



ARCHIVIO ISTITUZIONALE DELLA RICERCA

Alma Mater Studiorum Università di Bologna Archivio istituzionale della ricerca

The circumstances of migrant families raising children with disabilities in five European countries: Updating knowledge and pursuing new research

This is the final peer-reviewed author's accepted manuscript (postprint) of the following publication:

Published Version:

The circumstances of migrant families raising children with disabilities in five European countries: Updating knowledge and pursuing new research / Pierart G.; Arneton M.; Gulfi A.; Albertini-Fruh E.; Liden H.; Makharadze T.; Rekhviashvili E.; Dainese R.. - In: ALTER. - ISSN 1875-0672. - ELETTRONICO. - 14:4(2020), pp. 286-298. [10.1016/j.alter.2020.06.012]

This version is available at: <https://hdl.handle.net/11585/781915> since: 2020-11-24

Published:

DOI: <http://doi.org/10.1016/j.alter.2020.06.012>

Terms of use:

Some rights reserved. The terms and conditions for the reuse of this version of the manuscript are specified in the publishing policy. For all terms of use and more information see the publisher's website.

(Article begins on next page)

This item was downloaded from IRIS Università di Bologna (<https://cris.unibo.it/>).
When citing, please refer to the published version.

The circumstances of migrant families raising children with disabilities in five European countries: Updating knowledge and pursuing new research

La situation des familles migrantes ayant un enfant en situation de handicap dans cinq pays européens. Pour le renouvellement des connaissances et le développement de recherches

Geneviève Piérart^{a,*,1}, Melissa Arneton^b, Alida Gulfi^a,
Elena Albertini-Früh^c, Hilde Lidén^d, Tamar Makharadze^e,
Eliso Rekhviashvili^f, Roberto Dainese^g

^a School of Social Work, University of Applied Sciences and Arts Western Switzerland (HES-SO), Fribourg, Switzerland

^b Institute for Disability and Special Educational Needs (INS HEA), Suresnes, France

^c Oslo Metropolitan University - Department of Nursing, Oslo, Norway

^d Institute for Social Research (ISF), Oslo, Norway

^e Ivane Javakhishvili Tbilisi State University, Tbilisi, Georgia

^f Women's Union Rhea, Tbilisi, Georgia

^g Giovanni Maria Bertin Department of Education Studies, University of Bologna, Bologna, Italy

* Corresponding author. HES-SO – Haute école de travail social Fribourg, Route des Arsenaux 16a, Bureau 5.04, 1700 Fribourg, Switzerland.

E-mail addresses: genevieve.pierart@hefr.ch (G. Piérart), melissa.arneton@inshea.fr (M. Arneton), alida.gulfi@hefr.ch (A. Gulfi), elenaaf@oslomet.no (E. Albertini-Früh), hilde.liden@samfunnsforskning.no (H. Lidén), tamar.makharadze@tsu.ge (T. Makharadze), eliso.rekhviashvili1@gmail.com (E. Rekhviashvili), roberto.dainese@unibo.it (R. Dainese).

¹ <http://www.hets-fr.ch>.

A B S T R A C T

In 2017, specialists in several fields (health, education, and social work) from five European countries (France, Georgia, Italy, Norway, and Switzerland) established a network to jointly pursue studies on migration and disability. An initial workshop provided an opportunity to discuss their previous individual work and to develop a comparative research project. This article presents the key aspects of the discussion and the resulting plans for collaborative study. First, migrant children with disabilities remain statistically invisible in some countries. Separate policies and systems address their needs as migrants and their needs as persons with disabilities. Second, in all countries covered by the research network, there is an important gap between legal norms and the circumstances of migrant families raising children with disabilities. The same holds true for collaboration between public agencies, or between those agencies and NGOs (serving persons with disabilities, migrants, and/or national minorities). Further comparative and cross-disciplinary study must focus on increasing the social participation of children with disabilities and their families through social, educational, and health interventions within an intercultural context.

Keywords:

Children with disabilities
Migrant families
European countries
Comparative research

R É S U M É

En 2017, des spécialistes de différentes disciplines (santé, éducation et travail social) issus de cinq pays européens (France, Géorgie, Italie, Norvège et Suisse) ont créé un réseau afin de poursuivre leurs recherches sur le handicap et la migration. Le présent article expose les principaux résultats d'un premier *workshop* qu'ils ont réalisé et les pistes qui en découlent pour de futures recherches. D'une part, les enfants migrants en situation de handicap restent invisibles sur le plan statistique dans plusieurs pays. Leurs besoins en tant que migrants et personnes en situation de handicap sont pris en compte par des politiques et des dispositifs distincts. D'autre part, dans les cinq pays, un écart important entre les normes légales et la situation des familles migrantes ayant un enfant en situation de handicap est constaté. Il en est de même en ce qui concerne la collaboration entre les différents services publics, ou entre ces services et les associations soutenant les personnes en situation de handicap, les personnes migrantes et/ou les minorités. Les futures recherches seront centrées sur les moyens d'augmenter la participation sociale des enfants migrants en situation de handicap et de leurs familles dans des contextes d'interventions interculturelles et interdisciplinaires.

