



Social disinvestment and vulnerable groups in Europe in the aftermath of the financial crisis

The case of people with disabilities in Latvia

Taņa Lāce & Ritma Rungule



This project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement No 649447



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This report constitutes deliverable D3.1 for Work Package 3 of the RE-InVEST project.

August 2017

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General contact: info@re-invest.eu

p.a. RE-InVEST
HIVA - Research Institute for Work and Society
Parkstraat 47 box 5300, 3000 LEUVEN, Belgium

For more information Tana.Lace@rsu.lv

Please refer to this publication as follows:

Lāce, T., Rungule, R. (2017), *Social disinvestment and vulnerable groups in Europe in the aftermath of the financial crisis: the case of people with disabilities in Latvia*, Riga: Rigas Stradina Universitate/Leuven: HIVA-KU Leuven.

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This publication is part of the RE-InVEST project, this project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement No 649447.

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Introduction

This report is prepared in the framework of the Europe H2020 project ‘Rebuilding an inclusive, value based Europe of solidarity and trust through social investments’ (RE-InVEST). The RE-InVEST project aims to contribute to a more solidary and inclusive EU, through an inclusive, powerful and effective social investment strategy at EU level. Moreover, the project itself adopts a participative approach that gives voice to vulnerable groups and civil society organisations. The RE-InVEST consortium consists of members of the informal network ‘the Alliances to fight Poverty’, a network of civil society organisations, trade unions, policy makers and academics co-ordinated by the Flemish Christian labour movement *beweging.net*, and committed to a more inclusive Europe. The consortium covers a broad range of European countries, both geographically (12 countries, 13 regions) and in terms of representation of different welfare and labour market traditions. The analyses are carried out by the local partners, who consist of NGOs and/or researchers.

In particular, this report is one of the 13 national reports that make up the qualitative research of the RE-InVEST work package ‘The social damage of the crisis’. This work package focuses on the lived experience of vulnerable people, the impact of the crisis (and crisis-related policy reform) on vulnerable groups as well as the impact of growing inequality and social vulnerability on distrust. Our two key hypothesis in this regard are: 1. that growing distrust and indeed resentment among the population may be attributed to (a rejection of) the neoliberal policies employed by national as well as European elites in recent years; 2. that this integrated diagnosis can build on the idea of the erosion of/disinvestment in (individual and collective) capabilities and basic social rights in the EU. This means that experiences of insecurity, poverty and social degradation need to be re-analysed from those perspectives.

Next to the 13 qualitative case studies, this work package consists of a cross-validation with a report describing trends in selected quantitative indicators that reflect the relation between socio-economic vulnerability, human rights and capabilities. A third element consists of a statistical analysis of the dynamic relationship between vulnerability, shifts in social policies and trust: in which sections of the population has the trust in institutions declined most? Can different patterns between countries be observed, and can they be explained by differences in policy shifts and differences in resilience of civil society? A European synthesis report will combine the main findings from the three types of analyses.

The qualitative research focuses on the experience of vulnerable groups in each of the 12 countries (13 regions) participating in RE-InVEST. Mixed teams of researchers, NGO- and union workers, practitioners and people from vulnerable groups jointly analysed cases where the crisis has impacted on human rights and (individual as well as collective) capabilities.

This Latvian qualitative study focuses on women with disabilities. We would like to thank all participants of our group and the NGO “Zvaigzne” where we were hosted for their responsiveness and hospitality to discuss the situation of people (women) with disabilities and search for solutions in order to fight for their rights and development of their capabilities.

1. The crisis and poverty and social exclusion among people with disabilities

1.1 An overview of the crisis: austerity measures and their effects on poverty and social exclusion in Latvia

In 2008 – 2010 Latvia experienced the hardest economic downside among the EU member states. At the end of 2008 the state stood on the threshold of bankruptcy and it was forced to apply for assistance to international lenders (the European Community, the World Bank, the International Monetary Fund). The government implemented a restrictive fiscal policy from 2008 onwards. Six consolidation packages were adopted from 2009 until 2012 with the purpose of ensuring midterm financial sustainability. Generally, consolidation measures in the amount of 16.6 per cent of GDP were implemented from 2008 until 2011: 6.6 per cent concerned budget revenues and the remainder budget expenditure. Fiscal consolidation in Latvia was among the most severe in Europe. Within the framework of budget adjustments several changes were introduced in tax legislation which took the form of tax increases or expansion of the tax base (increased value added tax rates; abolishment of the reduced tax rate for electricity and natural gas; raised personal income tax; expansion the personal income tax base; decreased non-taxable monthly minimum as the economic situation deteriorated, increased compulsory social security contribution rate for the employed). This had a negative impact on welfare, particularly of the vulnerable segments of the population. The government provided budget adjustments mainly by increasing the employment income tax burden, which was already fairly high in Latvia (Dovladbekova, 2013).

Significant consolidation was carried out on government spending during this period. In the crisis situation significant budgetary cuts have affected education, health care, the welfare sector, transport services. The decrease of expenditures in the public sector has had a direct impact on the accessibility and the scale of many essential social services. Fiscal adjustments provided for notable cuts in funding for the Ministry of Transport, as well as the Ministries of Welfare and Health.

The government attempted to reduce the base of allowances due to the impact of the crisis. For this reason amendments to laws providing for restrictions on entitlements to unemployment benefits, sick pay, maternity, paternity or paternal benefits were adopted and remained until 2014. Adjustments in restrictions on unemployment benefits were also introduced. For example, in 2009–2011 childbirth allowances were cut by almost 35 per cent, child care and paternal benefits by 40 per cent and child care allowance for a child younger than 1 year by almost 38 per cent. The parliament adopted adjustments to the law on pensions on 14 June 2012 providing for the increase of the retirement age from 62 to 65 years by three months per year starting from 2014.

State consolidated general budget spending for 2012 is lower than in 2011 due to the restrictive fiscal policy. Spending on human capital intensive sectors as health care (–6.3 per cent), education and science (–11.2 per cent) and social security was reduced. As a result of the austerity policy the government did not have to make full use of the funds granted within the international aid programme: only 4.4 billion euros or 59 per cent were actually utilised (Dovladbekova, 2013).

The economy of Latvia went into deep recession – during the crisis the GDP decreased by ¼. Although the economy of Latvia has been growing in recent years, GDP is still by 5% lower than before the crisis - at the end of 2007. (Ministry of Economics of the Republic of Latvia, 2015).

Table 1.1 GDP and unemployment indicators, 2008-2014

	2008	2009	2010	2011	2012	2013	2014
Real GDP growth rate (percentage change on previous year)	-3.6	-14.3	-3.8.7	6.2	4.0	3.0	2.4
Unemployment rate (%)	7.7	17.5	19.5	16.2	15.0	11.9	10.8

Source Eurostat

Even after more than a year of recovery (2011), the unemployment rate remained devastatingly high. That is mainly because the recovery was relatively weak, especially given the depth of the severe economic contraction. But the official unemployment rate does not measure the full cost of this recession and weak recovery of Latvia's labour force. If we take into account those who are involuntarily working parttime and those who have given up looking for work, we get peak unemployment/underemployment rates of 30.1 percent in 2010, declining to 21.1 percent in the third quarter of 2011. It also does not include all the people who have left the country in search of employment since the crisis began. It is estimated that the net loss of population in 2009-2011 amounts to as many as 120,000 people, or 10 percent of the labour force (Weisbrot and Ray, 2011).

Fortunately, the situation appears to improve in the latest years. According to the labour force survey data for the period from 2011 to 2015, the number of employed has increased by 45.4 thousand or on average by 9.1 thousand per year. Employment growth is based on economic recovery – since 2010, GDP has increased by a fifth. Employment growth has contributed to reduced unemployment. Over 5 years, the unemployment rate has decreased by almost a half. The unemployment rate fell to 9.6% in 2016, which was by 0.3 percentage points less than in 2015 (Ministry of Economics of the Republic of Latvia, 2016; Central Statistical Bureau of Latvia, 2017).

The decrease of expenditures in the public sector has had a direct impact on the accessibility and scale of many essential social services. During the economic crisis the capacity of local, regional and national authorities was limited as no adequate funding was allocated for policy implementation and all the above authorities experienced significant budget cuts and dismissals, and institutions responsible for the formulation and implementation of these policies have insufficient human resources (Lace, 2012).

The depth of the crisis and budget consolidation measures undertaken by the government that affected every socially relevant sector, had a negative impact on the living standards of the population by significantly increasing the depth of poverty and the number of the people living in poverty.

