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Abstract:
This report focuses on the effect of the presence of a disabled child in a family and in particular on its demographically relevant consequences in a comparative framework. Couples who rear a disabled child are more frequently unstable, more often forego their fertility intentions, more frequently suffer from economic difficulties, show more traditional gender role arrangements, are more frequently in bad health, and have lower well-being than families without disabilities. The consequences are also different for mothers and fathers: fathers of disabled children have fewer emotional exchanges, while mothers tend to suffer more in terms of social contact. Feelings of emptiness, loneliness and rejection are more typical of mothers with disabled children. This report contributes to the existing literature by showing that comparative large-scale surveys on topics other than disability (such as the Gender and Generation surveys) can be quite a rich source of information on the family life of disabled children.

Keywords: disability, child disability, family disability, handicap

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Contents

1. Introduction

Along with precarious, migrant and poor families, families with a disabled household member are some of the most vulnerable groups of society. Of particular relevance to the FamiliesAndSocieties project is when that disabled family member also happens to be a child. The birth of a baby with a disability or finding out that a child suffers from a disability can be a traumatic event for parents and can have profound effects on the entire family. The parents of disabled children need more inner strength than other parents, not just to deal with the particular difficulties that inevitably arise in caring for the disabled, but also to cope with the challenges of everyday life.

No two parents are alike, however. Those who live in a positive environment and are equipped with the skills and resilience to deal flexibly with problems are the most likely to be able to build a sense of security and protection within which to raise their family. The risks and costs of caring for a child with a disability would be less of a burden to all families, in any case, if the state provided them with better services and greater support.

Several studies have pointed out the enormous amount of stress that goes along with being the parent of a disabled child. Depending on whether the disability is mental or physical and depending on its severity, the families of disabled children may have more financial difficulties, more strained emotional relationships among family members, a higher rate of depression, modified work and leisure activities, a limited social life, and greater time constraints due to care demands (for a short review Olsson and Hwang, 2003). Nonetheless, in contrast to earlier decades, current research indicates that some families now comment on the positive consequences of having a disabled child, and not just the negative. For example, some parents say they are better able to appreciate the important things in life. These positive emotions, in turn, fuel the parents' ability to cope with day-to-day life (Knox et al., 2000).
Numerous studies over the decades have amply demonstrated the psychological effects on parents of having a disabled child. Less has been done to study the demographically relevant consequences of childhood disability on families, or to use data from large-scale surveys to compare the effect a child's disability has on different kinds of families.

Moreover, most studies have looked at specific countries like the USA or the UK, or at specific regions or countries in Europe. They fail to take into account the international comparative dimension or the cultural and social welfare differences that might influence the well-being of families with disabled children in different contexts.

This report uses a comparative framework to isolate the demographically relevant consequences of having a disabled child. These include the potential instability of unions and decisions about whether to have other children, as well as effects on different aspects of health, well-being and gender roles. The results contribute to the existing literature by showing that comparative large-scale surveys of subjects other than disability can provide rich data on the family life of disabled children and their coresidents.

2. Theoretical background

Large-scale studies on the consequences of children disability on families can be found in the literature since at least the early 1970s, when it was finally recognized that “a family with a child who has a disability is a family with disability” (Glidden, 1993).

The literature underscores the particular vulnerability of the families of disabled children in a variety of family and individual life circumstances. Having a disabled child in the household affects the family members’ quality of life, the parents’ gender roles, financial resources and the employment status, the use of time, health and stress, and even the occurrence of demographic life events, such as divorce or the birth of another child. These considerations are usually made with reference to groups of children affected by a specific syndrome, with fairly similar types of symptoms. The literature on how Down syndrome, cerebral palsy and autism affects children’s lives and the lives of their caregivers is extremely rich, especially concerning the US. Studies on a group of disabled children and a comparison group of non-disabled children from the population are less frequent. Population based studies (see Brehaut et al. 2009 and Hogan et al. 2012) have the advantage that the samples are not selected on the basis of the demand/access to special health services and that they can compare children with and without disabilities, and can control for relevant confounders. These studies play an important role in recording survey data on social participation – and not just enrolment in education -, health conditions (including the degree of disability) and the type of limitations (Hogan et al. 2012), both for disabled and non-disabled children. The General Household Survey, carried out in Great Britain in 1974, was one of the first large-scale surveys used to estimate the prevalence of disability in children. Weale and Bradshaw (1980) report a prevalence rate of child disability of 7.6%, where disability is defined as a physical or mental impairment that produces functional limitations, activity restrictions or a social handicap (according to the WHO definition).

Usually the disability of (one of) the child(ren) places heavy burdens on the parents and may destabilize the marriage and decrease the quality of the couple’s relationship. Some authors report less marital satisfaction among parents of disabled children (Friedrich and Friedrich, 1981) and a higher prevalence of single parenthood (Cooke et al 1986. Hogan et al. 2012), usually due to elevated parental stress (Lavee et al. 2006). According to a study done in the US, divorce is relatively common among the parents of disabled (with congenital problems or chronic illness) children (Mauldon, 2012). If this is true, disabled children are more likely than healthy ones to be subjected to poverty, loss of parental time and the emotional stress that follows divorce (Mauldon, 1992). On the other hand, some parents might try to avoid divorce, even if their relationship has soured, because of the excessive emotional and financial costs that the remaining parent would have to bear. For example, for one type of child disability – Down syndrome – it has been shown that the parents are less likely to get divorced than the parents of children without disabilities or with other birth defects. This may be because the parents of children with Down syndrome are often older, better educated and married, all factors that are protective against divorce (Urbano and Hodapp, 2007). If the parents of a child with Down syndrome do get a divorce, then it happens early in the life of the child and usually involves low-educated fathers living in rural communities (Urbano and Hodapp, 2007). According to a Danish study, children with a disability or long-term illness are at greater risk of growing up in a single-parent household (Loft 2011, 2013).

In terms of family size and fertility decisions, the decision whether to have other children or not is difficult, for the parents must decide whether to devote all their resources to one disabled child (or to postpone the birth of the following), thus limiting the disabled child to a less dense sibling-based kin network to rely on when the parents are gone (Loft 2011, 2013), or to provide a sibling as a future caregiver (Hogan et al. 2012). MacInnes (2008) reports that “[…] mothers of children with disability have a lower hazard of having a second child; that is, raising a child with a disability slows or hinders further childbearing”. In any case, the desire to have a second non-disabled child and a more complete family with a second child (the desire for a normative motherhood experience, Park et al. 2003) could be stronger. Only after the birth of a subsequent child do mothers of a seriously disabled child have an increased likelihood of choosing postpartum or interval sterilization (Park et al. 2003). In a regional study conducted in the US, Burke et al. (2011) report that the families of children with disabilities (Down syndrome and spina bifida) are more likely than the families of children without disabilities to have subsequent children regardless of maternal race, marital status, and education level.

It is not surprising that the parents of children with disabilities generally exhibit higher stress levels and poorer mental health than other parents. When comparing children with developmental disabilities and the general population, Byrne et al. (2010), Guyard et al. (2011), and Rentnick et al. (2007), among others, found this to be true in the case of cerebral palsy. But the impact of children's disability on the family seems to be related not only to the child's characteristics, but also with personal, social, and economic variables of the family. In a small-scale Norwegian study on the parents of children with behavioural problems, which can be frequent in children with disabilities, those who were single, with low education, more often unemployed, less content with social support and with lower scores on comprehensibility were significantly more stressed than parents in the comparison group (Solem et al. 2011). In a study based in a province of Turkey, Ergün and Ertem (2012) report that the most frequent problems experienced by mothers of disabled children were sadness, anger and loneliness. Mash and Johnston (1990) conceptualize parental stress as involving behavioural affective and cognitive components. In the relationship with a child, the level of stress experienced depends on the difference between the situational demands and the individual's resources and goals. Eight categories of potential stress seem relevant to the parents of children with intellectual disabilities (as mainly proposed by Mc Cubbin et al. 1982, but also cited in Olsson and Hwang, 2003): financial hardship, strained emotional relationships within the family (in fact, mothers who have support from their partner experience less stress and depression), modification of family activities and goals, restricted social life, time restrictions caused by care demands, family contact with professionals (which can cause frustration, disappointment and anger), mourning and depression (depressive symptoms as a consequence of the mourning process - the birth of a child with a disability is a permanent stressful event in the life, Olsson and Hwang, 2003), type of disability (for example autism vs. Down syndrome). Longitudinal studies (Dyson, 1993) show stability over time (and therefore as the child grows older) of overall parental stress and family functioning. Parenting stress and its impact on family functioning, controlled by family annual income and parental education, has been associated with family functioning variables and with children's social skills (rather than other skills) (Smith et al. 2001).

Fathers and mothers usually experience the increased stress related to the presence of a disabled child differently: in most cases, it is the mother who gives up her job or career to stay home and take over most of the childcare responsibilities (Barnett and Boyce, 1995, Hedov et al. 2000, Lukemeyer et al. 2000, Powers 2011, Westbom 1992). Even if they continue working, the mothers of disabled children have been reported to have more sick days and more absences from work to care for sick children than other mothers (Westbom, 1992). In addition, poor families (with possibly a single parent) in low-income jobs with less job flexibility experience even greater problems when there is a child who has significant disabilities and learning and behavioural disorders (Bernheimer et al. 2003). Olsson and Hwang (2003) also report that the parents of children with intellectual disabilities in Sweden (where government and community support is higher than in other countries) experience the same kind of stress, especially in terms of a restricted social life and time constraints, as parents in other countries. The only exception is the financial burden, and it may be that public aid might allow the parents to spend less time at work and more time with the child (Olsson and Hwang 2003). On the other hand, family stress is not reduced if access to services is subject to strict eligibility requirements and a complicated screening process.

The presence of a disabled child affects the lives of non-disabled siblings: on the basis of parent reports and after adjusting for sibling demographic characteristics and household background, siblings of children with disabilities were more likely than siblings residing with typically developing children to have problems with interpersonal relationships, psychopathological functioning, functioning at school, and use of leisure time (Goudie et al., 2013).

Discussion in the literature concerning stress for family members of disabled children also describe positive effects from having a disabled child (Beresford, 1994). The parents of disabled children identify nine core themes: joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; source of family unity and closeness; increased tolerance and understanding; personal growth and strength; positive impacts on others/community (Stainton and Besser, 1998), including also more conscious behaviour towards the other children (Olsson and

Hwang 2003, for a review see Byrne and Cunningham, 1985). They also state that most of the negative effects of having a disabled child could be counteracted by promoting measures intended to help the parents (Barnett et al, 2003).