Mots clés :

Enfants en situation de handicap
Familles migrantes
Pays européens
Recherche comparée

1. Introduction

Raising a child with a disability can require a family to follow special strategies in order to support the child's development, organize daily life, and gather information on available psychosocial resources and support (Neely-Barnes & Dia, 2008; Pelchat, 2012). Migrant families face the additional challenges of adopting new cultural markers and rebuilding their social networks (Vatz Laaroussi, Bolzman, & Lahlou, 2008). The few existing studies that simultaneously address both disability and migration point out how the latter causes a family's social networks to contract, and how migrant families raising children with disabilities become more dependent on formal services for support (Ben-Cheikh & Rousseau, 2013; Jennings, Khanlou, & Su, 2014). In addition, linguistic and cultural differences (Amirpur, 2015; Bétrisey, Tétreault, Piérart, & Desmarais, 2014), precarious socio-economic circumstances (Albertini Früh, Lidén, Gardsjord, Aden, & Kvarme, 2016), or a lack of available services (Kittelsaa & Tøssebro, 2014; Mahele-Nyota, 2010) can make it harder to access support. These factors, all of which are associated with migration, systematically affect the ability of interventions to meet a child's needs (Greenwood, Habibi, Smith, & Manthorpe, 2015; Lindsay, King, Klassen, Esses, & Stachel, 2012; Pondé & Rousseau, 2013).

Migrant parents generally show little concern for their own needs, prioritizing those of their children (Bétrisey, Tétreault, Piérart, & Desmarais, 2015). This can lead to parental exhaustion, which can itself negatively affect a child's development. However, migrant parents also express a desire for more information on available resources and more assistance with decision-making. According to Piérart (2013), a family's migration pathway affects how it requests and uses support. Families raising children with disabilities face greater difficulty adapting to a host country, while a reduction in sociocultural reference points hampers their coping strategies. Furthermore, migrant families seem to prefer certain types of interventions: home visits by a practitioner (Bonomi & Bianchi, 2015), services provided by professionals of the same origin (Jegatheesan, Fowler, & Miller, 2010; Wiefferink, Vermeij, & Uilenburg, 2012), and care that takes the family's cultural background into consideration (Amirpur, 2015; Lindsay et al., 2012). Such approaches foster a relationship of trust between families and practitioners, thereby ensuring greater effectiveness.

The European Agency for Special Needs and Inclusive Education (2009) has studied the educational opportunities offered to migrant children with special educational needs (SEN) in 26 European countries. In fact, this research constitutes the first systematic comparison of patterns of intervention involving migrant families raising children with disabilities across multiple countries. The results show that migrant families with SEN children fail to fully mobilize support services for several reasons: linguistic differences, a lack of knowledge about the host country's welfare system, and difficulty asking for help. In their final recommendations, the study's authors underscore the importance of leveraging various media to provide families with more complete information, of promoting family group meetings, of facilitating the transfer of information from family to school, and of taking the needs of all family members (including siblings, grandparents, and other relatives) into account. However, the study focuses on the school inclusion of migrant SEN children, and provides little data on the children's families.

Although the needs of migrant families raising children with disabilities and the factors restricting access to available services have been clearly identified, the increasingly complex situation in Europe makes it challenging for host countries to meet the needs of such families and to improve their integration (Amirpur, 2015). There is therefore a need to pursue new research on interventions that families consider effective and that have a positive impact on child development, as well as on a family's integration within the host country. Furthermore, an intersectional perspective would allow for a reexamination of existing support structures, which tend to be organized by sector. This would require greater collaboration between experts in the field across various European countries. In particular, knowledge sharing and a programme of comparative research would make it possible to identify best practices for supporting families raising children with disabilities, given the welfare systems in place in specific countries.

In 2017, specialists in several fields (health, education, and social work) from five European countries (France, Italy, Switzerland, Norway, and Georgia) established a network to jointly pursue studies on migration and disability. An initial workshop provided an opportunity to discuss their previous indi-

vidual work and to develop a comparative research project. This article presents the key aspects of the discussion and the resulting plans for collaborative study. The first section describes the structure of the workshop and discusses how the participating scholars define and use the concepts of disability and migration. The subsequent sections present research results for each participating country. Finally, the article discusses similarities and differences across the five contexts of study, as well as emerging issues that call for further research.

2. Definitions and terminology

The World Health Organization (WHO) defines disability as “an umbrella term, covering impairments, activity limitations, and participation restrictions.

An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations” (WHO, n.d.).

Disability cannot therefore be reduced to an individual health problem. Rather, it must be treated as a complex phenomenon that reflects the interaction of personal, physical, and societal factors. The Convention on the Rights of Persons with Disabilities (CRPD) provides an international framework for ensuring and promoting the social inclusion of persons with disabilities. This includes protecting the rights of children with disabilities and their families. Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments that, in interaction with various barriers, may hinder an individual's full and effective participation in society on an equal basis with others.

This article treats parents and other family members raising children with disabilities as family caregivers. The latter are defined as family members who provide significant non-professional support, on a continuous or occasional basis, to a person in a state of dependence due to age, illness, or disability (Ducharme, 2012). However, the concept of care extends beyond the relationship between a dependent relative and a family caregiver. From a social and political perspective, it includes the development of resources aimed at reducing the potential vulnerability of family caregivers. Such resources are usually described as professional care (Giraud & Lucas, 2014).