Table 1.2 Monetary poverty and equality, 2008-2014

	2008	2009	2010	2011	2012	2013	2014
At risk of poverty or social exclusion	34.2	37.9	38.2	40.1	36.2	35.1	32.7
At risk of poverty rate	26.4	20.9	19.0	19.0	19.4	21.2	22.5
Severe material deprivation	19.3	22.1	27.6	31.0	25.6	24.0	19.2
Gini coefficient	37.5	37.5	35.9	35.9	35.7	35.2	35.5
Income quintile share ratio	7.3	7.4	6.8	6.5	6.5	6.3	6.5

Source Eurostat, EU-SILC data

Over the recent years there has been evidence of an improvement in the macroeconomic situation and a gradual recovery of national economy in Latvia in the wake of the 2008-2010 crisis. The stabilisation of the

economic situation has had a certain positive impact on the indicators describing the living standard of the population as well as changes in the key social indicators. Yet at the same time some negative trends have emerged that reveal the depth of the impact the economic crisis has had on certain at poverty and social exclusion risk groups of the population.

“The employment and social situation slowly improves while signs of divergence among and within Member States persist ... The number and proportion of people at-risk-of poverty or social exclusion stabilised overall in both 2013 and 2014. But social developments still point to further divergence across the EU as the scoreboard of key employment and social indicators shows in relation to at-risk-of poverty and inequality developments” (Draft Joint Employment Report 2016, 2015, p.2).

The constantly high income inequality in Latvia testifies to the inequality in the distribution of resources and income among groups of the population as well as the necessity to reconsider the redistribution models of the current social security and taxation policy with the aim of improving the living standards and income of the poorest population.

Accessibility of health care services is one of the topical policy issues in Latvia. In view of the considerable problems that exist in the health care sector and their impact on the living standards and welfare of the population, in 2014 and in 2015 Latvia has received the country specific recommendations concerning improving the cost-effectiveness, quality and accessibility of the healthcare system. Latvia has the highest proportion of the population with unmet needs for medical examination or treatment (because too expensive, too far to travel or waiting list) in EU28 member states. If during the period of 2010 – 2013 this indicator in the EU28 member states fluctuated slightly above 2%, then in Latvia it exceeded 12%. Significant differences from the average EU28 indicators can be seen in all income quintile groups in Latvia, exceeding them 5 times on the average (Eurostat, Unmet needs for medical care).

The dramatically high ratio of the poorest population with unmet needs for medical examination or treatment, even though there are discount payments for health care services or waivers of payment for the poor, shows that households with the lowest income level are more exposed to the risk of not receiving the required medical assistance than others.

The ratio of the public funding for health care in Latvia is about 60% of the total expenditure on health care while in other EU countries it fluctuates from 65% to 85% (Ministry of Health of the Republic of Latvia, 2014). Private spending for health care remains very high. As it has been emphasised in the Public Health Guidelines for 2014-2020, in Latvia the level of direct payments by patients is high in all income groups; however, households with low incomes are more likely to face proportionally high expenses for health care than households with high incomes (Ministry of Health of the Republic of Latvia, 2014).

As it has been concluded in the Public Health Guidelines, the current situation moves the health care system in Latvia even further away from the model that could be called universal due to the insufficient public funding, and the considerable private funding (and the underdeveloped system of voluntary insurance) health care is no longer equally accessible to all inhabitants and it does not have any mechanisms at work that can protect households against excessive losses in cases of diseases that require expensive and long-term treatment/care (University of Latvia, 2014).

The most important causes of the limited accessibility of healthcare services are: lack of funding, lack of human resources, high out of pocket payments, regional disparities in service provision and low solvency of patients. Costs of healthcare services is the main factor restricting the accessibility of healthcare services.

One of the main causes for this problem that is indicated by the health care policy-makers, is the low national budget funding for the sector, which was significantly reduced during the years of crises as was done in other social sectors as well. Already for years the funding as a percentage of GDP allocated for health care has been one of the lowest if not the lowest in Europe and it fluctuates from 3.3% of GDP in 2005 to 3.5% of GDP in 2012 and 3.2% in 2013 while other EU member states allocate 4.5% to 9% of GDP for health care (University of Latvia, 2014).

Alongside with the financial aspects of health care accessibility, another reason for the low accessibility is long waiting lists for medical examinations and treatments. The waiting period for out-patient health care services fluctuates from 20 days to even 680 days in respect of specific services (Ministry of Health of the

Republic of Latvia, 2014). For example, patients diagnosed with cancer have to wait on average 25 working days for treatment (chemotherapy, radiotherapy), for a rheumatologist's consultation patients have to wait up to 86 working days depending on the region (Zilvere, 2014).

1.2 The poverty and social exclusion among people with disabilities

Since the crisis began in 2008 Latvia is characterised by a significant increase in the number of disabled people - an increase in seven years of about 32% among adults and 5% among children. 8.5% of the total Latvian population are persons with disabilities in 2015.

Persons with disabilities are one of the social exclusion risk groups in Latvia whose social exclusion risk is very significantly influenced by employment and education problems as well as accessibility of health care services and the current social protection measures.

The social inclusion of people with disabilities is prevented by the many problems in health care. People with disabilities mentioned rehabilitation activities that have not been performed in due time or not performed at all, due to the social situation that individuals, in particular those who do not work, have limited financial resources for treatment and rehabilitation (Labklājības ministrija, 2014). In addition to the above the disabled also mention problems with reimbursable medication: in the new procedure the state reimburses the cheapest or reference medicine, which causes difficulties and higher costs if this particular medicine is not for sale in pharmacies.

There are also problems in the field of social services. Data at the disposal of the Ministry of Welfare show that currently on average 83% of all social care service recipients receive them at institutions. Alternative social services are received only by 17% of recipients.

Since 2009 and till 2013 the number of persons with disabilities significantly increased in the total number of people living in poverty in the country as well. A person living in poverty is eligible for receiving municipal social assistance benefits. A family (individual) is considered to be poor (needy) if the income per family member has not exceeded EUR 128.06 per month over the previous 3 months. The income threshold is the same for the whole country. The guaranteed minimum income benefit (GMI) level is set as a result of compromise and depends on the available budgetary resources of the municipalities (and partly on the political will to discuss an increase in the GMI level) (in 2016 – EUR 49.80 per person). As it has been emphasised in World Bank research, GMI eligibility is not directly linked to any calculations characterising the poverty threshold or budget standard approach; there is no obligation either to guarantee a minimum level of income or subsistence, or to increase GMI in line with wage rises or cost-of-living increases. Therefore the GMI level and the average GMI benefit amount are inadequate to keep GMI beneficiaries out of poverty. GMI programme recipients with no other income are at high risk of poverty. The other most frequently granted benefits are housing (apartment) support payments, payments for covering health care related costs, children's education and care and free-lunch payments at kindergartens and schools. No doubt, these benefits provide certain support, at the same time one has to admit that benefit amounts in various local governments can differ greatly (Lace, 2015).

Although people with disabilities were not affected by the reduction of the pension amount and social benefits, this particular group also acutely feels the impact of the economic crisis. In most part, this is related to the decline in the accessibility of health care services and rehabilitation services as the number of services paid by the state in the above areas has been significantly reduced.

It has been recognised in the "Guidelines for Implementation of the United Nations Convention on the Rights of Persons with Disabilities in 2014 - 2020" that disabled people are hired by employers with certain reluctance, and according to NGOs representing interests of the disabled, there are no stimulating measures at the national level targeting employers that could promote employment of the disabled on long-term basis, not only on a temporary basis. Although the development of social entrepreneurship is a significant instrument in promoting the employment and social inclusion of social exclusion risk groups, until now no real measures have been taken in Latvia for its development. Likewise the NGOs emphasise environment

accessibility problems that are topical in stimulating employment as well as education and prevent the disabled from active participation in the life of the society (Labklājības ministrija, 2014).

Although already for years many policy planning documents approved by the government have mentioned the implementation of inclusive education for the persons with disabilities in Latvia, until now no significant progress has been observed. Problems of inclusive education include lack of appropriately adapted physical and study infrastructure at schools of general education as well as insufficient training of specialists, etc.

According to State Employment Agency (SEA) the ratio of the disabled in the total number of the registered unemployed has increased - from 5.8% in 2010 to 10.5% at the end of March 2016. According to the data of the SEA, at the end of March, 2015, more than half (52.4%) of the registered unemployed with disabilities were long-term unemployed (Nodarbinātības valsts aģentūra, 2016).

1.3 The Added value of the research

The crisis has also significantly affected research that is why there are comparatively few research studies and publications on the impact of the crisis. To better describe the situation two periods can be distinguished – the pre-crisis period (2006-2007) and the crisis and post-crisis period (currently on-going research). The pre-crisis period is characterised by in-depth research of labour market problems where one of the aspects is social exclusion and long-term unemployment. The given research has also focused on the situation of the disabled in comparison with other at social exclusion - risk groups. The post-crisis research studies are not so extensive and large-scale, and there are no specific research studies on experience of the disabled in overcoming the crisis.