Physical health, including the presence or absence of chronic conditions, limited activity or overall poor health, is one of the strongest indicators of well-being. Physical health tends to be poorer in families with disabilities, after controlling for confounders (Brehaut et al 2009). Self-perceived health has also been reported to be poorer for the mothers of disabled children than for their partners or the mothers of non-disabled children (Hedov et al. 2000, Westbom 1992). The quality of life (measured through the reported survey of respondent health by means of the so called SF-36 battery of questions) reported among parents of children with cerebral palsy is lower than among others. Physical problems may emerge as a result of the care situation (chronic diseases, sight and hearing problems and physical pain), Pousada et al. (20013). The caregiver’s psychological and physical health can also be influenced by contextual factors (SES), child factors (level of disability, presence of behavioural problems and overall child adjustment), caregiver related characteristics (coping strategies, support from family and friends), and also by education and other demographic factors), Brehaut et al. (2009). The perceived severity of the disability affects a caregiver’s health more than the actual disability of the child (Brehaut et al. 2009).

In sum, the literature underscores that the effect of having a disabled child is multifaceted and involves various life-domains. The following sections take a descriptive approach to exploring the different issues within a European context.

3. Data and methods

The data used in this report stem from the Gender and Generation Surveys, an international program ccoordinated by the UNECE (United Nations Economic Commission for Europe) aimed at a cross-national, comparative, and longitudinal study of the dynamics of the family and family relationships in industrialised countries

Data were obtained from the GGP Data Archive (see United Nations 2005. Generations & Gender Programme: Survey Instruments. New York and Geneva: UN, 2005 for the model survey instruments). For this report, we use the data from wave 1 for every country that implemented the question about disability. Table 1 reports some basic characteristics of the samples (survey year, number of respondents and their age) in the countries where the information on disability is available.

Table 1 Gender and Generation survey (GGS), basic characteristics of the samples.

Country	Survey year	Number of respondents			Age range
		Males	Females	Total	
Bulgaria	2004	5,851	7,007	12,858	18-79
Russia	2004	4,223	7,038	11,261	18-79
Georgia	2006	4,405	5,595	10,000	18-79
France	2005	4,371	5,708	10,079	18-79
Hungary	2004	6,023	7,517	13,540	21-79
Italy	2003	4,455	5,115	9,570	18-64
Romania	2005	5,977	6,009	11,986	18-79
Austria	2008-2009	1,999	3,001	5,000	18-45
Belgium	2008-2010	3,435	3,728	7,163	18-83
Lithuania	2006	4,999	5,037	10,036	18-79
Poland	2010-2011	8,409	11,578	19,987	18-84

A nationally representative sample of men and women was surveyed in each country. Among the range of issues covered were fertility and partnership histories, the employment situation, demographic characteristics and information about health, family life, opinions and well-being.

The question used to identify whether one of the family members had a disability was “Is any member of your household limited in his/her ability to carry out normal everyday activities because of a physical or mental health problem or a disability? If yes, please put a tick in the “disability” column in the household grid”. This allowed identification not only of the occurrence of a disability among the household members, but also of the person affected by the disability. The question was used in a large-scale survey and therefore contains no details about the type or severity of the disability. The implementation of the question in the national questionnaires was quite straightforward, except for Poland, where a simplified version of the question was followed up by a request to indicate whether legal certification of the disability had been granted (see appendix A for a presentation of the national questions).

For each country, we selected all respondents who declared that at least one child (a biological child of the respondent with the current or past partner, a step-, adopted or foster child) under the age of 19 was living in the household.

We compared families with and without disabled children according to several demographically relevant aspects that have been identified in the literature as areas vulnerable to the effect of having a disabled child: stability of the relationship (partnership status of the respondent - the father or the mother of the children in the household grid or their new partner), quality of the relationship (thinking about separation in the last 12 months, percentage of people who declare their relationship is quite bad), the probability that a disabled child will have a younger sibling, traditionalism of gender roles (job status and participation of fathers in childcare), financial matters (ability to make ends meet), and, finally, indicators of health status, emotional exchange and different dimensions of well-being.

We will present the results in the form of tables and figures, usually broken down by country.

4. Results

4.1. Prevalence of disability

In this report, we compare the situation of different countries, using the rich data supplied by the Gender and Generation survey data. Table 2 shows the percentage of families with a disabled child in each country. Results from the questionnaire indicated that 771 out of the 40,620 families in the sample had a disabled child.

Table 2: Percentage of families with one disabled child under 19 out of all families with at least one child aged less than 19, by country

Country	Families without disabled children	Families with disabled children	% of families with disabled children
Bulgaria	4,804	53	1.09
Russia	3,947	61	1.52
Georgia	3,692	42	1.12
France	3,184	34	1.06
Hungary	3,936	94	2.33
Italy	3,262	45	1.36
Romania	3,706	88	2.32
Austria	2,411	45	1.83
Belgium	2,280	59	2.52
Lithuania	3,060	18	0.58
Poland	5,567	232	4.00
Total	39,849	771	1.90

Source: own elaboration on GGS data.

In 1.9% of all families in the sample there is a child with disability. The percentage of child disability varies across countries: the lowest is found in Lithuania (0.58%, where the sample of disabled children is also, in absolute terms, very small) and the highest in Poland (4.0%).

The differences are not imputable to differences in the age structure of the different populations (an age standardization provided about the same results); instead, they may arise from different interpretations of the question on disability in different contexts[1], from the issue of the existence of a “legal” definition of disability, and consequently to the presence of advantages (in terms of access to services) for families with a disabled child. The European Academy of Childhood Disabilities (see UNICEF, 2005) considers a disabled child rate (out of all children) of at least 2.5 per cent to be the ‘norm’. They also consider that an additional 8 per cent of the child population has learning and/or behavioural disorders. This makes the overall share of children with disabilities and special needs in any given population about 10 per cent. According to recent WHO (2011) estimates, the disability rate among children aged 0 to 14 for high income countries is 2.8%. In the GGS datasets the definition of disability is not specific for measuring children disability and does not distinguish between severities of disability. Moreover, the data reported in table 2 refers to families and not to the total number of children.

On average, countries in Eastern Europe (Bulgaria, Russia, Georgia, Hungary, Romania, and Poland) have a higher rate of child disability than the other countries in the sample: 1.9% vs. 1.4%. This is a possible indication that different health care systems have different effects in terms of the prevention, recognition and care of disabilities. Moreover, the change in the political system, the dramatic economic crises, the introduction of a market economy instead of a centralised one, a significant rise of inequality and cuts in the welfare system, which used to be universal, may have affected maternal and child health during the period of transition (UNICEF, 2005).

4.2. Family consequences of child disability

In the following subparagraph we analyse the GGS data on the issues of partnership quality and stability, number of siblings, gender roles, financial matters, and health and well-being of the respondents (usually the mother or the father of the children). The analysis by country refers to small sample data, and should be considered as general indicators. More detailed tables can be found in appendix B.

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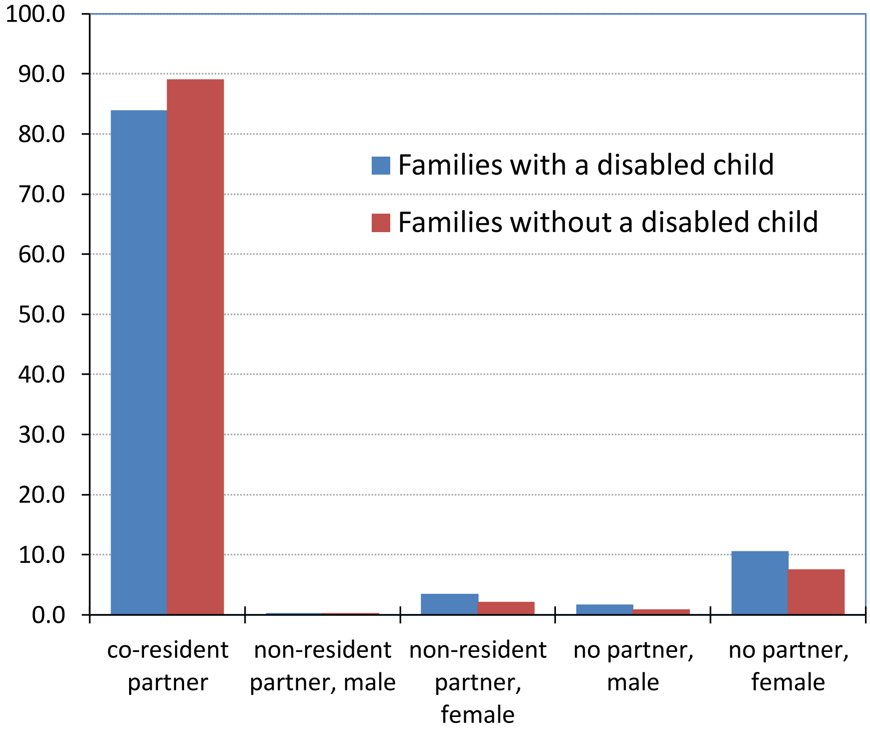
[1] For an overview of definition used in the national questionnaires of the GGS, see Appendix A. In all countries the same wording of the question is used, but the respondents answer according to a subjective evaluation of the disability and the limitations in everyday life that the disability causes.

4.2.1. Partnership stability and marital quality

Previous research showed that the presence of a disabled child in the family can have a negative impact on the couple's relationship, causing conflicts that decrease satisfaction with the quality of the relationship, potentially leading to separation or divorce.

Single parent families (with no current partner) tend to be slightly overrepresented in families with a disabled child, so families with an intact couple (whether or not they are both the biological parents of the disabled children) are slightly underrepresented in the same group, figure 1. It is the mother who most often remains alone with the disabled child and his/her siblings (if any) and who is, in any case, more likely than the mothers of non-disabled children to keep a relationship with a non-resident partner.