Family migration involves people of various ages (infants, children, young people, and adults) who migrate for a variety of family-related reasons (employment, education, asylum, humanitarian protection, etc.). This category accounts for 40% of global migration to Europe (and 50% of EU citizens who have settled in another EU country). Although each state has its own laws governing immigration and integration, international and supranational legislation regulates family migration, with the aim of protecting vulnerable migrants. In particular, the European Council Directive on the right to family reunification establishes minimum criteria for family reunification legislation (OECD, 2018). Clearly, large numbers of children participate in family migration. However, currently available data are not detailed enough to determine the actual number of children included in statistics on economic migrants, asylum seekers, refugees, etc. (ibid.). The variety of criteria used to define “migrant children” — nationality, the child's place of birth, the parents' places of birth, first language (when different from the host country's main language) — not only further complicate statistical and analytical comparisons, but also negatively impact the care and protection provided to these children (Bolzman, Bernardi, & Le Goff, 2017; IOM, 2018; Jante & Harte, 2016; OECD, 2018). This article uses the EU definition, which identifies two groups of migrant children: those born abroad (first-generation migrants) and those who have at least one parent who was born abroad (second-generation migrants) (Jante & Harte, 2016). From this perspective, migrant families are those where one or both parents or family caregivers were born abroad.

3. Methodology

Held in Switzerland in November 2017, the workshop brought together research teams from France, Switzerland, Norway, Georgia, and Italy. The objectives were to:

- update knowledge on the circumstances of migrant families raising children with disabilities in all five countries;
- identify emerging issues that would benefit from comparative research;
- lay the foundations of a collaborative research project.

The participating research teams updated their knowledge by sharing contextualized information on disability and migration in their respective countries. They also presented their own research on collaboration between migrant families and disability practitioners, as well as on best practices for promoting family support, integration, and child development. The Delphi method — whereby a panel of experts seek to develop a consensus on a specific topic — facilitated the identification of emerging issues. Participating experts were asked to respond to a question or set of questions. Their answers were then shared and a new question or set of questions was developed based on key points of divergence. This process continued until a consensus was reached (Slocum et al., 2006). In this case, the consensus regarded key issues to be addressed through comparative research and the appropriate methodology to use.

4. Results

Below, results are presented by country (Switzerland, France, Norway, Italy, and Georgia). Each subsection covers three topics: first, data and policies on disability and migration; second, local or national studies dealing with the needs of migrant children with disabilities and their families; and finally, research conducted by workshop participants.

4.1. Switzerland

Some aspects of Swiss migration and disability policy negatively affect the circumstances of migrant families raising children with disabilities. On the one hand, the country's immigration policy is very restrictive, creating insecurity for some migrant families (Piérart, 2013). On the other hand, its integration policy focuses on the structural dimensions of the process, meaning that children's disabilities can negatively affect their parents' ability to demonstrate financial independence, language skills, social participation, etc. (SEM, 2018). Raising a child with a disability may also hinder a family's efforts to obtain Swiss citizenship. In some cases, local authorities do not take disability into account when evaluating a young person's language skills and level of integration, or they may argue that the child is not capable of making decisions related to citizenship (Inclusion Handicap, 2017). Foreigners arriving in Switzerland also face a restrictive welfare system (Tabin, 2017). For example, migrant children with pre-existing disabilities may be ineligible for disability insurance. Meanwhile, migrant children with SEN account for 45.9% of students in special schools and programmes, compared to 26.6% of those in regular schools and programmes (OFS, 2018a). Published in 2016, the first report on the rights of persons with disabilities in Switzerland highlights the positive impact of recent political reforms for this group. However, the report has been widely criticized by NGOs working in the field, especially regarding the failure of existing measures to support real equality (Moser, 2017).

There is a lack of integrated data related to migration and disability in Switzerland. Migration statistics have long distinguished between first-, second- and third-generation migrant children (OFS, 2018b). Integration policy seeks to address the specific needs of migrant children through support measures in the education system (including preschool, childcare, and vocational training), as well as through improving access to health services for migrants (SEM, 2018). However, immigration measures do not directly address disability, which is widely considered a matter for the welfare system's social security and disability insurance programmes. And although welfare statistics distinguish between Swiss citizens and foreigners, the latter category includes many non-migrants. Indeed, because Swiss naturalization policy is so restrictive, many individuals are still considered foreigners even though their families have been in the country for multiple generations (Tabin, 2017). Migrants with disabilities therefore frequently face intersectional disadvantages. In other words, they are simultaneously disadvantaged as both migrants and persons with disabilities in both health and social services (Cattacin & Domenig, 2015).

According to Piérart (2013), migrant families raising children with disabilities in Switzerland have a lower quality of life and less access to services than non-migrant families. Migrant families also have a greater need for information, as well as for material and psychosocial support. Furthermore, their inability to bring their migration experience to a close – by settling permanently in Switzerland or returning to their country of origin – negatively affects efforts to accommodate children’s disabilities. Gulfi, Piérart, Scozzari, Tétreault, Desmarais, and Lindsay (2016) highlight how legal, financial, or social instability can prevent some migrant families from pursuing life projects. These constraints can also affect the feasibility and quality of professional interventions. More recent work by Piérart, Gulfi, Scozzari, Desmarais, Tétreault, and Lindsay (2020) addresses a series of family-related factors that amplify the impact of raising children with disabilities on migrant families. Separation from the extended family leads to either increased dependence on social services or parental burnout. The language barrier makes it difficult to understand the social care system. The possibility of having to leave the country discourages parents from investing in professional childcare. As a result, one parent will often withdraw from the workforce – hereby foregoing a source of income – in order to care for a child with a disability. Differences in educational benchmarks, disability support systems, and therapies between the country of origin and the host country can lead to a decreased sense of parental competence. Finally, stress, loneliness and tensions within the parental couple can lead to psychological vulnerability for many families.

Disability practitioners also report many personal, relational, and contextual challenges related to their work with migrant families (Gulfi, Piérart, Scozzari, Desmarais, Tétreault & Lindsay, 2020). They find such cases unusually complex, requiring them to “go above and beyond.” Nevertheless, some professionals have successfully adapted intervention strategies to the needs of migrant families. For instance, they have worked with multiple agencies to gather relevant information and customize services, they have assisted parents with fulfilling administrative requirements, and they have identified resource persons in other fields in order to expand a family’s support network. Such intervention strategies are highly individualized and are often developed in response to an emergency.