Data of the opinion poll conducted among the population of Latvia at the end of 2013 show that the most significant aspects of life that have changed under the impact of the crisis, are employment and the related growth of unemployment, in particular long-term unemployment, the decline of the living standards of the population and the related growth of poverty, deepening of the gap between the ruling political elite of the society and the general public and related social inequality. In Latvia like in other EU member states the influence of the crisis was most acutely felt by women, children and youths, the unemployed, people with a low level of education and skills unsuitable for the labour market. Shared efforts in overcoming difficulties may operate as a factor that consolidates as well as splits the society. As concerns the impact of the crisis more than half (59%) of the respondents agreed to the statement that the cohesion of the society has decreased as every individual has been more focused on taking care of himself-herself and their families. On the whole, two trends emerge in the lessons gained from the crisis – prudence, caution, frugality in money matters (70%) and reliance only on oneself (60%). Reliance on oneself, a higher degree of individualisation of the society are features of a modern society, however, the individual must have at his/her disposal resource that would help to actively develop and act. If the capability and activity is not strengthened the forecast for the country is stagnation rather than a rapid development (Lāce, Rungule, 2016).

Therefore, the capability approach is important for the continuation of the research on the impact of the crisis on the society of Latvia as it is line with the essence/nature of the identified problems.

Taking into account the situation in the research of the impact of the crisis in Latvia, we have chosen a target group whose experience in overcoming the crisis has not yet been researched. The choice of the NGO for the disabled was also determined by the comparatively high self-organisation level of these organisations in identifying and defending their interests. From this point the “contribution” in the context of Latvia may be also the summary of the experience of people and organisations for the disabled.

2. The participatory research approach

2.1 Participatory Action Human Rights and Capability Approach

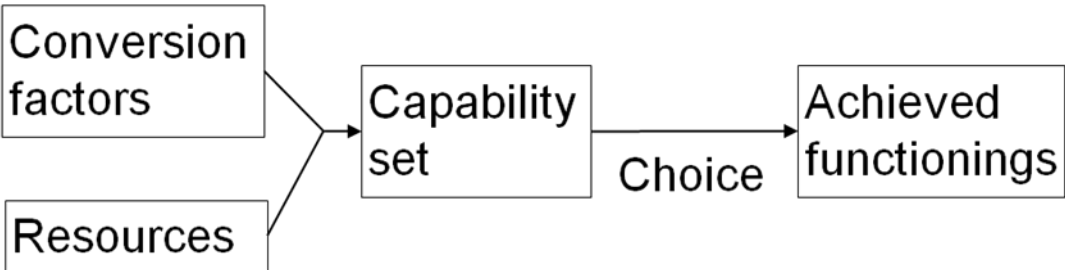
RE-InVEST aims at investigating the philosophical, institutional and empirical foundations of an inclusive Europe of solidarity and trust. To this end it draws on capability and human rights based participatory approaches. Human rights form a common European basis of values and describe at the same time core elements of what constitutes well-being and a good life. Further, human rights are transformative by empowering people.

Human rights are the basic rights and freedoms that belong to everyone. International law, including treaties, contain the provisions which give human rights legal effect. Ideas about human rights have evolved over many centuries and gained strong support after World War II when the United Nations adopted the 1948 Universal Declaration of Human Rights - which set out for the first time the human rights and fundamental freedoms shared by all human beings without discrimination of any kind.

Human Rights are universally agreed basic standards that aim to ensure that every person is treated with dignity and respect; they are interdependent and indivisible, they belong to all people without discrimination. Usually set out in law, through international or regional treaties, or national legislation, they form a legal statement of universally accepted principles of how the state should treat its citizens and other people living within its jurisdiction. Human Rights include Civil and Political Rights, such as the right to life, the right to a fair trial and the right not to be subjected to torture; and Economic, Social and Cultural Rights, such as the right to work, to join a trade union, to health, to education, and to an adequate standard of living.

Specific groups are protected in specific treaties such as women, children, and people with disabilities, minorities, and migrants. For vulnerable people the usage of a rights-terminology has proven to change their perspective by making them aware of their rights and the ways in which their current situation compromises these rights.

Figure 2.1 Resources, conversion factors, capability set and achieved functionings



The capability approach as developed by Sen (1999) and Nussbaum (2011) defines a person’s well-being in terms of the beings and doings (the functionings) a person achieves and her capability to choose among different combinations of such functionings. For leading a life one values and has reason to value resources and conversion factors are preconditions (Figure 2.1). Resources refer to the material conditions of a person: her income, the goods and services she disposes of. Conversion factors help her converting resources into doing and being well. There are personal conversion factors such as skills and bodily features, social conversion factors such as social norms and social institutions and environmental conversion factors such as

climate and geography. In the end both the achieved functionings as well as the freedom to choose a life one values matters.

For assessing the capabilities of vulnerable people RE-InVEST aims at giving them a voice. Their participation is fostered by relying on participatory action research that directly results in policy recommendations. Participatory action research views participants as co-researchers who have special knowledge about their own situation. Hence they are not only asked or interviewed on their views but take part in research by engaging in, examining, interpreting, and reflecting on their own social world, shaping their sense of identity.

It is a circle of knowledge generation that emerges from this method and includes the steps of knowledge production and sharing, empowerment by participation, newly generated knowledge and action that builds upon this knowledge (Figure 2.2). Crucial for this kind of knowledge generation is the “merging” or “crossing of knowledge” that comes from three parts: scientific knowledge as gained by researchers; knowledge which the poor and excluded have, from their first-hand experience, of the twin realities of poverty and the surrounding world which imposes it on them; and the knowledge of those who work among and with these victims in places of poverty and social exclusion (Figure 2.2).

Figure 2.2 Merging of Knowledge



These are the core elements of the Participatory Action Human Rights and Capability Approach (PAHRCA) developed in RE-InVEST. PAHRCA entails seven steps (Toolkit, 44-45): 1. Identify and meet partner NGO/gatekeeper, 2. Preliminary ‘meet ups’ (for trust building if necessary), 3. First meeting with participants – trust building, 4. Developmental: implement developmental human rights & capability approach, 5. Inquiry/data gathering, 6. Identifying patterns (key issues and themes of concern to the group) and 7. Undertake action/outcome using one or combination of approaches.

2.2 The making and involving of a group of participants with experiential knowledge

Application of CA in respect of the disabled

The capability approach (CA) cannot be applied in respect of people with disabilities without taking into consideration the specific character of this particular target group. If we discuss capability in the meaning used by Sen as the possibilities of functioning that correspond to the individual’s imagination, then it must be recognised that people with disabilities have certain health-related limited functioning. Capability of the disabled can be discussed only within the frame of these limitations. The disabled are more directly forced to take into account their possibilities of physical functioning and they also need the support of the community in expanding these possibilities. Individuals with disabilities are forced to be more acutely aware of their capabilities, the constraints imposed upon them and ways to overcome them. This ‘lived experience’ is precisely why, in our opinion 1) this group is very well suited as participants in research of social restrictions of capability, and 2) attention should be paid not only to identified changes that have taken place in the life

of the disabled during the crisis, but also to the experience of this target group in expanding and consolidating their capability. Furthermore, it can be assumed that this daily encounter with health-related capability constraints supports the ability to problematise and verbally reflect on it. For capability is easier to describe in theoretical terms than to investigate in practice: what people do and what they are (formulation by Sen) seem to be self-explanatory and most people are not used to reflect on this and talk about it.

Selection of NGO's and participants

For our research we selected and contacted two NGO's. Our "large" cooperation partner is the Latvian people with special needs co-operation organisation "SUSTENTO". It brings together 40 different organisations, whose members are more than 50 000 people with disabilities or chronic illnesses. SUSTENTO is a member organisation of the European Disability Forum (EDF), which brings together more than 80 million people with disabilities in Europe. Our "small" cooperation partner is the organisation "Zvaigzne", an organisation for women with disabilities located in Jelgava, a city not far from Latvia's capital Riga.

Participants were selected following two principles. We asked our "large" cooperation partner – the organisation SUSTENTO – to recommend individuals with disabilities for in-depth interviews who could not only talk about difficulties and problems but who could also share their experience in overcoming these difficulties. Interviews and group discussions were also undertaken with the participants of our direct "small" cooperation partner – the organisation "Zvaigzne". From September 2015 till April 2016 we organised 5 group sessions. These were complemented with individual sessions (in-depth interviews). The total number of participants being involved was 16. From these 16, 10 participants were present during all sessions. Since all participants were members of the organisation "Zvaigzne", the sessions resulted in a productive work together in a friendly atmosphere.