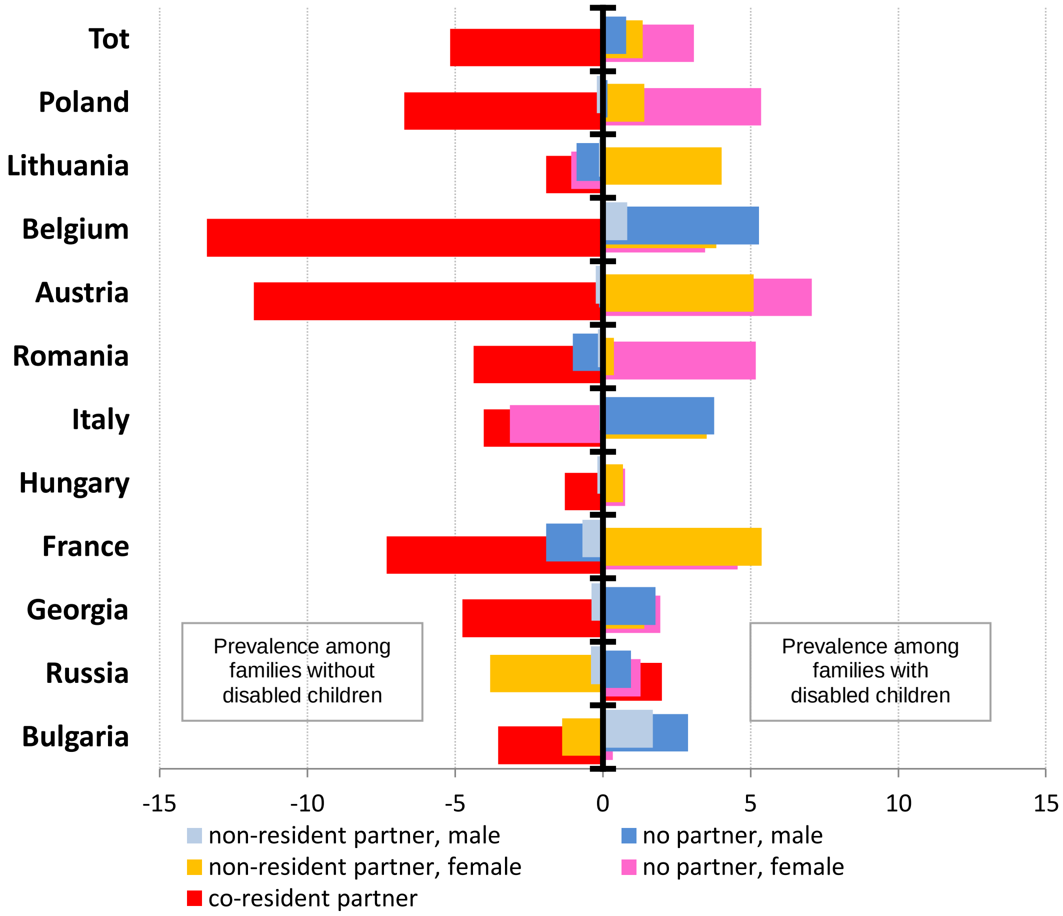
Figure 1 Partnership status at interview, by presence of a disabled child in the family, total sample



Source: own elaboration on GGS data

The picture is very different in the countries analyzed, figure 2. The figure compares the rate of different types of partnerships in families with a disabled child and in other families. The figure shows the prevalence (in percentage) of a specific type of partnership arrangements among the families with disabled children (if the bar is in the positive quadrant) or among the families without disabled children (if the bar is in the negative quadrant), by country and by type of partnership. With the exception of Russia, disabled children in all countries are much more likely to live in a one-parent household. Belgium and Austria are the most extreme cases. Households with lone mothers are more common in all families with disabled children except in Lithuania and Italy, and families where the single parent has a relationship with a non-resident partner are typically a female phenomenon; only in Russia and Bulgaria are they more common than in families with no disabled children. Interestingly, when there is a disabled child, fathers in Italy and Belgium are more frequently left alone with him/her (and siblings, if any) than if the child is not disabled.

Figure 2 Difference in percentage points among families with and without disabled children, in each category of partnership status, by country.



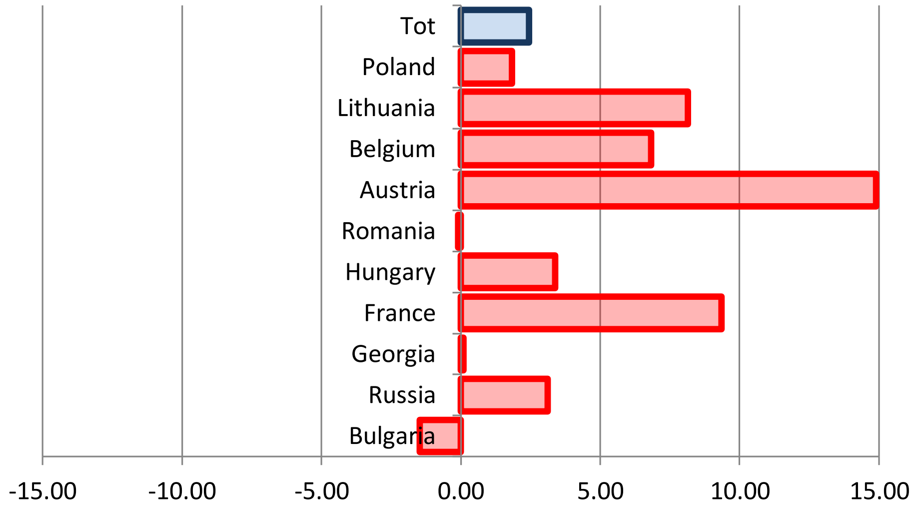
Source: own elaboration on GGS data

The partnership status at the interview could reflect events that happened before the birth of the disabled child. The GGS data provide rich information about the partnership histories of the respondents. Analysis on GGS data reveals that among the families with disabled children, almost 2% never had a partner. Among those that currently have no partner (11% of the total group) almost all of them (91%) separated following the birth of the disabled child. Among those that have a non resident relationship (4%), almost 60% separated after the birth of the disabled child. Even among the families with both partners in the household, about 6% separated after the birth of the disabled child, which indicates that the respondent is therefore currently in a new union.

We also know that the quality of the relationship could be lower among families with a disabled child in comparison with families without a disabled child.

When asked about the occurrence of thoughts about separation in the last year[2], partners belonging to families with disabled children declare slightly more often than the others that they did (11.4 vs 9.0), but what is striking is the value of the difference in some countries (Lithuania, Belgium, Austria and France), which reaches a value of about 15 for Austria. The differences are instead very small or almost non-existent in most of Eastern Europe, and in Bulgaria it is even reversed, figure 3.

Figure 3 Difference in percentage between families with and without disabled children of respondents thinking about separation in the last 12 months, by country



Source: own elaboration on GGS data

Moreover, the partners were asked to evaluate the quality of the relationship by means of a scale from 0(=bad) to 10(=perfect)[3]. The results may in some cases have been influenced by

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[2] Question 410: "Even the people who get along well with their partners sometimes wonder whether their marriage or partnership will work. Over the past 12 months, have you thought about breaking up your relationship? 1 – yes 2 – no".

[3] Question 407 "How satisfied are you with your relationship with your partner/spouse? Please use this card and tell me the value on the scale. Show Card 117: Satisfaction Scale. Value from Satisfaction Scale:___ Note: This section is asked from those who have either a co-resident or a non-resident partner."

the presence of the respective partner during the interviews[4] and a strikingly high percentage of respondents declare that their relationship is perfect (around 40%). When we compare the share of bad relationships among families with and without disabled children, we find that the percentage of men that judge their relationship with the partner quite bad (score under 6) is about the same whether or not they have disabled children. Women, instead, are not only slightly more negative in general about the assessment of their relationship, but there is on average a visible difference if there is a disabled child or not. About 9% of them give a value under 6 if there is no disabled child, but almost 15% give low values if there is a disabled child.

4.2.2. Number of siblings

The birth of a disabled child may influence a couple's fertility decisions in two main ways. On the one hand, the inevitable increase in time, energy and resources needed to care for the disabled child may make the parents decide to devote their energy to the disabled child and the older siblings, rather than having any additional children. The shock of having a disabled child could therefore act as a stopping mechanism. On the other hand, if the disabled child is the first born, the parents may want to have another child to provide the disabled child with a sibling and potential future form of support.

Table 3 indicates how many of the first born children already have a sibling (already born or about to be born), how many will have a sibling (if the lifetime fertility intentions of the parents are realized), how many will never have a sibling (either because the parents are too old, infecund or do not intend to have further children) and how many are in the "unknown" category (usually referring to unknown fertility intentions)[5]. The comparison shows that about 10 percentage points separate the probability of having a sibling for a disabled first born, as compared for a non disabled one.

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[4] In France the question was asked only if the partner was not present during the interview.

[5] The indicator includes both the information about the pregnancy of the respondent or his partner, and the perceived infecundity. Moreover, information on fertility intentions includes both the question on the intention in the near future (Question 622 "Do you intend to have a/another child during the next three years? 1– definitely not 2 – probably not 3 – probably yes 4 –definitely yes") and in the next period (Question 624 "Supposing you do not have a/another child during the next three years, do you intend to have any (more) children at all? 1–definitely not 2 – probably not 3 – probably yes 4 – definitely yes"). Answers to Q622 and Q624 were dichotomized in "(Probably or Definitely) Yes" and "(Probably or definitely) No".

Table 3: Percentage of first born children that has/will have a sibling, by disability

	First child disabled	First child not disabled
Already has a sibling	58.8	66.9
The parents intend to have another child	14.0	15.6
Total "yes"	*72.7*	*82.4*
The parents do not intend to have another child	20.8	14.7
Does not know/does not answer	6.5	2.8
Total	100.0	100.0

Note: This analysis does not include data from Italy.
Source: own elaboration on GGS data

The picture is not different for the second born, if we compare families where neither the first nor the second child is disabled, and those where the second child is disabled. In this case the influence of disability in the family is slightly less marked, but still the probability that a second born will have a sibling is 42.5% against 34.7% in the case that the second child is disabled, table 4.

Table 4: Percentage of second born children that has/will have a sibling, by disability

	Second child disabled	First and second child not disabled
Already has a sibling	30.2	34.8
The parents intend to have another child	4.4	7.7
Total "yes"	*34.7*	*42.5*
The parents do not intend to have another child	58.7	53.6
Does not know/does not answer	6.7	3.9
Total	100.0	100.0

Note: This analysis does not include data from Italy.
Source: own elaboration on GGS data

When looking at the country results (see Appendix B) two countries show slightly higher propensity – or no difference - to give a sibling to a first born if this is disabled, Lithuania and Georgia. For the second born the countries are Georgia Belgium and France. As usual, anyway, the results by country are based on quite a small number of cases, and should be read with this caveat in the mind.

4.2.3. Gender roles: economic activity and participation of fathers

The presence of a disabled child could encourage the family to adopt traditional gender roles, not only because the amount of care that has to be provided is usually higher for disabled children, but also because the care role cannot be easily, effectively and conveniently externalized (or transferred). This can be seen by comparing families with and without disabled children on questions regarding the employment status of the respondent. Not surprisingly, the percentage of women who report being employed is smaller if there is a disabled child in the family and, consequently, the percentage of women looking after the family is higher. In addition, men who have a disabled child report lower participation in the labour market, and more often report being in the "other" category, which mainly includes the retired, the permanently ill or those unable to work, table 5.