4.2. France

French disability policy tends to look beyond medical definitions in order to promote a sociological approach that identifies persons with disabilities based on various environmental factors. Furthermore, Law No. 2005-102, adopted on 11 February 2005, seeks to improve the social participation of persons with disabilities by decentralizing services and strengthening collaboration with disability organizations (Baudot, 2014). Nevertheless, several analyses point to the persistence of a medicalized approach in France (Arneton, Bourdelet, & Rachedi, 2014; Baudot, Borelle, & Revillard, 2013). Following a single window approach, Departmental Offices for Persons with Disabilities provide information to adults and children with disabilities regardless of their migration status.

The French Interior Ministry is responsible for granting asylum, issuing work and family reunification permits, and overseeing the naturalization process (Cornuau & Dunezat, 2008). Since 2016, migrants can also request residency permits for medical care. French integration policy is based on the principles of equality and assimilation. The naturalization process is generally expeditious, especially for children born to migrants in France or migrant children who grow up in the country. It is therefore difficult to compile data on the number of migrants in France, since people with an immigrant background tend to be French citizens (Simon, 2010). Some researchers estimate that 12.3% of the French population has at least one immigrant parent (Insee, 2017).

In theory, migrant children with disabilities have the same opportunities as French children. But as (Wang, 2013) points out, parents play a major role in securing support. Fulfilling administrative requirements therefore presupposes a shared understanding of disability between the family and the professionals responsible for providing information and managing cases. Accommodations for students with disabilities, whether in regular classes or special programmes, require authorization from a Departmental Office for Persons with Disabilities, which determines disability status. However, understandings of disability are not only administrative, but also cultural. Family members may interpret a child’s situation differently than the professionals who make the official determination. For instance, learning difficulties experienced by migrant children with disabilities in regular schools can

be underestimated due to the “ethnicized” perspectives adopted by teachers and health professionals (Selod et al., 2010). Moreover, Bedoin (2008) notes that even when migrant children are enrolled in special programmes, their needs tend to be oversimplified. For example, in cases of deafness, teachers tend to emphasize children’s disabilities and disregard their migration status on the pretext of treating all students equally. Paradoxically, the specific needs of a child may be neglected out of a desire to avoid discrimination.

Little information is available on the circumstances of migrants with disabilities in France (Bechrouri, Benichou, Blanchard, Demangeon, & Levesque, 2016). Each ministry compiles its own data, making it difficult to understand the overall situation in the country. The Ministry of Health is responsible for implementing disability policy through the Departmental Offices for Persons with Disabilities. Its records show that 12% of persons with disabilities registered in 2014 were children. Meanwhile, the Ministry of Social Affairs handles family services. Its records show that 4.03% of families that received financial support for childcare in 2011 were raising children with disabilities. Finally, the Ministry of the Interior reports that in 2009, 2% of residency permits (issued to either individuals or entire families) cited a need for healthcare.

The lack of institutional data is reflected in the small number of studies on the circumstances of migrants with disabilities in France. On 29 January 2018, an open search on Isidore, a French database indexing works in the humanities and social sciences, found 1613 articles referring to both “migration” and “disability.” However, only 155 of these articles address the impact of migration status or experience on the circumstances of persons with disabilities. There are very few sources of quantitative data, apart from the French Longitudinal Study of Children (ELFE) (Vandentorren et al., 2009). Using two samples from the ELFE cohort, Arneton and Girault (submitted) show an under-representation of children from migrant families among children with disability status. Even in cases where a migrant child is in worse health than a French child (based on the perceptions of the children’s parents), the migrant parents report that their child receives fewer medical or paramedical accommodations and more social accommodations.

4.3. Norway

According to its restrictive immigration policy, Norway only accepts certain categories of migrants. Since 2005, the number of EU workers has increased, and they now represent about half of all migrants to Norway. About a fifth of migrants are refugees – mainly from Somalia, Eritrea, Afghanistan, Iraq, and Syria – who arrived in the country during the last decade. Family reunion, including transnational marriages, constitutes another legal form of migration, accounting for about a third of all migrants to Norway (OECD, 2018). Migrants with permanent permission to stay in the country enjoy equal access to health and other welfare services. In the case of asylum seekers with serious health problems, access to specialist treatment and hospitals is restricted to life-threatening situations. However, each case is assessed individually, and the children of asylum seekers enjoy equal rights to health and education from day one. Norwegian integration policy treats each category of migrants differently. Refugee parents with a residency permit are required to complete a two-year introductory programme, during which time their children are expected to attend school or kindergarten. Public health supports for children with disabilities (resource teachers, physiotherapy, etc.) are mainly provided within regular schools or kindergartens. In terms of family policy, Norway aims to enable women to combine caring for young children with participating in the paid labour force. To ensure that they enjoy the same access to the labour market as other families (Arbeids- og sosialdepartementet, 2005), both parents of a child with a disability are eligible for support under the Norwegian welfare system. This allows them to live a normal family life despite their child’s extra care needs. Nordic welfare policies, including those related to children with disabilities, therefore rest on the principle of universality, which is reinforced by special support and service provisions for children with disabilities and their families (Eriksen, 2003; Ytterhus, Egilson, Traustadóttir & Berg, 2015). Over the last two decades, various policy efforts have sought to avoid marginalizing minority groups and especially people with special needs. However, little attention has been paid to migrants with disabilities (Berg, 2015).