Formulation of interview and data analysis guidelines

As the way people think in their daily life is not as theoretically nuanced as the theoretical framework of the research, some theoretical concepts had to be simplified to bring them closer to daily life. We described individual capability as what is inherent in the individual. In the case of the disabled individuals usually judge about their capability within the frame of their health- incurred constraints, and in response to questions – do you live the life you want to live and what is missing to be able to life that way? – they indicate actual issues related to the accessibility of environment or health improvement. We looked at collective capability by looking into the capacity of organisations. It is described by testimonies of individuals about what they gain by participating in an organisation as well as by the issues addressed by organisations. Human rights are rights guaranteed by the society or the state. In the case of the disabled we pay attention to their "right" to universal human rights, services and preferential treatments that are guaranteed for this group only.

When interviews are structured in the context of the respondent's life story, the focus is on the events in the respondent' life, his/her options and choices, restrictions and ways of overcoming them. The issue of data analysis methodology is about the way how theories of Sen and Nussbaum are related to the stories of respondents. From the theoretical point of view there are three options: 1) theoretical approaches and their classifications dominate, the material of interviews is analysed and classified according to the theoretical setup; 2) theoretical approaches and the material of interviews are treated as equal in value – as discussion or argumentation from the one party and from the other party; 3) the material of interviews is considered to be primary and theoretical approaches are applied in its interpretation. With due respect to the theories of Sen and Nussbaum the third approach prevailed in our research as we assumed that then there would be fewer possibilities of incorrect interpretation and this approach would be easier to understand for our cooperation partners.

3. Living with disability

As an illustration of our data we chose two in-depth interviews with women who had different types of disability, different experience of disability and belonged to a different age groups Anna has a rare disease and restrictions caused by here disability are related to motoric disorders. Rita was given the disability status two years ago when she underwent an oncological operation, constraints caused by her disability are not visible and as such she has encountered a discriminatory attitude.

3.1 Anna's story

(46 years old, a rare disease)

Anna was diagnosed with a rare disease during her teens; however, a clear diagnosis that it was a rare and progressing disease with no cure available was given only when she attained majority. Anna has the status of a disabled person since the age of 18.

'At the time Mother said, wishing me well, that I should apply for the disability status she says – we will have money... But that is horrible! I was only 18, it was crazy, I thought: how can I agree to receive some certificate only to get some money. Well, certainly, she managed to convince me; I agreed and applied for it. Certainly, it is practical, how I perceive all this differently but at the time it seemed to me – that is the end, I am given a life sentence. The disability status for my lifetime!'

Anna has secondary vocational and higher education. She is a marketing specialist. However, as the disease progressed, the university period was particularly difficult, not because of the studies but because classes were held on the 5th or 6th floor in buildings with no elevators. Anna was helped by her closest friends; she had concealed her diseases from other fellow students. After graduation from the university she worked in a shop but as she found it increasingly more difficult to walk, she stopped working. It is not the case that Anna cannot have a salaried job, she just needs special conditions.

'In my case it is the legs, the walking, I can work with my hands, I can write. I only need a special schedule – something like part-time. I need rest, it would be fine if there was some room for recreation, some couch, so that I do not have to be in that sitting position all the time, so that I could lie down for a moment. If I could work for some three hours and then have an hour of rest.'

Anna has experienced also the situation when she was not hired because, in her view, demands set for employers when they employ people with disabilities are too strict and difficult to comply with. That is why employers are reluctant to employ individuals with disabilities. Anna believes that the law should be made more employer-friendly so that they are not afraid to employ the disabled.

'I wanted to have a job but the employers did not want to have an official employment contract. They said that the disabled were much protected. The law provides such protection for these people that the employer cannot get rid of the person even if the person cannot cope with his/her work duties. Very considerable responsibility for this person, an awful lot of documents and reports, in actual fact, employers are not at all interested.'

Anna describes how at the beginning she had resisted the wheelchair and had not wanted to accept the new identity, about her depression and desire to isolate herself from other people, what she had experienced. Her support is her husband who is also her assistant. Anna has been married for 15 years. The fact that her husband is also her assistant, makes her life much easier, her possibilities have increased while restrictions have declined.

'It is a huge relief that we have the assistants now. That the person who provides assistance can also get remuneration because in reality it is a difficult daily job. For example, if my husband went to work, I would have to hire a person who should be paid because these services are expensive. It really helps that the person who helps can be employed; it may not be the husband but somebody else.'

Anna's pension and the assistant's salary her husband receives constitute their family income; it can cover all the necessary expenses and if one is economical with money they can even save enough for brief trips.

'I have my pension. As I have in-service time it is not the minimum pension and the assistant's salary also stays in the family. If we put it together, we can pay for all services – the apartment, electricity, the internet, for food as well. If we do a bit of planning and save we can also travel somewhere. If we do everything in due time, half- a year in advance, we can get the ticket at a good price ...'

Anna's family had not felt the period of crisis in any particular way as they have to be economical all the time. Benefits were not reduced, so they did not experience any shortfall in incomes. They single out the drop in prices as a feature of the crisis period.

'I remember that everybody spoke about that crisis. However, if you are used to shifting for yourself if the rhythm of your life makes you see to it that you have enough for everything, then we did not feel anything. Perhaps it was more experienced by those who had more. Before the crisis we had those blown – up prices, they declined.'

When Anna describes opportunities in her life she emphasises that she has had to fight for them all the time and to protect her rights. She says that many people lack the determination to defend themselves and to demand something for themselves. Bureaucratic obstacles and the number of documents that must be filed prevent people from demanding services that are due to them. Anna recognises that knowledge, tenacity and determination are needed to defend one's rights.

'For example, about those assistants. The person must do a lot prior to that. However, these people are not encouraged, there are attempts to dissuade them, they are told – you will find it difficult, you will have to file documents. I am told this, for example – fine, I gladly do it and file the documents. However, people do not want to do it. To fight for yourself you must be very educated in the given field, you must know what you are entitled to and you have to go and to demand.'

Anna describes various daily situations encountered by a person in a wheelchair and what she has learnt to cope with – to take the public transport, to travel abroad, to participate in summer camps, etc.

'Yes, and I go by that trolleybus! And there are people around! It is important to be among people, that you are part of them. It is important to be together with others, not to sit in your own separate cage.'

Another significant aspect of Anna's story is related to the acceptance of her disease and the development of one's identity. Anna had divided her life and also people into the "healthy people" and "people in wheelchairs", gradually this division was overcome and the difference - "the wheelchair" – does not seem so important any more. However, in Latvia many people are still plagued by stereotypes: the healthy find it difficult to accept the disabled while people with visible disabilities keep away from others, try not to leave their homes. That is why people in wheelchairs are so seldomly seen in the streets and on the public transport.

'In my case, I spent the part of my life as a healthy person without any contact with people who had such problems. In a way I tried to dissociate myself because I did not want to belong to people in wheelchairs. I divided people in my mind into the healthy and those in wheelchairs. I wanted to think that I was not like them but that was self-deception. Some sort of psychological delusion. Later at the camp and in the organisation I met more and more of such people.'

Anna recognises that accessibility for the disabled has improved after Latvia joined the European Union.

'It seems to me the situation improved after we joined the European Union, because we can take over much more from them. Because it is required by regulations and requirements, accessibility improved.'

Family support and adapted environment are the key factors that expand the functioning options of the disabled, subsequently also their capability. Anna recognises that in Riga people who have disability status (group I) have a good life in comparison with other cities and towns in Latvia.

However, the person cannot do anything alone, family support, an adapted environment are also needed ... Yes, by the way, Riga is the best place to live for people with group I disability – we have all public transport free of charge, in addition we have the transport money, care if the pension is not high, if the person is eligible for the status of a poor person, we have compensation for the utilities. Everything is better in Riga ...'

In her future plans Anna has studies in personnel management at a college that are organised by the Social Integration Agency; she has also thought about getting a driver's licence. However, the greatest hope Anna has is that medication will be invented for her disease.

3.2 Rita's story

(52 years old, group I disability since 2014)

Rita started to work as a cook at a kindergarten already during the soviet period. She continued to work at the same place after the restoration of independent statehood when the kindergarten was turned into an orphanage. The salary was not high, work was difficult; however, Rita emphasises also several positive factors that had made her stay in one place of work for such a long time: she could easily reconcile her work and family life, the social guarantees and colleagues with whom she worked.

The work place was close to my home, the work schedule was convenient – I worked for two days and then had two days off. Another good thing was that it was a public institution – the taxes were paid, it was possible to have a sick leave, to have the annual leave [...], double payment if I worked during national holidays. I was used to it, the work team was also good – we lived like a large family.'