Table 5: Parental employment status in families with and without a disabled child

Activity status	Families without a disabled child		Families with a disabled child	
	Father	Mother	Father	Mother
Employed*	85.5	70.3	78.3	57.2
Unemployed	9.1	9.7	8.6	9.8
Looking after home/family	0.3	16.1	0.7	26.0
Other	5.2	3.9	12.4	7.1
Total	100.0	100.0	100.0	100.0

*including those in maternity, parental, childcare leave
Source: own elaboration on GGS data

As far as the care role of the fathers is concerned, table 6 reports the percentage of fathers involved[6] in taking care of a sick child (table 6a) and of playing with the children (table 6b), in families with and without a disabled child. These activities are usually performed independently from the age of the child, and the question was asked if there was at least one child under the age of 14 living in the household. The participation of the fathers refers to the percentage of respondents who report that a certain activity is done by both partners equally or mainly ("usually" or "always") by the fathers. On average, fathers are more involved in playing (on average almost 60%) than in taking care of the child when ill (on average about 18%), also because the time dedicated to playing usually does not interfere with the father's time at work. There is almost no difference between the fathers of disabled and non disabled children in terms of the "taking care when ill" activity, but it seems that disabled children play less often with their fathers than non disabled ones (54.5% vs. 59.2%). The diversity among countries is more pronounced among fathers of disabled children than among the others. The difference among the highest and the smallest participation, by country and disability, is about 18.3 for taking care of ill non-disabled children (the highest value was registered in Belgium, and the lowest in Russia); for taking care of ill disabled children the difference is about 25.1

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[6] Question 201"Does R have any children younger than 14 in the household? If yes: I am going to read out various tasks that have to be done when one lives together with children. Please tell me, who in your household does these tasks? Always Respondent, usually Respondent, Respondent and Partner about equally, usually Partner, always Partner, always or usually other persons in the household, always or usually someone not living in the household, children do it themselves, not applicable". Tasks: "staying at home with the children when they are ill", "playing with the children and/or taking part in leisure activities with them".

(highest in France, lowest in Georgia). The analogous value for playing with a non-disabled child is 37.9 (highest in France, lowest in Georgia) and for playing with a disabled child is 49.8 (highest in Hungary, lowest in Georgia).

Table 6a: Percentage of fathers taking care of the child when ill, by country and disability. Data ordered by participation of fathers in families with a disabled child.

Country	Families without a disabled child	Families with a disabled child
Georgia	12.2	6.9
Russia	12.0	13.0
Bulgaria	12.7	13.5
Austria	17.4	15.8
Romania	15.9	15.8
Total	**18.2**	**18.0**
Lithuania	13.7	18.2
Poland	26.0	18.5
Belgium	30.3	21.4
Hungary	16.3	22.5
France	27.0	32.0

Source: own elaboration on GGS data, Italy n/a

Table 6b: Percentage of fathers playing with the child, by country and disability. Data ordered by participation of fathers in families with a disabled child.

Country	Families without a disabled child	Families with a disabled child
Georgia	35.2	31.0
Lithuania	56.3	36.4
Romania	61.8	36.8
Poland	59.8	50.5
Total	**59.2**	**54.5**
Bulgaria	55.2	56.8
Austria	61.1	57.9
Russia	53.4	63.0
Belgium	70.7	66.7
France	73.1	68.0
Hungary	71.1	70.8

Source: own elaboration on GGS data, Italy n/a

4.2.4. Resources, economic difficulties

As already reported in the literature, families of disabled children seem to suffer more economic difficulties than other families. In our data, this is true on average and also in each country except Russia, table 7.

The percentage of people saying that they make ends meet[7] with difficulty or with great difficulty varies in general across the countries, with the lowest values in Austria and the highest in Bulgaria; however, it is constantly higher among the families with a disabled child, with the largest differences in Romania, Lithuania and, surprisingly, in Austria, where the percentage is in any case still well under the values most eastern European countries experience in general, but is triple for families with disabled children.

Table 7: Percentage of families declaring to make ends meet with difficulty/great difficulty, by country and disability status.

Country	Families without a disabled child	Families with a disabled child
Bulgaria	59.8	86.3
Russia	52.4	52.5
Georgia	56.1	66.7
France	27.9	33.3
Hungary	18.1	25.8
Romania	30.0	52.3
Austria	10.0	31.1
Belgium	16.9	20.3
Lithuania	16.9	29.4
Poland	28.6	40.7
Total	34.0	43.1

Source: own elaboration on GGS data, Italy n/a

4.2.4. Health status and well-being of family members

The presence of a disabled child in the family can increase the physical demands made on the caregiver, increase depression and anxiety, cause a general feeling of exclusion from "normal" life, influence the perception of the individual well-being (emotional contact with other people, social capital, feelings of being rejected and excluded), and it can also influence physical health. It can be expected that the effects of having a disabled child differ according to gender, with women being more affected than men.

This is clearly seen in the perceived health[8] as declared by the respondent, table 8. For both women and men living with children, the percentage of people declaring that that their health status is bad or very bad is very low (less than 5% on average), but higher for those living

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[7] Question 1002: "A household may have different sources of income and more than one household member may contribute to it. Thinking of your household's total monthly income, is your household able to make ends meet...1–with great difficulty 2 - with difficulty 3 – with some difficulty 4 – fairly easily 5 – easily 6 – very easily".

[8] The data does not allow us to distinguish if the respondents have similar disabilities to those of their children.. Rather than reporting on the disability of the parents, we analyze here their subjective health status. Question 701 "How is your health in general? 1–very good 2–good 3–fair 4–bad 5–very bad".

with disabled children (almost double for women). The parallel measure, the percentage of people declaring their health status is at least good is on average about 76% for men and 71% for women, but around ten percentage points lower for parents living with disabled children (64% for men and 60% for women, data not shown). Some of the differences among countries are striking: especially disadvantaged seem to be fathers of disabled children in Georgia, Lithuania and Bulgaria, and mothers of disabled children in Georgia, France and Austria. In some cases, the percentage reporting being in bad health seems to be higher for fathers of non disabled children in a few countries, but this is not reflected in the parallel measure about being in at least in good health status, and is likely due to the small sample size.

Table 8: Percentage of people saying that their health status is bad or very bad, by country, sex of the respondent and disability status

Country	Father		Mother	
	Families without a disabled child	Families with a disabled child	Families without a disabled child	Families with a disabled child
Bulgaria	2.3	15.4	2.6	7.4
Russia	5.0	4.3	7.3	7.9
Georgia	8.6	23.5	9.8	24.0
France	2.8	8.3	2.7	18.2
Hungary	8.0	5.4	7.7	10.5
Romania	3.1	5.0	3.8	8.3
Austria	0.6	0.0	1.6	10.3
Belgium	3.1	0.0	2.5	2.9
Lithuania	2.2	18.2	2.4	0.0
Poland	3.9	5.6	4.1	8.1
TOT	4.2	7.5	4.6	9.4

Source: own elaboration on GGS data, Italy n/a

Men and women also differ in terms of the amount of social contacts they maintain. As part of the emotional well-being, the percentage of people reporting that they had any exchange of personal experiences[9] in the last 12 months is on average about 60% for men and 74% for women, tables 9a and 9b.

The comparison between women and men is interesting when we compare the results for non disabled and disabled children: the difference in the amount of emotional exchange when there is a disabled child is only visible among men, and it is lower than the average (52% against 61%), but for women, on the whole it remains stable (74% vs. 72%).

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[9] Question 713 “Over the last 12 months, have you talked to anyone about your personal experiences and feelings? 1- Yes, 2- No”.

Table 9a: Percentage of people reporting as having had no exchange about personal experiences in the last 12 months, male respondent

Country	Families without a disabled child		Families with a disabled child	
	yes	no	yes	no
Bulgaria	64.5	35.5	50.0	50.0
Russia	64.2	35.8	60.9	39.1
Georgia	74.8	25.2	82.4	17.6
France	52.4	47.6	58.3	41.7
Romania	45.3	54.7	47.5	52.5
Austria	80.3	19.7	66.7	33.3
Belgium	56.4	43.6	50.0	50.0
Lithuania	58.6	41.4	63.6	36.4
Poland	59.6	40.4	42.3	57.7
TOT	60.8	39.2	52.2	47.8

Source: own elaboration on GGS data, Italy and Hungary n/a

Table 9b: Percentage of people reporting exchange about personal experiences, female respondent

Country	Families without a disabled child		Families with a disabled child	
	yes	no	yes	no
Bulgaria	74.4	25.6	77.8	22.2
Russia	77.7	22.3	68.4	31.6
Georgia	80.8	19.2	64.0	36.0
France	75.8	24.2	77.3	22.7
Romania	50.4	49.6	58.3	41.7
Austria	92.3	7.7	89.7	10.3
Belgium	72.4	27.6	85.7	14.3
Lithuania	71.0	29.0	71.4	28.6
Poland	70.9	29.1	70.2	29.8
TOT	73.8	26.2	72.4	27.6

Source: own elaboration on GGS data, Italy and Hungary n/a

In the GGS questionnaire, the respondents were also asked about several dimensions of their well being: having somebody to lean on in case of trouble, experiencing a sense of emptiness, missing having people around, being able to count on a lot of people, feeling rejected and, on the contrary, feeling close to enough people[10]. Figure 4 reports the percentage of people answering in a negative way to those dimensions (no people to lean on in case of trouble, experiencing a sense of emptiness, missing having people around, not being able to count on people, feeling rejected or not feeling close to enough people), by gender and disability status of the children in the family. The figure highlights the most difficult situations.

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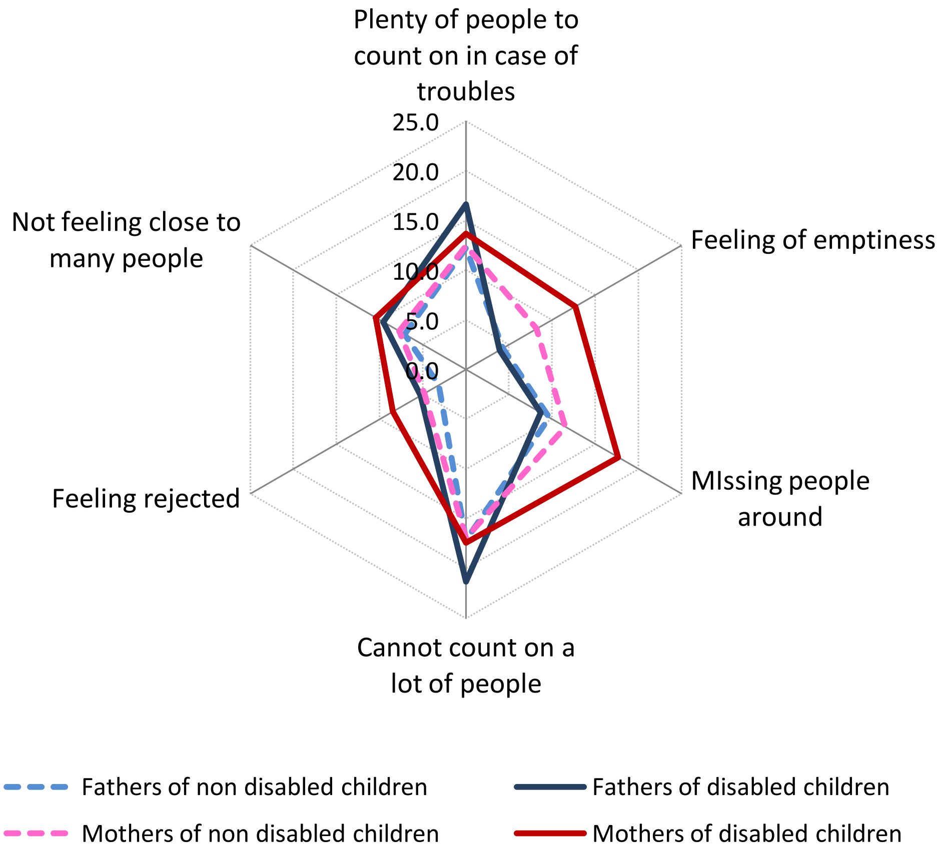
[10] Question 720: "I am going to read out six statements about your current experiences. Please indicate for each of them to what extent they have applied to you recently: Yes, More or less, No. a. There are plenty of people that I can lean on in case of trouble, b. I experience a general sense of emptiness, c. I miss having people around, d. There are many people that I can count on completely e. Often, I feel rejected f. There are enough people that I feel close to".