Norwegian research on disabilities emphasizes the difficulties that parents raising children with disabilities face when applying for special support and services. Families may lack information about

their rights or the healthcare system. They often find the system fragmented and available services inadequate or poorly adapted to their needs. Requests for additional assistance are frequently rejected, requiring families to make repeated time-consuming attempts to access support. And yet, parents rely on the support provided to be able to live normal lives (Demiri & Gundersen, 2016; Kittelsaa & Tøssebro, 2014). Despite their diverse characteristics, migrant families face many of the same issues, such as language barriers and other communication problems, as well as a limited knowledge of the health and welfare system. In particular, families often lack information on available support and are unfamiliar with application procedures (Albertini Früh et al., 2016; Berg, 2015; Söderström, 2012). Research shows that raising a child with a disability compounds the challenges already faced by migrant parents in their efforts to find the support they need (Fladstad & Berg, 2008; Kittelsaa, 2012). Migration disrupts a family's social networks and limits its members' ability to get help from close kin. Some families find the welfare state's support system odd and challenging (Sajjad, 2012), while migrant parents are less likely to join patients' rights organizations than Norwegian citizens (Demiri & Gundersen, 2016). Professional intervention is therefore vital for proactively providing these families with timely information, practical help, and professional support. Such assistance increases the chances of success when applying for social welfare support (NAV), as well as other key forms of support managed at the municipal level (Albertini Früh et al., 2016). The results of one study (Kvarme et al., 2016) show that conditions and opportunities for families raising children with disabilities improve when practitioners are vigilant in providing adequate information and language support, in reducing communication barriers, and in ensuring that children received support from a health and social services coordinator responsible for following up on their complex needs. Health and social practitioners tend to base cooperation on trust relations, by recognizing the needs and skills of parents (Albertini Früh, Lidén, & Kvarme, 2017).

4.4. Italy

Established in 2010, the National Observatory provides advice and technical support for policy development related to ensuring the rights of persons with disabilities. The initiative includes a working group on implementing the CRDP. National Health Service reforms launched in the 1970s led to the closure of institutions for persons with disabilities and the development of inclusion measures (Fea, 2016). However, the inclusion of persons with disabilities within the education system, the labour market, and social life remains incomplete, especially due to gaps in the welfare system (Fea, 2016). Currently, Italian migration policy is focused on illegal immigration, as well as the humanitarian protection of refugees in coordination with the European Union. The most significant immigration flows are tied to labour and family migration, which are closely correlated (OECD, 2018). Recent policy developments have aimed to improve the integration of refugees, unaccompanied minors entering adulthood, and the children of migrants within the education system and labour market (OECD, 2017). In Italy, the children of migrants remain foreigners (non-citizens) even when they are born in the country. Considering the high percentage (37%) of children of migrants who were born in Italy (Caritas/Migrantes, 2011), an amendment to the country's immigration law would appear necessary.

Since the 1970s, the Italian education system has developed an inclusive approach to children with SEN, while using a very broad definition of special needs (Sandri, 2014). Children with disabilities and migrant children with special needs are integrated within the regular education system, and there has been considerable research on strategies for teaching, welcoming, and including non-native Italian-speaking students and students with disabilities. However, only a handful of studies have addressed the combined impact of migration and disability (for example: Caldin, 2014; Goussot, 2011). The results of one school-based research study (Caldin, Argiropoulos & Dainese, 2010) highlight the difficulties teachers face when trying to communicate with migrant families raising children with disabilities. In particular, educators lack the necessary time and cultural mediation resources. Information and communication gaps often make it difficult for parents to get involved. In this regard, education and social professionals point out the need for parents to have access to a local case manager, as well as a network of family and friends from a similar cultural background. Furthermore, migrant families raising children with disabilities face additional everyday challenges, such as precariousness, maternal isolation, and language barriers (Caldin, 2011, 2014; Caldin et al., 2010). Schools

and education services play a key role in meeting the needs of children with disabilities by making them feel welcome and by fostering inclusion. In this regard, communication with families and their participation in the education process are the most crucial success factors for an inclusion strategy. Finally, Caldin (2014) shows that educators and education services play a positive role in the integration of migrant families by fostering cultural exchange and dialogue among children. The inclusion and participation of migrant families also improve in the presence of cultural mediators. Schools provide families with access to a complex system of services for their children with disabilities. For teachers, it is very important to build a relationship based on trust, an empathetic attitude toward parents, and the ongoing exchange of information. However, these strategies are easier to implement in preschool than with the families of children of compulsory school age.