Rita married her husband in 1981; the family has three children, now adults. When their daughter went to England, the grandson stayed with the grandparents for some time but then their daughter took her son with her to live in England. One of the children got “in huge problems”, that Rita does not want to discuss in detail and that is why they have been bringing up their granddaughter from the age of 4 months, at present she is 12 years old. Rita and her husband are her official guardians. Rita has a total of four grandchildren, and she is very proud of her grandson who lives in England.

He is an excellent pupil at school, the best in almost the whole school, better than the English children, thus he may have the chance of getting higher education in England free of charge.'

The family lives in a four room apartment. When they both worked and her husband had good earnings, the payment for the family did not seem high; they were well-to-do, bought good clothes and attended cultural events. Now the income has declined, she stresses that the apartment “costs abnormally much – it is at least 250 Euros in winter when the heating is on” (Rita's pension is 299 Euros). The automobile was bought on credit, however, it had gotten into a traffic accident, the insurance did not cover all the repair-related costs and thus now they use an old second hand car.

The material situation of the family deteriorated concurrently with the crisis because the scale of construction shrank. Rita's husband is a professional driver with high qualifications and considerable experience – “he has got all the possible categories, he can drive all vehicles”. At the beginning of the crisis the construction company where her husband worked on the cement haulage vehicle went bankrupt. It was difficult to find a new stable job, her husband mostly had seasonal jobs in summer and “sat at home without any wages” in winter. At present her husband has an official permanent job – since September he has been working in a repair company for the railway but Rita is concerned about the news in the mass media that there might be

staff cuts at the end of the year. Rita explains it by sanctions against Russia that have resulted in the decline of transport flows.

The next blow came when Rita lost her job due to the liquidation of the kindergarten. It was at the end of 2013 and she was in 2014 already in the status of an unemployed. Rita emphasises that employees were made redundant in compliance with the procedure prescribed by law; she received the severance pay in the amount of three monthly wages and registered with the Employment State Agency to receive the unemployment benefit and to look for another job.

‘Everybody was laid off “according to the law” – everybody got an advance notice, everybody was given a document to sign a month in advance. The law provided that in the event of liquidation employees with a long in-service time were to receive three monthly salaries.’

Rita started to experience health problems about 4-5 years ago. After she had lost her job, Rita decided to undergo a thorough medical examination and the required tests. The ultrasonographic examination revealed that there was suspicion of a tumour and Rita was referred to a specialist urologist – oncologist in Riga. Before the operation Rita had to undergo a whole range of examinations and tests. It was important to have them as soon as possible which is why most often she had to choose services for payment. Rita recognises that she had not counted how much it had cost her; she says that the three wages that she had got as the severance pay had come in handy. Rita did not have to pay for the operation, only for the time she had spent in hospital – about a month.

‘Then we started to look for places where to get the required examinations. Other people helped, I got on the waiting list in several places – wherever I could get first. I paid for consultations. I had magnetic resonance in Riga Hospital No.1; it was the most expensive examination, about 140 Euros.’

Since July 2014, Rita has disability status (group I). She has also been given a long list with benefits and reliefs that individuals with disability status group I are entitled to. Rita has read it but she says that it is not clear, it is difficult to understand, and what is important has not been separated from the irrelevant. In her still short-term experience of disability she has observed and felt that the disabled are not equal in rights, that there is more preferential treatment for people in wheelchairs – parking lots, toilets, airplanes, assistants... Rita’s disability is not visible; that is why she has to experience unpleasant moments, for example: she was denied service at the counter intended for the disabled.

‘Last time when I went to have the ultrasonographic examination I was harshly reprimanded that I was standing at the counter for the disabled. I said I have Group I disability and got the answer that it was for those in wheelchairs that I had to get into the regular queue.’

Rita has been unpleasantly surprised when she found out that according to the Traffic rules, parking lots for the disabled with the special sign can not be used by any person with disability, that they are intended only for people with motoric disorders and impaired eyesight.

‘At the time when I could neither sit nor stand, I as a person with Group I disability could not park my car in the parking lot for the disabled. Can you imagine what these laws are like? It is allowed only for those with motoric disorders or impaired eyesight and it is forbidden for the rest, if it is not respected – then you pay the large fine like everybody else. You must not park there! Nerdist!’

Rita had gone to England together with her friend to visit her daughter’s family. Rita needs assistance at the airport and in the airplane as she cannot handle anything heavy and that is why she needed her friend’s assistance.

‘I read the airport rules; there are many benefits for people in wheelchairs. Very little is meant for people like me. I would need help to pick up the suitcase; I need a person to help me get on the airplane as those who see you off are not allowed to accompany you.’

According to Rita's observations, in England there is a much more benevolent attitude to the disabled. She could see a lot, for example: she had been allowed to use the Ferris wheel free of charge while her companion had paid half the price for the ticket. Rita has already examined the accessibility of several museums in Latvia and her conclusion is that rules are different in each place.

'[In Ventspils] I did not have to pay anything anywhere, we were pleasantly surprised. We do not have many such places – the Rundāle museum gives two free tickets, the Open Air Museum as well. I do not know any other places of the kind. In Tukums free tickets are given to residents of Tukums, In Cēsis one free ticket is given to the disabled person, the accompanying person does not get any free ticket. Everywhere I go – I find it out beforehand because the system is different in each place.'

Rita is surprised that in England she was better treated as a disabled person than in Latvia because here she has to know what she is entitled to and she has to fight to get these reliefs.

'Here, in Latvia, where I have worked for many years, I have three children, bring up the fourth child I am not entitled to anything, I have to fight for everything. In a foreign country I get a discount for nothing, an absolutely different attitude.'

Rita tries to receive all benefits that individuals with Group I disability are entitled to not because of principle but due to necessity. Her disease and the crisis has changed her life to a considerable degree – she has had to restrict herself, she does not attend concerts, does not do her shopping in good shops. Her youngest daughter who lives in Latvia, was a “stay at home” mother with a small child, Rita had to buy food not only for her own family but also for her daughter's family.

Rita does not think that the crisis is over – it is maintained only by newspapers. People around her have suffered from the crisis – they have either lost their jobs or their wages have been cut. Rita's friend lost her job during the crisis; she was evicted together with her two children as she could not pay the rent. She lived together with her son (18 years old) in the shed of Rita's gardening plot, while her daughter lived with Rita. When the boy graduated from school he went to England where Rita's daughter helped him to find a job. At present Rita's friend and her daughter live in a small flat, earn very little, however, her son helps her by sending money from England. Rita has her two sisters and her daughter living in different places in England. Rita believes that her daughter will stay there, her family has settled down there and they will not return to Latvia.

Rita's brief disability experience has strengthened her conviction that everybody lies in Latvia. She does not believe that in Latvia the average salary is about 800 Euros because she does not know a single person who receives such a salary. Likewise she is convinced that what is written about the disabled is one thing while the reality is just the opposite: *“While you read about discounts for the disabled it seems that everything is really fine but when you find yourself in such a situation, you see that nothing is like the description.”*

4. Analysis: women with disability in crisis

What am I able to do and be? This basic question summarises the capability and human rights approach. In its naivety it opens a whole world of feelings, experiences, wishes and potentialities. It opens a window on how people want to organise their lives, their possibility to raise their voice, to build their future. At the same time it accentuates the importance of the societal context. It focuses on the obstacles, the hurdles and the possibilities society creates.

4.1 Impact of the crisis

It is possible to speak about the impact of the crisis from several points of view: as the experience of one's personal crisis or in a wider sense – as the impact of the crisis on the family and the closest relatives and friends. People with disabilities have yet another significant aspect of the crisis – its impact on the accessibility of medical services. However, it should be discussed on a more extensive scale – as the crisis in medicine as persisting insufficient funding for this particular sector has a particularly adverse effect on people with disabilities.

4.1.1 Why some did not notice the crisis

People with disabilities have diverse experiences with the crisis. Part of them has not felt the social-economic crisis in their daily life. This is related to their low income level and the skills that they have developed in the course of their life to make both ends meet, to make do with what they have. The discussion has revealed the case of a young woman who has to survive on 86 Euros per month.

'... A woman with Group II disability since childhood, her child is four years old and attends a kindergarten. She receives a pension of 75 Euros, a child allowance of 11 Euros, a total of 86 Euros. The question is – how to survive? She has to pay 40 Euros per month for a room in the social house, leaving 46 Euros per month for other expenses.'

During the crisis the benefits were not reduced, therefore the income level for all those who do not work did not decline. They did not notice the impact of the crisis because in actual fact, they spend their daily life in a crisis situation. Anna pointed out that she has to live in a certain austerity regime all the time, to follow her expenses and to calculate what she can afford and what she cannot afford.

'I remember that everybody spoke about that crisis. However, if you are used to shifting for yourself if the rhythm of your life makes you see to it that you have enough for everything, then we did not feel anything. Perhaps it was more experienced by those who had more.'