Figure 4 Percentage of respondents reporting negatively in terms of the dimensions of well-being: having somebody to lean on in case of trouble, experiencing a sense of emptiness, missing having people around, being able to count on a lot of people, feeling rejected, feeling close to enough people , by gender and disability (all countries)



Source: own elaboration on GGS data

In general, mothers report more disadvantages than fathers, and mothers of disabled children report more suffering than anybody else. There are two dimensions where the fathers of disabled children are more negative than either the mothers or fathers of non-disabled children: on being able to lean on someone or on a lot of people in case of trouble. Missing having people around and experiencing feelings of emptiness and rejection are typical of the mothers of disabled children. Both parents of children with a disability report not feeling close to many people more often than mothers and fathers of children without disabilities. Especially relevant is the item “feeling of being rejected” because there has traditionally been a negative attitude towards disability and handicap, especially in the past (Munyi, 2012).

4.2.5. Summary of findings

Although the GGS data were not designed to explore disability, and especially child disability, its detailed information on family member characteristics, life course events, background information, and opinions related to gender role and family life make it a useful source of data for comparing the lives of families with special needs.

In general, all the results reported in the literature about demographically relevant aspects of having a disabled child are confirmed in the data. Families where a child is disabled are more frequently unstable, more often forego their fertility intentions, more frequently suffer from economic difficulties, have more traditional gender roles, are more frequently in bad health, and have lower well-being (measured according to the given indicators) than families without disabilities. The consequences are also different for mothers and fathers: the fathers of disabled children have fewer emotional exchanges, while the mothers present no differences from the mothers of non-disabled children. Among the dimensions of well-being, fathers of disabled children have more negative attitudes regarding being able to lean on someone in case of trouble, or of counting on enough people (utilitaristic dimensions of well-being) than both the mothers of disabled children and the parents of non-disabled children. Instead, women suffer more in the area of social contacts: feeling of emptiness, having fewer people around and feeling rejected are more typical of mothers with disabled children.

As far as the international comparative dimension of the analysis is concerned, the sample sizes are very small and the results cannot be conclusive, although they do provide some interesting thoughts for consideration. It appears that Eastern European countries are not always the disadvantaged ones when it comes to quality of life for families of children with disabilities. The negative aspects seem to be concentrated in the economic consequences of child disabilities, and in the traditionalism of the gender roles of their partners. Other aspects, like unstable partnerships, whether or not to provide the disabled child with siblings, and the couple’s quality of relationship seem to have more negative characteristics in western countries. In interpreting these results one cannot disregard the fact that the inclusion of children with disabilities in society, for example through classroom mainstreaming, has reached different levels of implementation in Europe. Children with special needs are being educated in special schools more often in northwestern Europe than in Southern Europe or Scandinavia. In many of the Southern European or Scandinavian countries, among them Italy, Norway and Sweden, about 95 percent of students with special needs attend regular schools.

This means that in some countries the feeling of being “different” is already present in the disabled child’s early years of the life, thus augmenting the child’s stress levels and dissatisfaction with the situation.

5. Funded FP projects dealing with disability

The topic of child disability and its impact on family life has been already touched on in several FP projects, aimed either at developing questionnaires to study child disabilities, at providing instruments for their development, or at studying more in depth the processes that link children’s behavioural problems to parenting stress.

Both the DISABKIDS project (“Quality of life in children and adolescents with disabilities and their families - assessing patient views and patient needs for comprehensive care”) and the KIDSCREEN project (“Health Related Quality of Life Questionnaire for Children and Young People and their Parents”), funded by the FP5 in 2001-2004, develop two types of questionnaires to analyse the health related quality of life of children and adolescents (aged 4-16 in the first project, and 8-18 in the second), describe the impact of a disease or treatment on children’s well-being, assess paediatric health outcomes to use in health economic research and give parents and children a voice in health care. The newly-launched PARENTING STRESS project (“Pathways between Children's behaviour problems and Parental Stress and Parenting among Parents of Children with Autism Spectrum Disorders”), funded by the FP7, focuses on the relations between parental stress, parenting negativity, and parent-child interaction among mothers of children with autism spectrum disorders in comparison to mothers of typically developing children. In particular, the first study of the project will examine the mediating role of the mothers’ cognitions regarding their parental skills and the mother’s executive function abilities between child behaviour problems and parenting stress. Other projects funded through FP6 and FP7 include one supporting the development of children through music (UMSIC – Usability of music for social inclusion of children), one investigating the indicators of quality of life, care and support for people with disabilities (DIS-QOL - Quality of care and quality of life for people with intellectual and physical disabilities), and another promoting exchanges in collaborative research projects on health and disability in Europe (MURINET - Multidisciplinary Research Network on Health and Disability in Europe).

6. Policies supporting families with children with disabilities

6.1. The need to support families with disabled children

Results shown in the literature and in the analysis in this report show that families with disabled children are constantly disadvantaged in many aspects of everyday life. The members of families with disability are more subjected to stress, instability, economic problems and feeling of being isolated than others. A broad circle of legal acts and policies aims to counteract the described negative consequences for families with disabled children. They are directed mainly towards the improvement of the situation of the disabled but also towards provision of support to the family. This section aims to describe briefly the main approach that underlies relevant contemporary policies, outlining their main features and directions of development. Specific policy instruments and measures are not discussed here.

6.2. The legal background

Two conventions serve as the basis of these policy approaches: the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, both promoted by the United Nations.

The Convention on the Rights of the Child was adopted in 1989 and enacted in 1990. It has currently been ratified by 194 countries (ref. United Nations Treaty Collection. Convention on the Rights of the Child , retrieved in April 2014) and affirms that “The child should grow up in a family environment, in an atmosphere of happiness, love and understanding” (Preamble, p. 4). While, as stated in the Universal Declaration of Human Rights, parents are responsible for the well-being of their children, the Convention on the Rights of the Child stipulates that the state must support parents in exercising their responsibilities.

The Convention on the Rights of Persons with Disabilities was signed in 2008; it now has 20 ratifications and 158 signatories. One of eight guiding principles underlying the convention refers to: “Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities”. A variety of fundamental human rights specified for disabled persons includes many issues that refer to children, including the right to participation, inclusive education, and the respect of families.

The legal status of these conventions requires that diverse public policies should be fitted to the conventions’ requirements. As a general rule, issues relevant to children with disabilities are regulated fragmentarily: health policies for their health, specific services that correspond to their daily needs, specific schools for their education. Family benefits are thus implicit, insofar as some of these regulations may bring about a mitigation of family problems related to the disabled child.

An integrated policy approach to the needs of families with children with disabilities is therefore advocated. The necessity for developing a coherent public family policy was underlined, for example, at the Conference of European Ministers responsible for family affairs held in May 2006 in Lisbon, organized by the Council of Europe (see Report by Gudbrannson: “Rights of children at risk and in care”).

An appropriate environment to this end is constituted by the family policies with respect to three fundamental pillars: family benefits, parental leave, and day care centres.

Family benefits for families with disabled children are supplemented with diverse additional financial supplements. For example, in Austria it is 138 euros monthly (according to the OECD family database, www.oecd.org/social/family/database). In Italy the monthly financial support to families is known as the invalidity allowance.

Providing this type of financial support is a frequently implemented policy measure in many countries. It is expected to help families cover the daily living expenses of the disabled child. Policies consider other financial support, such as the provision of specific housing requirements such as lifts or specialized toilets.

Economic support to families with disabled children needs to be extended because costs for raising a disabled child are three times those of a non-disabled child. (Langerman and Worrall 2005: 1). It is doubtful whether the financial support provided by governments can cover this large difference so that families can be guaranteed a normal life.

Parental leave should be provided for the provision of continuous care for the disabled child. It should be available for both parents, thus counteracting the tendency towards the preponderance of the traditional breadwinner model in families with disabled children. Good practices also include “Short term breaks for children to enable parents to regain strength, cope better with stress and prevent burnout and breakdowns” (Kmita 2006).

Day care centres have a special meaning for disabled children; a related topic is institutionalization or de-institutionalization, which is considered below.

Many more issues related to families with children are also regulated with relevant policies or other action by the state and non-governmental organizations (NGO's). Their relevance is considered in the next section's description of contemporary approaches and development.

6.3. Contemporary developments in the policies approach

Recent approaches to the provision of support to families with disabled children are a direct outcome of the two Conventions on the Rights of the Child and the more recent Convention on the Rights of Persons with Disabilities. Adhering to these conventions, advanced societies take measures to protect the rights of disabled children to a decent living, good health, social inclusion, inclusive education, and rights to participate in society, and they raise awareness of the need to support disabled children and their families. Below is a short list of issues where the protection of rights is relevant.

6.3.1. Institutionalization and de-institutionalization

The institutionalization of disabled children is a traditional approach to providing support in their daily living, health, and education. The traditional institution is a large house where a diversity of care is supplied centrally. Disabled children live apart from their families.

Institutionalization brings about a range of negative effects in the rearing of children with disabilities. For one, they are torn from their families and thus they lack the warmth and affection of their closest ones. For another, they are separated from society and live with children like themselves; they are therefore excluded from society. Due to this non-participation, they remain unaware of major aspects of daily societal life. The quality of care might sometimes be low, as it cannot compare with that provided by the family.

During the past two decades, the de-institutionalization movement has expanded, whereby disabled children stay at home with their families and diverse services are provided at home. Rehabilitation is also provided at the home where feasible.