4.5. Georgia

After ratifying the CRDP in 2014, Georgia introduced a broad programme of deinstitutionalization that led to the closure of almost all institutions for persons with disabilities. Foreign policy considerations – specifically, a desire to join the European Union, NATO, and other international organizations – have provided a strong incentive for the country to improve the circumstances of persons with disabilities and other vulnerable groups. The Georgian government has also acknowledged the importance of networking with local NGOs, which are the main service providers for persons with disabilities (Makharadze, Kitiashvili, & Bricout, 2010). Due to Georgia's geopolitical situation, its migration and disability policies differ from those of countries in Southern and Northern Europe. Shaped by two armed conflicts, migration flows are characterized by high rates of emigration and internal migration (OECD, 2018). Immigration policy aims to prevent irregular migration and human trafficking, while promoting the integration of asylum seekers and internally displaced persons (Siar, Chindea, Majkowska-Tomkin, Mattila, & Pastor, 2008). As a multilingual and multiethnic country, Georgia has developed programmes to improve the integration and education of ethnic minority children, including through linguistic and cultural preservation efforts. However, cultural minorities remain highly marginalized within Georgian society, and poor knowledge of the national language remains a key impediment to the full participation of these groups in the political, social, and cultural life of the country (Mekhuzla & Roche, 2009). Persons with disabilities face similar barriers, insofar as they have limited access to health and social services, to education, and to employment (Makharadze, 2009; Makharadze et al., 2010; Public Defender of Georgia, 2015; Sumbadze, Makharadze, Abashidze, & Zhvania, 2015). Many families raising children with disabilities also experience poverty and marginalization (Public Defender of Georgia, 2015). In addition, many persons with disabilities struggle to receive the comprehensive and specialized medical care they require, including access to medication. In particular, this is the result of inaccessible physical environments and financial constraints (families often cannot afford the many medical services and medications not covered by the national medical insurance programme) (Makharadze, 2016). Like Italy, Georgia has pursued a policy of inclusion for children with special needs, including the introduction of measures for children with disabilities and migrant children. However, there are no available data on the number of migrant children who also have a disability (Rekhviashvili, 2017).

In Georgia, many persons with disabilities remain underserved and continue to live in social isolation. This is especially true in rural areas, where very limited information is available on social programmes for persons with disabilities and on services provided by social workers (Makharadze, 2016). Among ethnic minorities, the lack of support for families raising children with disabilities is often compounded by a poor knowledge of the national language and by life in a remote community. And since the government does not consider these issues a priority, inclusion programmes for children with disabilities and their families depend almost exclusively on the activities and resources of NGOs (Rekhviashvili, 2017).

There are no available studies on foreign migrant families raising children with disabilities in Georgia. Local research has failed to address this issue. However, given the specific context described above, studies on internally displaced families and/or families with diverse cultural backgrounds remain a priority and could benefit from international comparative research.

5. Discussion

5.1. *Updating knowledge*

The results presented at the workshop indicate that each of the five countries covered by the research network – France, Italy, Switzerland, Norway, and Georgia – has a national legal framework for managing migration and disability policy. The data highlight two key issues. First, migrant children with disabilities remain statistically invisible in some countries. Separate policies and systems address their needs as migrants and their needs as persons with disabilities. Second, in all countries covered by the research network, there is an important gap between legal norms and the circumstances of migrant families raising children with disabilities. Whereas all the countries have signed the CRDP and promote integration for children with disabilities, migrants continue to face obstacles to effective integration. This gap is especially clear in countries where statistical studies have been conducted (France, Italy, and Norway). Second, public services create inequality for migrants raising children with disabilities, as well as for the children themselves. Some of the studies conducted by workshop participants highlight the specific challenges related to collaboration between migrant families and disability practitioners in the fields of health (Norway), education (Italy), and social work (Switzerland). The lack of a political framework and institutional measures to support individual and interpersonal solutions is especially noticeable in the results of Georgian and Swiss studies. The same holds true for collaboration between public agencies, or between those agencies and NGOs (serving persons with disabilities, migrants, and/or national minorities).

5.2. *Emerging issues*

To begin with, the lack of a common research methodology makes it difficult to compare results. Second, individual studies focus on a specific field of intervention (education, health, or social work), while disability and migration relate to all these fields. Finally, there is a general lack of information on these issues in France and Georgia.

The workshop participants all agree that further comparative and cross-disciplinary study must focus on increasing the social participation of children with disabilities and their families through social, educational, and health interventions within an intercultural context. Strengthening comparative research will require developing studies that share a common methodology and that explore all levels of the ecological system, including social programmes and policies; health, education, and social work programmes and services; challenges faced by practitioners and families; as well as strategies and best practices developed through collaboration.

There is a growing need for a better understanding of the mechanisms that produce inequality. An international comparative research programme would allow for analysing relevant structural factors, including policies, institutional procedures, and representation. Furthermore, the intersectional impact of disability and migration (Amirpur, 2015) provides a new framework for issues analysis. Indeed, the findings presented at the workshop highlight how the challenges faced by both families and professionals are the result of the dynamic effect of disability and migration. It is therefore not simply a matter of adding together the impacts of disability and those of migration.

More generally, there is a significant need for empirical data on the circumstances of migrant children with disabilities in Europe, including on how those circumstances shape political perspectives on the integration of migrants. It would be interesting to expand the research network by including more countries and participants from Southern Europe, as well as Eastern Europe. The latter region includes countries where similar developments may have occurred more quickly than in Georgia, and where the presence of national minorities may have similarly shaped both immigration and emigration policy (Makharadze, 2009). As North American research has shown, comparing the circumstances of national minorities and migrants can lead to methodological bias (Greenwood et al., 2015; Piérart, 2013). However, the societal challenges faced by Eastern European countries have allowed for the development of inclusive responses based on a broad understanding of special needs, responses that avoid the pitfalls associated with the sectoral approaches developed in Western Europe.

6. Conclusion

Professionals who work with migrant families raising children with disabilities require additional support. Although some best practices have been identified at the local level, more knowledge is required about the broader context of their work. An intersectional approach covering all the countries covered by the research network would make it possible to compare results using a common theoretical framework. However, the conceptual framework must be discussed in depth to ensure that it reflects the realities of both migrant families raising children with disabilities and the professionals who support them. Another challenge will be to develop comparative European research that includes a participatory component, while also taking national and international contexts into account. Only then can it truly contribute to a collective emancipatory movement.

