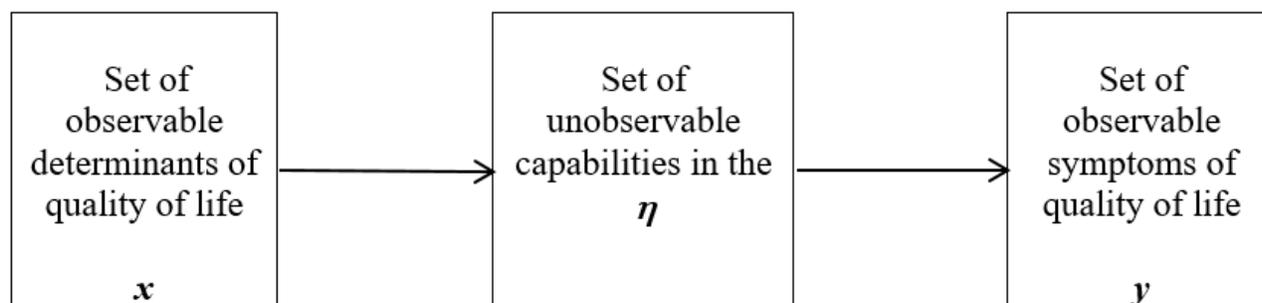
Figures



Source: own study on the basis of [38].

Figure 1

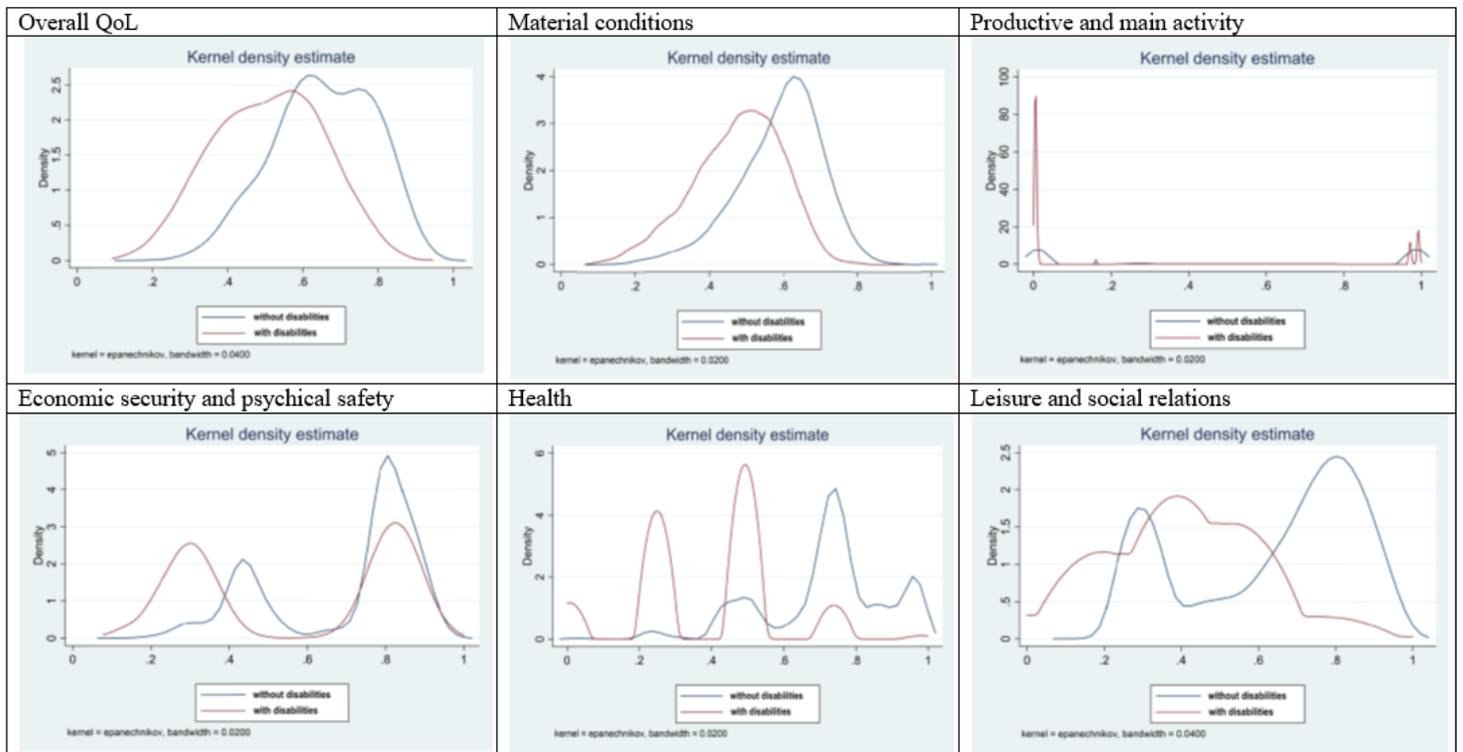
Relationship between commodities, capabilities and functionings in the capability approach



Source: own study.

Figure 2

MIMIC model for quality of life as part of the capability approach.



Source: own calculations.

Figure 3

Density functions of the QoL

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Annex1listofvariables.docx](#)
- [Annex2Modelresults.xlsx](#)