De-institutionalization is not possible for children with specific disabilities. In these case the new trend is towards the use of family-like housing in place of the large-scale institutions.

De-institutionalization changes considerably the life of disabled children. When they live with the family they keep warm relations with their brothers and sisters and feel secure under the care of their parents.

6.3.2. Inclusive education

Some children with disabilities need adequate education for whose provision specialized schools for the disabled are necessary. These include schools for the blind or intellectually disabled children. When feasible, however, regular schools should be attended. Thus the disabled children will not feel socially excluded and their socialization will develop smoothly.

Certain specific requirements need to be fulfilled. These include the availability of transportation of the children to and from the school, as well as special furniture and building construction (like lifts, toilets).

Abuse and stigma in schools are a special issue. Schools can successfully contribute to fighting these negative trends through the introduction of special school programs where values of humanity and solidarity are appreciated. Teachers may need specific qualifications.

6.3.3. Housing

A recent trend in residential architecture is known as “design for all”. It is meant to support families with aged persons, with disabled members, whether children or adults, as well as for families who do not need to provide care to any family member. “Design for all” makes it easier for families with disabled children to make visits and to move home as other families do.

6.3.4. Enhance social inclusion, fight abuse, stigma, discrimination

Families with disabled children are vulnerable to all these undesirable occurrences. Regretfully, they are observed in all advanced societies, although the tendency is towards their decline. Especially important is the problem of finding work: parents of disabled children may experience difficulties in finding appropriate work as employers might expect that they will frequently use family leaves.

Policies include the implementation of diverse programs. Especially important are those related to the spread in society of human values as mentioned above: tools may include special education programs in schools, the distribution of leaflets, or the use of mass media.

6.4. Future of policies

A major policy approach is mainstreaming disability. Thus the problems of disabled people and children in particular can be considered in every aspect of public life and the relevant public policies. A conventional example is that of public transport, where people in wheelchairs should be able to use the public facilities without obstacles.

Mainstreaming disability in family policies helps enrich family policies with instruments that will support families with disabled children. This support is explicitly configured and complemented by implicit family-related aspects of other public policies, like the issue of transportation in the example above.

Mainstreaming is a means of policy development where one issue cuts across diverse policies. While this approach makes it possible to assure for the policy relevance of diverse aspects of disability, it has the disadvantage of inferiority in policy construction, as disability will not be the central topic in those other policies. In other words. mainstreaming may produce fragmented policy development. To counter this effect, policy development based on mainstreaming should be extended to include the achievement of cohesion and policy integrity, by specifying circles of relevant issues and how they can be addressed by diverse previously available policies.

Both mainstreaming disability and policy integrity need monitoring. This can be achieved with the introduction of specific complex indicators based on detailed statistical data. The need for specialized agencies may arise.

NGOs can play a substantial role in this respect. They can provide advocacy to families with disabled children but also inform them about available forms of policy support that parents might not be aware of. Citizenship can thus assure its main principles: solidarity and participation.

7. Summary and conclusions

The consequences on families of having a child with disabilities are manifold; they can be so strong that the lives of these families differs significantly from that of others. The analyses described in the preceding sections showed that a child with disabilities may act as a stopping criterion for the parents to have more children, and thus they may not reach their desired number of children. Gender roles change significantly in families with disabled children. One of the parents, usually the mother, is forced to stay at home longer to provide care for the disabled child. So the mother may work on a part-time basis or not even work at all. The father remains the main breadwinner of the family. Thus, these families maintain a pattern of labour division in the family that is characteristic for the traditional male-breadwinner gender model. Moreover, higher expenses in the family forces the father to work additional hours, thus decreasing his leisure time and time spent with the family, leading to diverse negative consequences for the whole family. The tension caused by caring for a disabled child may bring about dissonance between the parents. Their mutual affection may decline and potentially lead to divorce or separation as the ultimate outcome. The economic situation in the family worsens as additional expenses arise for the provision of remedies and rehabilitation, for special home furniture, for clothing and food, for special toys or books, for specific utensils such as wheelchairs. Members of families with disabled children live in a specific life-cycle, forced by the specific division of labour and the restricted time for fundamental life-course activities such as education, work and leaving home of the healthy children. These families may remain stigmatized and excluded; their members experience increased stress and sometimes psychological and physical disorders. Still, they are only a small part of the population, but the risk of becoming part of them is destabilizing for many.

Many of the consequences of having a disabled child are not inevitable and can be counteracted by adequate policy measures. Personal resources and the ability to cope flexibly with problems, together with a favourable environment can prove relevant in providing some feeling of safety and protection. Moreover, the risk and the costs of having a disabled child might be more acceptable to the families if the state were to provide better services and more support to families with disabled children. The promotion of programmes directed at the psychological support of the parents and at improving and managing their emotional resources seem to be a crucial point.

In the comparative analysis it emerged that eastern European countries do not always perform worse than the western European countries. This could be due to a different concept of “inclusion” of people with disabilities, but also to a different role of the familiar networks that become active to provide assistance to families with disabilities, usually if support from the state is lacking.

Although the GGS data were not specifically designed to explore child disability, and the absolute number of families with disabilities remains limited by country, they provide a rich source of information about family member characteristics, life course events, background information, and opinions related to gender role and family life, making it a useful source of data for comparing the lives of families with special needs and contributing to the existing literature.

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Appendix A

Definition of "disability"

In the model GGS survey the question about the presence of a family member is implemented in the household grid section:
"113 a. "Is any member of your household limited in his/her ability to carry out normal everyday activities, because of a physical or mental health problem or a disability?"
1–yes 2–no (*go to 114*)
b. Who are these persons? Tick mark in column 'Disability' in Household Grid."

In the following, we report the implementation of the same variable in the national questionnaires, by country.

Italy

In the original national implementation of the GGS survey in Italy, all persons belonging to a family were interviewed. The international version of the data, consistent with the harmonizing guidelines, reports the information as declared by only one member of the family. The question asked to identify disability, asked to all members of the family and successively attributed to the proper position in the household grid, is:
"3.1 Do you suffer from a chronic illness or from a permanent disability that reduces your independence, requiring you to ask other people for help regarding everyday life needs inside or outside your house?
No ....….........................1
Yes, occasionally and only for some needs. 2
Yes, constantly and for important needs.......……………………………………….3

Bulgaria

The information is obtained from the household grid:
"1.18. a. IS THERE ANY MEMBER OF YOUR HOUSEHOLD WHO IS RESTRICTED IN HIS/HER DAILY ACTIVITIES DUE TO PHYSICAL OR MENTAL HEALTH PROBLEMS OR DUE TO DISABILITY? (whatever the age of that person)
yes – 1 -> b. WHO IS THIS PERSON?
no – 2

Russia

The information is obtained from the household grid:

“1.10a. [INTERVIEWER! AFTER YOU HAVE SPOKEN ABOUT ALL THE PEOPLE LISTED IN THE HOUSEHOLD GRID, ASK THIS QUESTION]

Please make a note of whether any of the household members have any physical or mental limitations that hinder his/her everyday activity or make him/her unable to work?

YES... 1

NO.. 2 ⇒ [GO TO 1.11. ON P. 5.]

Georgia

The information is obtained from the household grid:

“113. a. Is any member of your household limited in his/her ability to carry out normal everyday activities because of a physical or mental health problem or a disability?

1. yes ☐

2. no ☐ go to 011

France

The information is obtained from the household grid:

Certains membres de votre ménage sont-ils limités dans leur capacité à effectuer des activités quotidiennes normales en raison d’un problème physique ou mental ou d’un handicap ?

1. Oui

2. Non

Hungary

The information is obtained from the household grid:

“A6. Is any member of your household (including yourself) limited in his/her ability to carry out normal everyday activities because of a physical or mental health problem or a disability?

1 – yes

2 – no

IF YES, WRITE DOWN HIS / HER SERIAL NUMBER FROM THE TABLE IN A5”

Romania

The information is obtained from the household grid:

Information about state of health:

“703. a. Suferiţi de o limitare a capacităţii de a participa la activităţile obişnuite din cauza unei probleme sau a unui handicap fizic sau psihic?

1. da ☐ 2. nu ☐ treceţi la 704”

“Do you suffer from a limitation of the ability to participate in normal activities because of a problem or a physical or mental disability?”

Austria

The information is obtained from the household grid:

“113. a. Gibt es in Ihrem Haushalt jemanden, eingeschlossen Sie selbst, der in seiner Fähigkeit normale Alltagsverrichtungen auszuführen aufgrund von körperlichen oder geistigen Problemen oder Behinderungen eingeschränkt ist?

1 – ja 2 – nein ☐☐Filter to 114

b. Wer ist/sind diese Person(en)? Als Ausprägungen sind die Namen aller HHMitglieder anzuführen. Mehrfachnennung möglich.

Belgium

The information is obtained from the household grid:

1.43 [Prénom] est-il/elle limité(e) dans sa capacité à accomplir les activités quotidiennes en raison d’un problème de santé physique ou mental ou d’un handicap ?

1. Oui

2. Non

Autoriser Ne sait pas (code 7) et Refus (code 8)

Lithuania

The information is obtained from the household grid:

113. a. Ar jūsų namų ūkyje yra asmenų, kurių gebėjimai savarankiškai atlikti kasdienę veiklą yra riboti dėl fizinių ar protinių sveikatos sutrikimų ar neįgalumo? INTERVIUOTOJUI: Registruoti teigiamą atsakymą, jeigu Respondentas sako, kad negali atlikti kokį nors su asmens priežūra susijusį veiksmą (atsikelti, nusiprausti, apsirengti, pavalgyti, judėti ir pan.) arba negali savarankiškai pasigaminti maisto, tvarkyti namų, naudotis telefonu, vartoti vaistus, vesti pinigų apskaitą ir pan.

1 – taip 2 – ne ☐ 105 (3 psl)

b. Kas yra tie asmenys? Pažymėti (varnele) skiltyje „Negalia“ Namų ūkio schemoje.

“113. a. In your household is there a person who cannot (or can only limitedly) independently carry out everyday activities because of physical or mental ill health or disability? INTERVIEWER: Register positive response if the respondent says that he/she cannot perform any personal care that is associated with an action (getting up, washing, dressing, eating, moving, and so on), or is not able to prepare food, manage a home, use the phone, take medication, keep cash accounting and so on.

1 - yes 2 - no ->105 (p. 3)

b. Who are those people? Mark under "Disability" in the household scheme.

