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Family Consequences of Children Disability

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Short abstract

This paper 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. 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 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. Using data from Gender and Generation Surveys, and using descriptive statistics, we show that 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. After showing these results in different European countries, we will analyse more specifically the situation of Italian families with and without disabled children. In fact, Italian data are collected for all members of the family and provide a rich source of information on the family members’ well-being. This paper 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: Family; health; well-being; children disability; GGS; European countries; Italy.

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 concern 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. Knox et. al (2000) report that some parents say they are better able to appreciate the important things in life and that these positive emotions, in turn, fuel the parents' ability to cope with day-to-day life.

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 paper 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. After showing these results in different European countries, we will analyse more specifically the situation of Italian families with and without disabled children. In fact, Italian data are collected for all members of the family and provide a rich source of information on the family member's well-being.

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.

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). For this paper, we use the data from wave 1 for every country that implemented the question about disability.

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.

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.

In the following step, we will analysis specifically the characteristics of the families with and without disabled children in Italy. Italian data are collected for all members of the family and permit us to measure the well being of each family member, including brothers and sisters of the disabled child. They stem from the nationally representative "Multiscopo" survey (Istat, 2003 and 2009), each including information on the socio economic and demographic characteristics of all members of about 20000 families.

Comparative results

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 (see preliminary results in Di Giulio et al., 2014 http://www.familiesandsocieties.eu/wp-content/uploads/2014/12/WP23GiulioEtAl.pdf). 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.

Further analysis

In a second part of the paper, we will analyse specifically the situation of Italy. Not only the Italian sample is outstanding because it collects information on all family members, but in Italy the care of family members is left primarily to the family itself, probably aggravating some of the possible negative consequences of the presence of a disabled child in the family.

References

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