As concerns people with disabilities there are more grounds to speak of an indirect impact of the crisis that has manifested itself in such aspects as the decrease of the total family income and the accessibility of medical services.

4.1.2 Decrease of the family income

During the crisis the family income level rapidly fell if any of the family members lost his/her employment. It was particularly acutely felt by families where the main breadwinner lost a well-paid job. Such a situation was described by one of the participant, whose husband had worked in construction before the crisis struck.

During the crisis he lost his stable employment. Unfortunately, this coincided with the loss of work by Rita herself and her illness. The fall of the family income level necessitated changes in the usual lifestyle and caused difficulties in covering housing costs.

Another aspect of the fall of the income level is the so-called “wage cut” – the reduction of salaries for employees of public institutions as an austerity measure to overcome the crisis. It was described by the mother of Beta (a 16 years old girl with the Down syndrome). When the crisis started her salary was reduced by 100 Euros. She emphasises that that will restrict her possibilities to invest in Beta’s development as she would have to reduce the scale of activities that Beta has been engaged in until now. In order to compensate for this shortfall, Beta’s mother applied to the Social Service of the Riga City Council for the special care benefit and received it. She had applied for this benefit earlier, however, she had never received as, in her own words, she had not been sufficiently persuasive in justifying the need for this benefit.

‘Yes, 100 Euros were cut off at one go and then I said that I would not have anything to invest in her development. I believe that this benefit is not for me as her mother but for her development; if she has it I give it to her.’

Beta’s mother has had to solve various problems in life therefore she does not perceive her wage cut as a big problem, she only points out that the reduced amount has not been “put back”, that a comparatively large amount of money was taken away in one go, while the wage rise is very slow, concurrently with the rise in the minimum salary. Beta’s mother also says that the decrease in incomes was the cause of emigration for many people, yet she has never considered taking such a step.

‘At the beginning when the salary was reduced it was quite tough. Many people panicked because they did not know how to survive and what to do. I have never had any thought of leaving the country. I do not want to start everything from a scratch, nor do I want to leave my relatives.’

During the discussions participants have indicated that the decline in incomes was experienced also by those pensioners who worked during the crisis because the government had taken the decision that working pensioners would receive only 50% of their salaries. Many pensioners due to that decision were forced to leave their jobs.

The decline of the family income level has had its impact on generational solidarity and mutual assistance that is particularly important for people with disabilities. To compensate for the reduced income people had to seek additional sources of income that, in its turn, affected the time devoted to their family members. For example, during the discussion one of the women pointed out that she had been denied assistance, mentioning her children who should help her, however, children are busy at work.

‘For example, wherever I go I am told - you have two children; you are not a single person. Children do not live together with me and they are employed in such jobs that they can come to me only at the end of the week.’

Likewise the families with children have found it more difficult to cover all their expenses during the crisis. One of the participant indicated during the interview that during the crisis she had helped her daughter’s family by buying food for them.

‘Children themselves work in two jobs, it is necessary to be able to send two children to school, to enable one of the children to participate in a dancing group and the other to sing (in a choir). Everything must be paid for. For medication, food and the rest.’

On the whole, people with disabilities can tell more about the impact of the crisis on their family as well as their relatives and friends rather than about their own experience of the crisis and it gives grounds to conclude that the crisis has affected them more indirectly, yet had a more profound impact on them than they themselves perceive.

4.1.3 Crisis in health care

Health and quality of life of people with disabilities are more dependent on the accessibility of health care services than for other groups of the population. Therefore they pay more attention to this particular issue than to the impact of the social economic crisis on the income level and welfare.

4.1.3.1 Queues for services

The national budget pays for certain medical services, however, the demand is higher than the allocated funding and it results in the appearance of queues for services. If the patient wants to receive the service quicker, he can do it for payment at medical institutions. Not all inhabitants can afford it and many people do not understand this system. During the discussion husband who accompanied his wife in a wheelchair told us the following:

I have a cataract in my eye, it is not a very serious operation, just 2-3 minutes but there is a long queue – I have to wait for two years. I am a former Chernobyl liquidator with Group II disability, and I asked if I could not have the operation sooner. No, I was told, I had to wait in the queue like the rest. It is two years; however, if I can pay 700 [Euros] plus something at once, then I can have the operation at once. So it means that – the operation lasts 2-3 minutes, people just go one after another ... Where does the money go? That money goes into the same health cash desk; couldn't they speed up the queue? I do not know what place we live in, if we can sink any deeper! All people over 60 have this disease. But two years!'

Rita also talks about the queues when she was diagnosed with an oncological problem and thus various urgent examinations had to be done. Before her disease Rita hadn't had much experience with the procedure for receiving medical services and she did not know that alongside the queue for services there was another queue – as she called it “the payment queue” where these services could be received sooner, however, for payment.

I was sent also for ultrasonography. It was not possible to get in all places as there was a long waiting list. At the time I did not know that ultrasonography could be received also for payment, for example, for 20 Lats without the long wait in the queue. There was no information anywhere about it ...'

Inhabitants do not have the feeling of security that they will get to the doctor when they will need it. For example, in order to get the necessary examination sooner people with disability have to sign up in several queues. It is possible that other people follow the same practice and it creates an incorrect impression about the number of people on the waiting lists. Participants also mentioned that it was not possible to register for the visit to the doctor over the phone as it was difficult to get a connection with the hospital – the telephone lines were busy, and thus people often travel to Riga only to register for the visit to the doctor.

'After that I had to go to the oncologist to ascertain the progress of my recovery. It is very difficult to get a connection with the Hospital in Riga. I have a relative in Riga; she went herself there and registered me for the visit. Other people from Jelgava go to Riga just to register for the visit. I was lucky because my relative registered me for the visit.'

The described situation applies to all inhabitants and it was recognised also during the discussion.

I want to say that the situation with medicine is not much better for ordinary people (people with no disabilities). They are as at-risk as we are.'

4.1.3.2 Cannot afford services for payment

In Latvia people with disabilities are aware that medical and rehabilitation services for payment are not accessible for them.

It is vividly revealed by the story of a woman participating in the discussion who was an assistant to another woman who had left Latvia 10 years ago and now had returned to undergo rehabilitation after a stroke and she could pay for it.

'A lady returned from England, she had had a stroke, she was paralysed down her left side – the arm, the leg, and the eyesight was also impaired. She had been a resident of my native town and had moved to England 10 years ago. She had had an operation there and a stroke. I agreed [to be her assistant]. We went to Jaunķemeri and stayed there for almost a

month. Yes, we – the disabled and the pensioners – cannot afford it. She had to pay 39 Euros per day for the treatment and 18 [Euros per day] to me. She paid for everything. She really wanted me to go with her to England, I said that I could not go; I had my own home, my family, three children. I wanted to say – it is not possible for us, just make a calculation – we stayed there from December 6 until January 7, she paid for everything 39+18 Euros per day.'

Participants of the group have also emphasised that stricter restrictions have been introduced in hospitals concerning services provided by one or another hospital. The range of services has been shrinking. Thus, if earlier operations or examinations could be performed by the local hospital, now patients have to go to Riga. It causes additional difficulties for the disabled in terms of time and expenses. Participants also admitted that the range and scale of health care services accessible free of charge have also shrunk. There are increasingly more services for payment.

Payment for medication constitutes a significant part of expenses for people with disabilities. Thus reimbursement for medication is a theme that worries people with disabilities of the retirement age. Although the total number of reimbursable medicinal products is high, still in the case of the disease of each specific person it turns out that medicinal products that the said person specifically needs are not reimbursable.

'We – the disabled pensioners – pay for medicinal products, it is not reimbursed and our pensions are below the subsistence minimum, the medicinal products are not reimbursed because we do not work, we do not pay the taxes. I spend 100 Euros per month on medicinal products, I have Group I disability.'

'When we met Parliament members, they just recited statistics, but then I ... told them that life was different from statistics, that those medicinal products were not reimbursed ...'

According to the disabled participating in discussions, in reality the reimbursable medicinal products are quite expensive. Participants of the discussion point out that they must include in these expenses a whole set of payments from their already modest budget: the visit to the family doctor (GP) to receive the prescription for the reimbursable medicinal products, payments at the pharmacy for medication (the state reimburses the cheapest medicinal products for specific diagnoses in the amount of 50%, 75% or 100% of the price), and thus they mostly have to be ready for expenditures. However, the cheapest option may not be suitable for everybody and then the difference must be paid by the patients themselves. At the pharmacies 0.71 Euro cents must be paid for every prescription of reimbursable medicinal products. The disabled are also concerned about the constant growth of prices of medicinal products.

Another problem encountered by people with disabilities is that physicians do not provide sufficient explanation concerning side effects of the prescribed medication and restrictions in the use of the specific medication. Physicians also prescribe medicinal products where the user's leaflets clearly state that the given medication must not be used by patients with the specific diagnosis. This also incurs additional expenses for people with disabilities as they have to buy new medication.