Poland

The information is obtained from the household grid:

“A16 Czy osoba jest niepełnosprawna?
1. tak
2. nie → pytanie A18”

“A16 Does the person have a disability?
1 yes
2 no → question A18

The following question refers to legal status of disability, required to get support:

A17 Czy osoba ma orzeczenie prawne niepełnosprawności?
1.tak 2. Nie

“A17 Does the person have legal certification of disability?
1 yes 2 no”

Appendix B – Additional tables and figures

Partnership status – comparative analysis

a) Partnership status at interview, by disability status and country

Families without disabled children

Country	With partner Abs	%	Single mother Abs	%	Single father Abs	%	Other Abs	%	Total Abs	%
Bulgaria	4,425	92.1	255	5.3	43	0.9	81	1.7	4,804	100.0
Russia	3,214	81.4	466	11.8	27	0.7	240	6.1	3,947	100.0
Georgia	3,428	92.8	192	5.2	22	0.6	50	1.4	3,692	100.0
France	2,668	83.8	323	10.1	61	1.9	132	4.1	3,184	100.0
Hungary	3,526	89.6	305	7.7	41	1.0	64	1.6	3,936	100.0
Italy	3,031	92.9	175	5.4	22	0.7	34	1.0	3,262	100.0
Romania	3,489	94.1	145	3.9	38	1.0	34	0.9	3,706	100.0
Austria	2,159	89.5	151	6.3	3	0.1	98	4.1	2,411	100.0
Belgium	2,004	87.9	153	6.7	34	1.5	89	3.9	2,280	100.0
Lithuania	2,609	85.3	373	12.2	27	0.9	51	1.7	3,060	100.0
Poland	4,933	88.6	470	8.4	39	0.7	125	2.2	5,567	100.0
Total	35,486	89.1	3,008	7.5	357	0.9	998	2.5	39,849	100.0

Families with disabled children

Country	With partner Abs	%	Single mother Abs	%	Single father Abs	%	Other Abs	%	Total Abs	%
Bulgaria	47	88.7	3	5.7	2	3.8	1	1.9	53	100.0
Russia	51	83.6	8	13.1	1	1.6	1	1.6	61	100.0
Georgia	37	88.1	3	7.1	1	2.4	1	2.4	42	100.0
France	26	76.5	5	14.7	0	0.0	3	8.8	34	100.0
Hungary	83	88.3	8	8.5	1	1.1	2	2.1	94	100.0
Italy	40	88.9	1	2.2	2	4.4	2	4.4	45	100.0
Romania	79	89.8	8	9.1	0	0.0	1	1.1	88	100.0
Austria	35	77.8	6	13.3	0	0.0	4	8.9	45	100.0
Belgium	44	74.6	6	10.2	4	6.8	5	8.5	59	100.0
Lithuania	15	83.3	2	11.1	0	0.0	1	5.6	18	100.0
Poland	190	81.9	32	13.8	2	0.9	8	3.4	232	100.0
Total	647	83.9	82	10.6	13	1.7	29	3.8	771	100.0

b) *Percentage of respondents thinking about separation in the last 12 months, by disability status and country*

Families without disabled children

Country	Yes Abs	%	No Abs	%	Not asked*** Abs	%	DK/refusal Abs	%	Total Abs	%
Bulgaria	158	3.3	4,276	89.0	304	6.3	66	1.4	4,804	100.0
Russia	686	17.4	2750	69.7	502	12.7	9	0.2	3,947	100.0
Georgia	91	2.5	2431	65.8	214	5.8	956	25.9	3,692	100.0
France*	263	8.3	1703	53.5	1215	38.2	3	0.1	3,184	100.0
Hungary	262	6.7	3254	82.7	346	8.8	74	1.9	3,936	100.0
Italy**					3,262	100.0			3,262	100.0
Romania	93	2.5	3395	91.6	183	4.9	35	0.9	3,706	100.0
Austria	242	10.0	2012	83.5	155	6.4	2	0.1	2,411	100.0
Belgium	240	10.5	1839	80.7	189	8.3	12	0.5	2,280	100.0
Lithuania	444	14.5	2189	71.5	400	13.1	27	0.9	3,060	100.0
Poland	339	6.1	4686	84.2	509	9.1	33	0.6	5,567	100.0
Total	2,818	7.1	28,535	71.6	7279	18.3	1217	3.1	39,849	100.0

*In France, the question was not asked if the partner was present during the interview
**Italy n/a
***"Not asked" also includes those without a current partner

Families with disabled children

Country	Yes Abs	%	No Abs	%	Not asked*** Abs	%	DK/refusal Abs	%	Total Abs	%
Bulgaria	1	1.9	47	88.7	5	9.4	0	0.0	53	100.0
Russia	12	19.7	40	65.6	9	14.8	0	0.0	61	100.0
Georgia	1	2.4	26	61.9	4	9.5	11	26.2	42	100.0
France*	5	14.7	17	50.0	12	35.3	0	0.0	34	100.0
Hungary	9	9.6	74	78.7	9	9.6	2	2.1	94	100.0
Italy**					45	100.0			45	100.0
Romania	2	2.3	76	86.4	8	9.1	2	2.3	88	100.0
Austria	10	22.2	29	64.4	6	13.3	0	0.0	45	100.0
Belgium	9	15.3	40	67.8	10	16.9	0	0.0	59	100.0
Lithuania	4	22.2	12	66.7	2	11.1	0	0.0	18	100.0
Poland	17	7.3	181	78.0	34	14.7	0	0.0	232	100.0
Total	70	9.1	542	70.3	144	18.7	15	1.9	771	100.0

*In France, the question was not asked if the partner was present during the interview
**Italy n/a
***"Not asked" also includes those without a current partner

c) *Percentage of respondents evaluating their relationship quality on a scale of 0-10, by disability status and country*

Families without disabled children

	Less or equal 5		More or equal 6		Not asked***		DK/refusal		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	355	7.4	4,043	84.2	304	6.3	102	2.1	4,804	100.0
Russia	554	14.0	2742	69.5	502	12.7	149	3.8	3,947	100.0
Georgia	223	6.0	3255	88.2	214	5.8	0	0.0	3,692	100.0
France*	84	2.6	1883	59.1	1215	38.2	2	0.1	3,184	100.0
Hungary	253	6.4	3239	82.3	346	8.8	98	2.5	3,936	100.0
Italy**					3,262				3,262	100.0
Romania	97	2.6	3426	92.4	183	4.9	0	0.0	3,706	100.0
Austria	65	2.7	2187	90.7	155	6.4	4	0.2	2,411	100.0
Belgium	52	2.3	2031	89.1	189	8.3	8	0.4	2,280	100.0
Lithuania	238	7.8	2395	78.3	400	13.1	27	0.9	3,060	100.0
Poland	304	5.5	4732	85.0	509	9.1	22	0.4	5,567	100.0
Total	2,225	5.6	29,933	75.1	4214	10.6	412	1.0	39,849	100.0

*In France, the question was not asked if the partner was present during the interview
**Italy n/a
***"Not asked" also includes those without a current partner

Families with disabled children

	Less or equal 5		More or equal 6		Not asked***		DK/refusal		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	7	13.2	41	77.4	5	9.4	0	0.0	53	100.0
Russia	7	11.5	45	73.8	9	14.8	0	0.0	61	100.0
Georgia	2	4.8	36	85.7	4	9.5	0	0.0	42	100.0
France*	2	5.9	20	58.8	12	35.3	0	0.0	34	100.0
Hungary	9	9.6	74	78.7	9	9.6	2	2.1	94	100.0
Italy**					45	100.0			45	100.0
Romania	4	4.5	76	86.4	8	9.1	0	0.0	88	100.0
Austria	4	8.9	35	77.8	6	13.3	0	0.0	45	100.0
Belgium	3	5.1	46	78.0	10	16.9	0	0.0	59	100.0
Lithuania	1	5.6	14	77.8	2	11.1	1	5.6	18	100.0
Poland	26	11.2	172	74.1	34	14.7	0	0.0	232	100.0
Total	65	8.4	559	72.5	102	13.2	3	0.4	771	100.0

*In France, the question was not asked if the partner was present during the interview
**Italy n/a
***"Not asked" also includes those without a current partner

Number of siblings – comparative analysis

d) Percentage of children who have or will have a younger sibling, by country, disability status and order of birth

First child non-disabled

Country	Already has a sibling Abs	%	The parents intend to have another child Abs	%	The parents do not intend to give another child Abs	%	Don't Know/don't answer Abs	%	Total Abs	%
Bulgaria	2,940	60.8	875	18.1	956	19.8	62	1.3	4,833	100.0
Russia	2,334	58.8	908	22.9	658	16.6	72	1.8	3,972	100.0
Georgia	2,824	75.9	573	15.4	298	8.0	24	0.6	3,719	100.0
France	2,478	77.3	395	12.3	294	9.2	37	1.2	3,204	100.0
Hungary	2,912	73.0	116	2.9	412	10.3	549	13.8	3,989	100.0
Italy										
Romania	2,237	59.5	585	15.6	904	24.0	34	0.9	3,760	100.0
Austria	1,726	70.9	396	16.3	298	12.2	16	0.7	2,436	100.0
Belgium	1,695	73.9	256	11.2	304	13.3	39	1.7	2,294	100.0
Lithuania	1,898	61.8	593	19.3	528	17.2	51	1.7	3,070	100.0
Poland	3,781	66.3	1086	19.0	730	12.8	107	1.9	5,704	100.0
Total	24,825	67.1	5,783	15.6	5382	14.6	991	2.7	36,981	100.0

*Italy n/a

First child disabled

Country	Already has a sibling Abs	%	The parents intend to have another child Abs	%	The parents do not intend to give another child Abs	%	Don't Know/don't answer Abs	%	Total Abs	%
Bulgaria	10	47.6	5	23.8	6	28.6	0	0.0	21	100.0
Russia	13	37.1	11	31.4	6	17.1	5	14.3	35	100.0
Georgia	12	80.0	2	13.3	1	6.7	0	0.0	15	100.0
France	8	57.1	3	21.4	1	7.1	2	14.3	14	100.0
Hungary	26	63.4	0	0.0	9	22.0	6	14.6	41	100.0
Italy										
Romania	18	52.9	1	2.9	13	38.2	2	5.9	34	100.0
Austria	12	60.0	5	25.0	3	15.0	0	0.0	20	100.0
Belgium	16	64.0	3	12.0	5	20.0	1	4.0	25	100.0
Lithuania	6	75.0	1	12.5	1	12.5	0	0.0	8	100.0
Poland	60	63.2	12	12.6	19	20.0	4	4.2	95	100.0
Total	181	58.8	43	14.0	64	20.8	20	6.5	308	100.0

*Italy n/a

Second child non-disabled (and first child non-disabled)