Funding

This work was supported by the Swiss National Science Foundation (IZSEZO.177596/1) and the HES-SO - University of Applied Sciences and Arts Western Switzerland (AGP.78399).

Disclosure of interest

The authors declare that they have no competing interest.

References

- Albertini Früh, E., Lidén, H., Gardsjord, R., Aden, P., & Kvarme, L. G. (2016). Innvandrerfamilier med barn med spesielle behov – mødres tilknytning til arbeidslivet. *Søkelys på arbeidslivet*, 33(3), 269–290. <http://dx.doi.org/10.18261/issn.1504-7989-2016-03-05>
- Albertini Früh, E., Lidén, H., & Kvarme, L. G. (2017). Tillit til velferdstjenester? Innvandrerforeldre med barn med spesielle behovs møter med hjelpeapparatet. *Tidsskrift for velferdsforskning*, 20(3), 191–208. <http://dx.doi.org/10.18261/issn.2464-3076-2017-03-02>
- Amirpur, D. (2015). *Migrationsbedingt behindert? Familien im Hilfesystem. Eine intersektionale Perspektive*. Bielefeld: Transcript Verlag.
- Arbeids- og sosialdepartementet. (2005). *Strategiplan for familier med barn som har nedsatt funksjonsevne*. Oslo: Arbeids- og sosialdepartementet.
- Arneton, M., Bourdelet, A., & Rachedi, Z. (2014). Quand trois regards disciplinaires explorent des rapports parlementaires préparatoires à une loi. In E. Née, J.-M. Daube, M. Valette, & S. Fleury (Eds.), *Actes 12èmes Journées internationales d'analyse des données textuelles* (pp. 45–56). Paris: JADT.
- Arneton, M., & Girault, C. (2020). *Comparer les situations de handicap à partir des aménagements déclarés par les familles issues ou non de l'immigration - application à partir des données longitudinales françaises issues de ELFE*. Alterstice (submitted).
- Baudot, P.-Y. (2014). Figures de l'État local. Une approche relationnelle des politiques du handicap. *Sciences de la société*, 90, 92–109.
- Baudot, P.-Y., Borelle, C., & Revillard, A. (2013). Politiques du handicap. *Terrains et Travaux*, 23, 5–15.
- Bechrouri, N., Benichou, S., Blanchard, R., Demangeon, M., & Levesque, C. (Eds.). (2016). *L'emploi des femmes en situation de handicap. Analyse exploratoire sur les discriminations multiples*. Rapport remis au défenseur des droits en novembre 2016. Retrieved May 2018 from https://www.defenseurdesdroits.fr/sites/default/files/atoms/files/rapport_sur_lemploi_des_femmes_en_situation_de_handicap-accessiblefinal.pdf
- Bedoin, D. (2008). Enfants sourds et malentendants en situation d'immigration à l'école : une double stigmatisation? *Alter*, 2, 292–311.
- Ben-Cheikh, I., & Rousseau, C. (2013). Autisme et soutien social dans des familles d'immigration récente : l'expérience de parents originaires du Maghreb. *Santé Mentale au Québec*, 38(1), 189–205.
- Berg, B. (2015). Immigrant Families with Disabled Children in Norway. In R. Traustadóttir, B. Ytterhus, S. Egilson, & B. Berg (Eds.), *Childhood and Disability in the Nordic Countries* (pp. 215–230). Basingstoke, UK: Palgrave Macmillan.
- Bétrisey, C., Tétreault, S., Piérart, G., & Desmarais, C. (2014). Les mesures de soutien privilégiées par les parents immigrants d'un enfant mineur qui présente des besoins spéciaux : une étude de la portée. *Service social*, 60(2), 29–52. <http://dx.doi.org/10.7202/1027989ar>
- Bétrisey, C., Tétreault, S., Piérart, G., & Desmarais, C. (2015). Services de soutien utilisés par les parents migrants d'un enfant en situation de handicap. *Revue Internationale de l'Éducation Familiale*, 38(2), 119–144.
- Bolzmann, C., Bernardi, L., & Le Goff, J.-M. (Eds.). (2017). *Situating Children of Migrants across Borders and Origins. A Methodological Overview. Life Course Research and Social Policies* (7) <http://dx.doi.org/10.1007/978-94-024-1141-6>
- Bonomi, M., & Bianchi, M. (2015). La rencontre avec l'Autre. Les visites domiciliaires, un outil de connaissance et un espace pour construire des liens. *La Pensée sauvage. L'Autre*, 3(16), 326–332.
- Caldin, R. (2011). Alunni con disabilità figli di migranti. *Educazione interculturale*, 9(1), 27–37.
- Caldin, R. (2014). Inclusive social networks and inclusive schools for disabled children of migrant families. *Alter*, 14(8), 105–117.