Accessibility of rehabilitation services has also declined (the part that is financed by the state or local governments). Participants of the discussion indicate that social assistance services pay for part of rehabilitation services; however, there is a waiting list for these services, they are accessibly less frequently than before the crisis and a smaller scale of services are paid for.

During interviews and discussions people with disabilities recognise that as patients they have experienced a humiliating attitude in hospitals. Physicians are reluctant to recognise mistakes in treatment or incorrect diagnoses. However, it is very important for the disabled as it influences their treatment options as well as services and benefits they are entitled to.

4.2 Capabilities of women with disabilities

People with disability must take into account certain limited functioning also in respect of their capability; they describe their capability within the frame of this limited functioning. First they have to accept their

disability and the limited capability it causes, and then they have to develop their capability to be able to live as they wish. It is well demonstrated by stories of respondents. The interviewed women differ by the type and length of disability, i.e., how long they have had to live with health disorders: Beta (16 years old) was born with the Down syndrome, her story was told by her mother, Anna (46 years old) was given the disability group at the age of 18 while Rita (52 years old) received her disability group two years ago as a result of an oncological operation.

Anna spoke of her resistance and reluctance to accept the status of disabled and to get into the wheelchair and how she had coped with it (see Anna's story). Rita indicated that prior to getting her disability group she had had an absolutely different notion about the support that was available for the disabled and this opinion changed when she herself became disabled and found out that the reality was much worse than her initial views about it (see Rita's story).

In this chapter we will focus on those social limitations that were discussed by the respondents. It covers a quite extensive range of social factors that prevent respondents from living the life they would like to have. It is important to note that they have experienced, identified and tried to overcome these limitations. Stories related by respondents can be classified in three groups: 1) their own stereotypes and stereotypes prevailing in the society about people with disability; 2) fighting for rights; 3) the feeling of unfairness and inequality.

4.2.1 Their own stereotypes and stereotypes prevailing in the society about people with disability

Beta's mother has spoken about the fact that many parents whose child has a visible disability try to protect the child and keep their child away from the public; however, it is damaging for the child's development, the child is incapable of leading an independent life as the child is used to mother's care.

Well, it is also because of the prejudices in the society. However, we ourselves are also to be blamed for that – we do not take them out into the public. A person is afraid of what he/she does not know ... [...] I was alone with Beta, I would also keep away, nobody could approach me anymore, I would want only to be left alone... I know people who sit at home with their child; the child neither goes anywhere nor does anything. And then the child turns 18 and if anything happens to his/her mother. And thus people appear who have nowhere to go – only the option of a home for the disabled.'

Anna also recognises that life in a closed environment, even though it is safer, still increases the fear of the outside. Often this is also stimulated by the inaccessibility of the environment and difficulties that must be overcome to get outside the familiar environment.

I know from my own experience that this insecurity only grows if you live in such a closed environment. At home everything is familiar while outside everything is unknown. At the beginning I was afraid to go out in the street, it seems that everybody is coming at you.'

The disabled react acutely to cases when they encounter a humiliating attitude toward them in health care. According to participants of the group, they have encountered multiple discrimination - not only on the grounds of disability but also on the grounds of old age. One of the examples that can be mentioned in this respect is the case when the physician refused to perform an operation for a disabled woman who suffered from constant strong pain. The justification of his decision was that there was no use in performing the operation as the patient was already over 60. If she had been 40 years old the operation would have been performed. At present the patient should keep taking painkillers.

It is not that the society pushes people away by its stereotypical attitude and puts obstacles to their integration into the society; in actual fact, these stereotypes exist also in the minds of people with disabilities, they themselves worry about what other people will think of them. That is why it is possible to say that stereotypes constitute one of the factors preventing the improvement of capability.

There was one moment when I thought – I will not get into any wheelchair. For the most part I thought about what other people would think about me. Because I did not see any relief there that it would help me; I saw it with such a thought in my

mind that if I was seen in such a way in the street then people would think – there is some weakling, somebody disabled... It was very much on my mind ...'

Anna also emphasises that categorisation, labelling of people, putting them into certain frames restrict development.

'A disability group for life! Now I also read about achievements in science that studies the brain and I also know that it is very bad that this information is embedded, the person is put in something like a frame. This knowledge that the person knows what frame he/she has been put in, does not allow the person to be what he/she might be if they were not what they are as it tags along... It sits in our head – I am like that, it is difficult for me. It covers everything – layer after layer. And gradually the person becomes the victim of his/her condition.'

A vicious circle develops: like in the case of the disabled in order to be eligible for social support other people also have to acquire a certain status (for example, the status of a poor person) that makes them eligible for this assistance; however, the acquisition of this status places the person in a certain category that provides the grounds for the receipt of social assistance but lowers their self-esteem and does not stimulate capability.

4.2.2 Fighting for rights

People with disability are entitled to state support prescribed by law for the compensation of their limited functioning and maintaining their capability. However, as it has been indicated in the interviews, one must fight for it to receive it.

It is not the case that the person who receives a disability group also receives a clear explanation of his/her options. For example, Rita has had Group I disability since July, 2014. She has also been given a long list with benefits and reliefs that individuals with Group I disability are entitled to. Rita has read it, however, she says that it is not clear, it is difficult to understand, and what is important has not been separated from the irrelevant.

Anna also emphasises that it is important to know the “bureaucratic system” to know what one is eligible for and how to apply for it.

'The bureaucratic system is unwieldy and complicated. When you have got into it in some way then you can also find more.'

Anna has observed that people with disability have to fight for themselves, they must know what they are entitled to and they must insist on it. Many of them are not ready for the fight and that is why they do not receive anything.

'It would be normal if the Social Service told the people – you can receive this, this and this - and then helped them. With us everything is the other way round – the person has to fight for it himself/ herself. And if the person does not fight for it, if nobody else fights for the person and tells the person that this and this and this should be done, the person will not get anything.'

The story told by Beta's mother reveals the emergence of an approach that differs from the approach cultivated during the soviet period – to wait patiently when somebody will take the decision and grant the required assistance or service, and to be grateful for anything that you have managed to receive. Parents who have children with special needs try to understand the needs of their child and to protect his/her rights.

'Yes, one generation has become adults, and people know more and demand more. We are the first trailblazers and we show the young people that people can speak about it, they are not afraid to speak about it, they can demand, they can establish the needs of their child, we can identify and demand what we need. The process has started ...'

The advice of Beta's mother could be useful also for people with disability. This is done also by their organisations that follow amendments to laws, defend and explain the rights of the disabled. It is more difficult to fight for yourself individually in the role of a supplicant.

This principle of fighting for yourself by the disabled could be taken over also by other people to stimulate their capability. For example, Beta's mother also mentions options that mothers of such children can use to have some rest and restore their strength.

Mothers also have opportunities. If you take the child at special service place – the child stays there for twenty four hours. At the beginning 45 twenty four days periods were envisaged, now there are 30 days periods per year. You take the child there – you forget all about the child. You can go on an excursion, take care of yourself, you may tidy up the house, you may visit a psychologist – we do not have to pay for these consultations.'

She holds the view that such assistance would be necessary also for those mothers who bring up their children alone, receive the child benefit and make do with the minimum salary. Preferential treatment for the development of children would be required also in such cases.

'She also needs it because a normal child must also develop; she cannot offer the child to study at a music school... in my case the music school was free. There is a speech therapist at school. Will you have a speech therapist or a psychologist in an ordinary school? You will not have them. We can get a psychologist from the social services, free of charge. ... That person is given much less.'

This example reveals the approach in the provision of social assistance – not to allocate the benefit in cash that can be easily spent in a shop on the needs of the moment but to “invest it in development”, to stimulate the progress and development of the child so that the material situation of the family does not become an obstacle to the child's wholesome development.

To be able to live the life they want, the options of individual choice should be expanded for people with disabilities – not by giving something to everybody but by taking more note of the individual needs of each person, for example: Rita said that she had been offered the possibility to attend a training course to become a cook, however, this job would be physically too difficult for her.

'Is it possible to live the life you want? It would be fine if funding was allocated to people with disabilities to enable them to choose the courses themselves and to engage in work at home that they like. Not to press everybody to take the cooking courses.'

4.2.3 Feeling of unfairness and inequality

During the crisis a large part of the population in Latvia developed a strong conviction that the state did not take much care about the welfare of the population, which was also revealed by the data of surveys (Kruks et.al, 2016). This opinion emerged also in the interviews. People with disabilities compare their situation with possibilities of the disabled in other EU member states. The comparison is not in favour of the situation in Latvia. For example, a comparison is made of the accessibility of the environment.