	Already has a sibling		The parents intend to have another child		The parents do not intend to give another child		Don't Know/don't answer		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	559	19.1	126	4.3	2178	74.5	59	2.0	2,922	100.0
Russia	747	32.2	279	12.0	1214	52.3	81	3.5	2,321	100.0
Georgia	1,009	35.9	364	13.0	1399	49.8	36	1.3	2,808	100.0
France	1,095	44.4	241	9.8	1061	43.1	67	2.7	2,464	100.0
Hungary	1,125	39.1	41	1.4	1347	46.8	367	12.7	2,880	100.0
Italy										
Romania	712	32.2	87	3.9	1,367	61.9	42	1.9	2,208	100.0
Austria	613	35.7	212	12.4	884	51.5	6	0.3	1,715	100.0
Belgium	727	43.2	125	7.4	768	45.7	61	3.6	1,681	100.0
Lithuania	512	27.1	155	8.2	1155	61.1	69	3.6	1,891	100.0
Poland	1,473	39.7	270	7.3	1819	49.0	151	4.1	3,713	100.0
Total	8,572	34.8	1,900	7.7	13192	53.6	939	3.8	24,603	100.0

*Italy n/a

Second child disabled

	Already has a sibling		The parents intend to have another child		The parents do not intend to give another child		Don't Know/don't answer		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	2	10.0	1	5.0	17	85.0	0	0.0	20	100.0
Russia	2	14.3	3	21.4	8	57.1	1	7.1	14	100.0
Georgia	6	37.5	3	18.8	7	43.8	0	0.0	16	100.0
France	9	64.3	0	0.0	3	21.4	2	14.3	14	100.0
Hungary	5	15.6	0	0.0	25	78.1	2	6.3	32	100.0
Italy										
Romania	9	31.0	0	0.0	18	62.1	2	6.9	29	100.0
Austria	5	45.5	0	0.0	6	54.5	0	0.0	11	100.0
Belgium	7	50.0	0	0.0	4	28.6	3	21.4	14	100.0
Lithuania	1	14.3	0	0.0	6	85.7	0	0.0	7	100.0
Poland	22	32.4	3	4.4	38	55.9	5	7.4	68	100.0
Total	68	30.2	10	4.4	132	58.7	15	6.7	225	100.0

*Italy n/a

Gender roles – comparative analysis

e) Activity status of the mother, by country and disability status.*

Families without disability

	Mother is employed		Mother is not employed		Don't Know/don't answer		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	3,332	69.4	1,427	29.7	45	0.9	4,804	100.0
Russia	3,045	77.1	874	22.1	28	0.7	3,947	100.0
Georgia	1,071	29.0	2,599	70.4	22	0.6	3,692	100.0
France	2,323	73.0	800	25.1	61	1.9	3,184	100.0
Hungary	3,161	80.3	734	18.6	41	1.0	3,936	100.0
Italy	1,858	57.0	1,382	42.4	22	0.7	3,262	100.0
Romania	2,144	57.9	1,524	41.1	38	1.0	3,706	100.0
Austria	1,959	81.3	449	18.6	3	0.1	2,411	100.0
Belgium	1,727	75.7	519	22.8	34	1.5	2,280	100.0
Lithuania	2,472	80.8	561	18.3	27	0.9	3,060	100.0
Poland	3,682	66.1	1,846	33.2	39	0.7	5,567	100.0
Total	26,774	67.2	12,715	31.9	360	0.9	39,849	100.0

*This table reports the activity status both of female respondents and of the partners of male respondents.

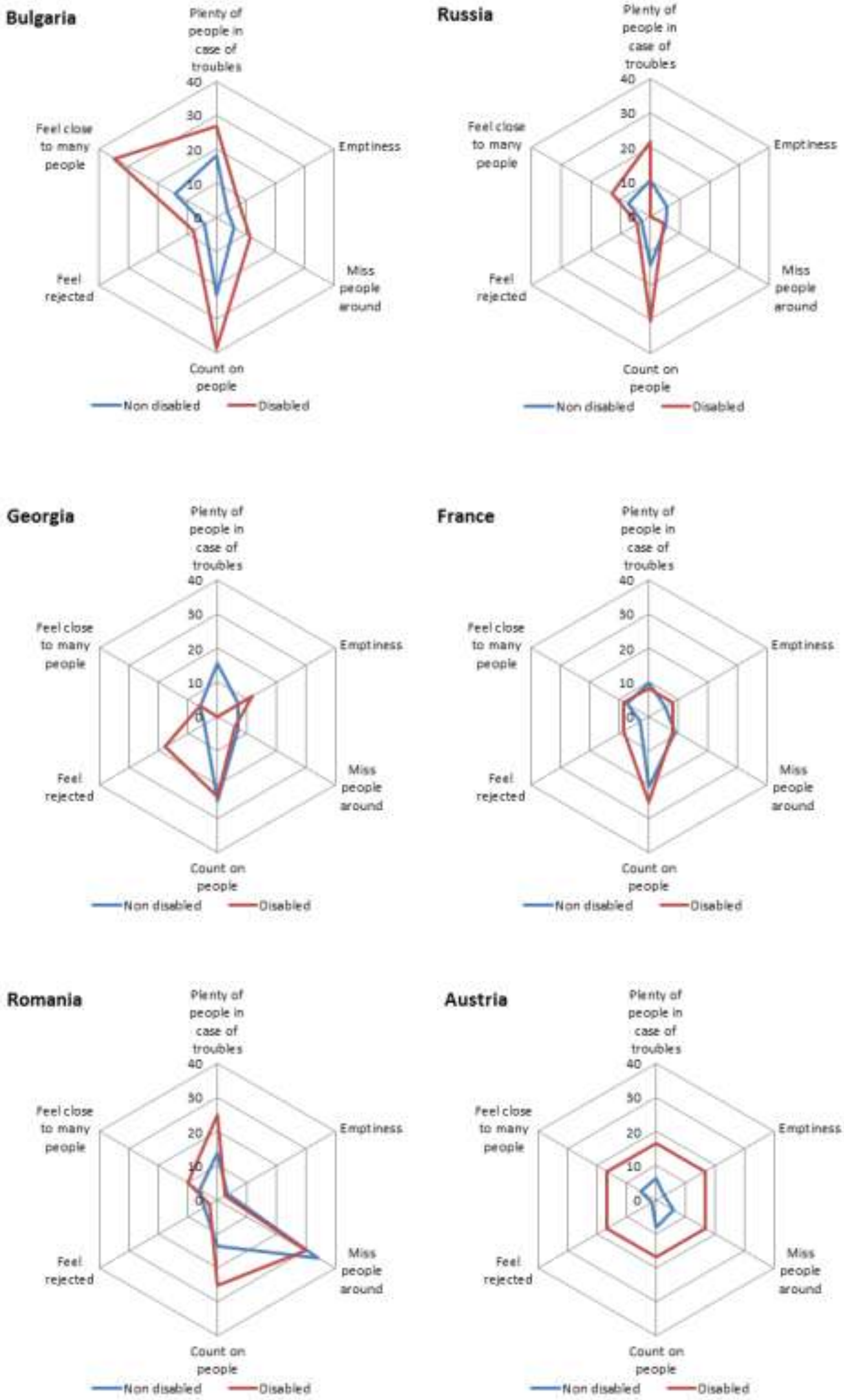
Families with disability

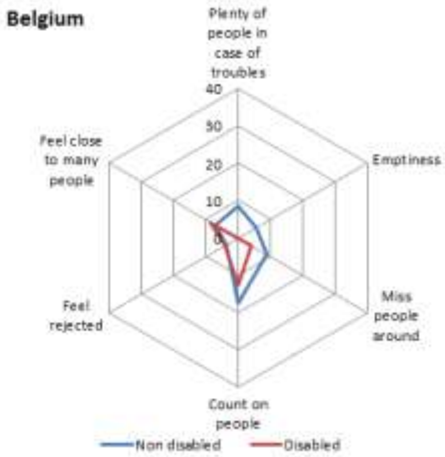
	Mother is employed		Mother is not employed		Don't Know/don't answer		Total	
Country	Abs	%	Abs	%	Abs	%	Abs	%
Bulgaria	20	37.7	31	58.5	2	3.8	53	100.0
Russia	41	67.2	19	31.1	1	1.6	61	100.0
Georgia	11	26.2	30	71.4	1	2.4	42	100.0
France	22	64.7	12	35.3	0	0.0	34	100.0
Hungary	65	69.1	28	29.8	1	1.1	94	100.0
Italy	23	51.1	20	44.4	2	4.4	45	100.0
Romania	47	53.4	41	46.6	0	0.0	88	100.0
Austria	30	66.7	15	33.3	0	0.0	45	100.0
Belgium	37	62.7	18	30.5	4	6.8	59	100.0
Lithuania	12	66.7	6	33.3	0	0.0	18	100.0
Poland	101	43.5	129	55.6	2	0.9	232	100.0
Total	409	53.0	349	45.3	13	1.7	771	100.0

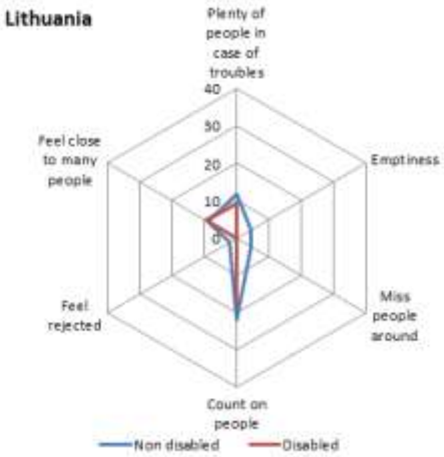
* This table reports the activity status both of female respondents and of the partners of male respondents.

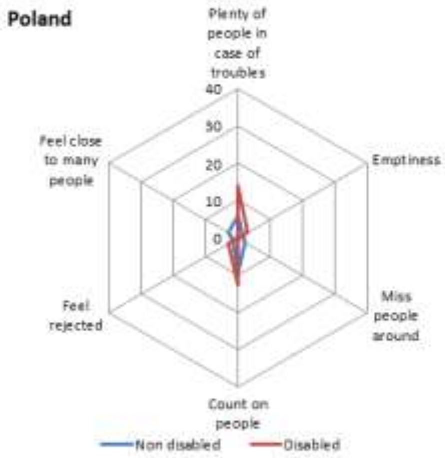
Well-being – comparative analysis

Percentage of respondents declaring that the situation is bad regarding the named dimensions (people to rely on in times of need, feelings of emptiness, missing having people around, possibility to count on a lot of people, feelings of rejection, feeling close to many people), by country and disability




Belgium
Plenty of people in case of troubles
40
30
20
10
0
Emptiness
Miss people around
Count on people
Feel rejected
Feel close to many people
Non disabled
Disabled


Lithuania
Plenty of people in case of troubles
40
30
20
10
0
Emptiness
Miss people around
Count on people
Feel rejected
Feel close to many people
Non disabled
Disabled


Poland
Plenty of people in case of troubles
40
30
20
10
0
Emptiness
Miss people around
Count on people
Feel rejected
Feel close to many people
Non disabled
Disabled