'Yes, we were, for example, in Barcelona. They have descent ramps – a metre, a metre and a half, not special ramps, for nothing at all but they are simply there. They are covered in large tiles, there they have tiles everywhere. All people can use the ramps, also with prams. They are not as narrow as here where the people must go one after another, there they are wide. Here everything is built in such a way that suits somebody and does not suit others, to separate people.'

However, Anna also points out that there are countries where the situation is much worse than in Latvia; she emphasises the EU accession of Latvia has stimulated an improvement in the accessibility of the environment.

'I, for example, spoke to a person who had been to Thailand. There nothing has been adapted. There are such narrow pavements that if there is somebody with a pram coming towards you, then it is already a problem. While in the EU countries there are no problems.'

Rita had visited her daughter in England and she had received discounts in museums and other tourist sites. The feeling of unfairness develops in her because she is treated better in another country than at home. Rita

is surprised that in England she was better treated as a disabled person than in Latvia because here she has to know what she is entitled to and she has to fight to get these reliefs.

Here, in Latvia, where I have worked for many years, I have three children, bring up the fourth child I am not entitled to anything, I have to fight for everything. In a foreign country I get a discount for nothing, an absolutely different attitude.'

Rita is also surprised by the fact that in Latvia there is inequality among the disabled, that it is easier to receive reliefs and advantages for people with visible disability. It is not Rita's case and that is why she has been reprimanded for using advantages intended for the disabled. Rita has experienced it herself that the parking for the disabled are intended only for the disabled with motoric disorders and impaired eyesight. This issue requires more in-depth research as the right to use a parking lot is assigned to a specific vehicle, it is given for a period of ten years, for comparison – people get the disability group only for a period of two years.

The crisis in the medical system has generated uncertainty and tension in people; the disabled compare themselves with people of other vulnerable groups and treat “competitors” – the homeless, refugees and other categories – with suspicion.

We say – we do not have the funds. However, for example, a destitute is picked up in the street, taken to hospital and everything is done for him/her - magnetic resonance as well, all services are free of charge. While we have to get in the queue when we have to go for help, now we have to queue even if you pay.'

The accessibility of medical services is compared to the situation during the soviet period. Participants express a view that in soviet time accessibility for health care was better than now. It should be taken into account that at the time participants of the discussion were much younger and had different health problems and it influences the comparison. Dissatisfaction may have at its basis also communication problems between patients and the staff – failing to understand the way how the system for providing medical services functions now, people want to return back to the time when everything seemed better understandable.

Now this is the free Latvia but I remember the soviet times when you got to hospital and you were also treated there, you could get to the gynaecologist as well as the dentist. Last year I fell down on the street, bruised my legs. I was taken to hospital and when I said that I could not get to the toilet on my own, that the surgeon should come and have a look I got the answer – here you undergo treatment for blood pressure, legs will come later. Isn't it crazy?'

It is the inaccessibility of medical services that consolidates the conviction of many people about their exclusion from the state.

Prices [of medical services] do not correspond to our pensions and salaries. It is not normal, we are doomed to extinction. The state needs neither the disabled nor the pensioners.'

In view of the above limitations optimum ways should be sought to overcome them. One of them is unification for the protection of their interests and for addressing the problems.

4.3 Collective capabilities

As it has been already mentioned above, we look into collective capability on the basis of the capacity of organisations, it is described by stories of the disabled about what they gain from their involvement in the organisation and the description of the issues addressed by organisations.

Anna points out that is important that organisations participate in the legislative process – if the law applies to the disabled then their opinion should be expressed about the law, it should be considered how the law will influence people with disability. As a rule, decision-makers do know the problems as well as the people who face them on daily basis.

The task of the organisation is to inform and to educate for people to know what they should do. We can participate in the process of legislation itself. We tell and inform people. Likewise the SUSTENTO also offers to take a look from the other side – from our point view what the law will look like.'

Another aspect is addressing problems of people with disability by common effort; participants indicated that the organisation helped to purchase various aids.

'... we have organisation which is a member organisation of the "SUSTENTO". We have a very good leader; it is due to him that almost every year we receive cargos with aids. There are long waiting lists for aids. Cooperation partners in Iceland send them to us.'

The local organisation involves the disabled in various activities; remind them of important issues, for example, the disabled can apply for services necessary for the disabled. Projects were also mentioned that had been submitted to a tender which the organisation had also won. For example, they helped people with disabilities to receive psychosocial assistance, equine-assisted therapy, dolphin therapy (for children). Participants of the group recognise that they would not have been able to do it alone without the assistance of the organisation.

The local non-governmental organisation also regularly works with the social assistance service of the local government and informs them about needs of the disable. It also promotes mutual understanding and cooperation.

The organisation is also important in organising leisure activities as it offers possibilities to attend cultural events, to go on excursions in cooperation with the local government.

'Participation in the organisation is essential as you get fed up with sitting at home. And the cultural events are also too expensive. Previously I could afford more, now I have less money.'

Participation in the monthly activities of the organisation "Zvaigzne" also helped us better understand problems and interests of women participating in the organisation and to get involved in the process of addressing these problems.

5. Conclusion

RE-InVEST wants to emphasise the lived experience of vulnerable people, the impact of the crisis (and crisis-related policy reform) on vulnerable groups as well as the impact of growing inequality and social vulnerability on distrust. Our two key hypotheses in this regard are: 1. that growing distrust and indeed resentment among the population may be attributed to (a rejection of) the neoliberal policies employed by national as well as European elites in recent years; 2. That this integrated diagnosis can build on the idea of the erosion of/disinvestment in (individual and collective) capabilities and basic social rights in the EU. This means that experiences of insecurity, poverty and social degradation need to be re-analysed from those perspectives.

In this report we've translate the two hypotheses into the questions about the kind of life respondents would like to live and obstacles to do so. This basic question summarises the capability and human rights approach. If we discuss capability in the meaning used by A. Sen as the possibilities of functioning that correspond to the individual's imagination, then it must be recognised that the disabled have certain health-related limited functioning. Capability of the disabled can be discussed only within the frame of this limitations. The disabled are more directly forced to take into account their possibilities of physical functioning and they also need the support of the community in expanding these possibilities. Individuals with disabilities are forced to be more acutely aware of their capability and to try to expand it than other social groups. We tried to emphasise the experience of this particular group in overcoming constraints of their capability. Therefore, in the course of the research we examined not only the impact of the crisis but also the experience gained in overcoming restrictions.

The first hypothesis was that retrenchment of the state, in conjunction with rising inequality and income insecurity, may have undermined trust, especially among the vulnerable people.

Our analysis confirms the hypothesis of a loss of trust. It was promoted by the government's crisis management strategy, which called for very strict austerity measures that in turn lead to significant increase in depth of poverty and social exclusion. The participants feel that inequality during the crisis has increased: between the political elite and ordinary people, between the rich and the poor, between private and public patients (including people with disabilities) in the health care system. The crisis and crisis-related policies implemented by government have weakened social cohesion and trust in political institutions. The research data revealed that the level of trust in political actors and institutions is very low among the participants.

People with disabilities are paying more attention to the crisis in health care and issues of accessibility of medical services than to the socio-economic impact of the crisis, as their incomes were not high even before the crisis. They have always been living in an austerity mode, balancing on the edge of poverty.

The second hypothesis explores the idea of the erosion of (or disinvestment in) social rights and capabilities in the EU and the impact on vulnerability. Our analysis confirms the erosion of social rights. Research data reveals significant decline in the very important needs and rights of people with disabilities (health care, housing, incomes, work and equality).

Their rights are not granted, they have to fight for each right. Experience of people with disabilities shows that it is essential to fight for their rights and also to know them, otherwise they are not implemented in Latvia situation.

The support of the society in the form of social assistance is more focused on ensuring existence (survival) rather than promotion of capability. However, it is important to "invest in development". i.e., benefits

must be linked to possibilities of education and further development. Assistance should be more individualised, linked to the interests and needs of every person; benefit recipients should be more involved in the process of making decisions what they need and how to use the services and benefits.

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RE-InVEST - Rebuilding an Inclusive, Value-based Europe of Solidarity and Trust through Social Investments

In 2013, as a response to rising inequalities, poverty and distrust in the EU, the Commission launched a major endeavour to rebalance economic and social policies with the Social Investment Package (SIP). RE-InVEST aims to strengthen the philosophical, institutional and empirical underpinnings of the SIP, based on social investment in human rights and capabilities. Our consortium is embedded in the 'Alliances to Fight Poverty'. We will actively involve European citizens severely affected by the crisis in the co-construction of a more powerful and effective social investment agenda with policy recommendations.

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Co-ordinators

Ides Nicaise (HIVA-KU Leuven), general project co-ordinator/scientific co-ordinator
Michel Debruyne (Beweging vzw), network co-ordinator



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