- Caldin, R., Argiropoulos, D., & Dainese, R. (2010). Genitori migranti e figli con disabilità. Le rappresentazioni dei professionisti e le percezioni delle famiglie. *Ricerche di Pedagogia e Didattica*, 5(1), 1–38.
- Caritas/Migrantes. (2011). *Dossier statistico immigrazione 2010*. Roma: IDOS Centro Studi e Ricerche.
- Cattacin, S., & Domenig, D. (2015). Menschen mit pluralen und komplexen Identitäten im Gesundheits- und Sozialbereich. In D. Domenig, S. Cattacin, & I. Radu (Eds.), *Vielfältig anders sein—Migration und Behinderung* (pp. 104–123). Zürich: Seismo.
- Cornuau, F., & Dunezat, X. (2008). L'immigration en France : concepts, contours et politiques. *Espace populations sociétés*, 2, 331–352.
- Demiri, A. S., & Gundersen, T. (2016). *Tjenestetilbudet til familier som har barn med funksjonsnedsettelse, NOVA-rapport 7/2016*. Oslo: NOVA.
- Ducharme, F. (2012). Prendre soin d'un parent âgé vulnérable, une réflexion sur le concept de 'proche aidant' et de ses attributs. *Les cahiers de l'année gérontologique*, 4(2), 74–78.
- Eriksen, J. (2003). Public payment for informal care of disabled children: Some dilemmas of the Norwegian welfare state. *European Societies*, 5, 445–463. <http://dx.doi.org/10.1080/1461669032000127688>
- European Agency for Development in Special Needs Education. (2009). *Multicultural Diversity and Special Needs Education*. Odense: European Agency for Development in Special Needs Education.
- Fea, F. (2016). Services for Persons with Intellectual and Developmental Disabilities in Italy. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.), *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan* (pp. 555–561). Cham: Springer.
- Fladstad, T., & Berg, B. (2008). *Gi meg en sjanse! Minoritetsfamilier med funksjonshemmete barn i Bydel Bjerke*. Trondheim: NTNU Samfunnsforskning AS, Avdeling for innvandringsforskning og flyktningstudier.
- Giraud, O., & Lucas, B. (2014). Care policy as government of life: Three models illustrated by Swiss examples. In V. Reddy, S. Meyer, T. Shefer, & T. Meyiwa (Eds.), *Care in context: transnational gender perspectives* (pp. 68–84). Cape Town: HSRC Press.
- Goussot, A. (2011). *Bambini «stranieri» con bisogni speciali. Saggio di antropologia pedagogica*. Roma: Aracne.
- Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic caregivers' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature. *Health and Social Care in the Community*, 23(1), 64–78.
- Gulfi, A., Piérart, G., Scozzari, E., Desmarais, C., Tétreault, S., & Lindsay, S. (2020). Les professionnels du champ du handicap dans leur travail auprès des familles migrantes. Une étude en Suisse romande. *Education comparée, Nouvelle série*, 20, 91–109.
- Gulfi, A., Piérart, G., Scozzari, E., Tétreault, S., Desmarais, C., & Lindsay, S. (2016). La collaboration entre les familles migrantes d'enfants en situation de handicap et les intervenants sociaux qui les accompagnent: entre défis à relever et ressources mobilisées. *Revue suisse de travail social*, 19/20, 73–91.
- Inclusion Handicap. (2017). *Rapport alternatif. Rapport de la société civile présenté à l'occasion de la première procédure de rapport des Etats devant le Comité de l'ONU relatif aux droits des personnes handicapées*. Retrieved May 2018 from https://www.inclusion-handicap.ch/admin/data/files/asset/file_fr/424/rapport.alternatif.cdph.inclusion.handicap.1.0_23082017.f.pdf?lm=1503592225
- Insee (Institut national statistique d'études économiques). (2017). *Immigrés et descendants d'immigrés. INSEE Références – France portrait social édition 2017*. [available on line] <https://www.insee.fr/fr/statistiques/fichier/3197277/FPORSOC17L3.F2.3.pdf>.
- IOM. (2018). *World migration report 2018*. Geneva: International Organization for Migration.
- Jante, B., & Harte, E. (2016). *Education of migrant children. Education policy responses for the inclusion of migrant children in Europe*. Cambridge: Rand corporation.
- Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom to recognition to services: how South Asian Muslim immigrant families navigate autism. *Disability and Society*, 25(7), 797–811.
- Jennings, S., Khanlou, N., & Su, C. (2014). Public health policy and social support for immigrant mothers raising disabled children in Canada. *Disability and Society*, 29(10), 1645–1657.
- Kittelsaa, A. (2012). Erfaringer fra møter mellom familier og hjelpeapparatet. In B. Berg (Ed.), *Innvandring og funksjonshemming* (pp. 103–128). Oslo: Universitetsforlaget.
- Kittelsaa, A., & Tøssebro, J. (2014). Foreldrenes erfaringer med hjelpeapparatet. In J. Tøssebro, & C. Wendelborg (Eds.), *Oppvekt med funksjonshemming. Familie, livsløp og overganger* (pp. 153–179). Oslo: Gyldendal Akademisk.
- Kvarme, L. G., Albertini Früh, E., Brekke, I., Gardsjord, R., Halvorsrudog, L., & Lidén, H. (2016). On duty all the time: Health and quality of life among immigrant parents caring for a child with complex health needs. *Journal of Clinical Nursing*, 25, 362–371.
- Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*, 34(23), 2007–2017.
- Mahele-Nyota, J. (2010). Familles immigrantes et handicap de développement: une double minorisation ? *Reflets : revue d'intervention sociale et communautaire*, 16(2), 214–234.
- Makharadze, T. (2009). Social integration of adults with intellectual disabilities in Georgia: Lessons from Poland and the USA. *International Social Work*, 53(1), 1–13.
- Makharadze, T. (2016). *Research Report: Accessibility of Healthcare and Social Services for Persons with Disabilities in Georgia*. Ivane Javakhsishvili Tbilisi State University.
- Makharadze, T., Kitiashvili, A., & Bricout, J. C. (2010). Community-based day-care services for people with intellectual disabilities in Georgia: a step towards their social integration. *Journal of Intellectual Disabilities*, 14(4), 1–13.
- Mekhuzla, S., & Roche, A. (2009). *National Minorities and Educational Reform In Georgia*. Flensburg: European Center for Minority Issues (ECMI).
- Moser, M. (2017). Remise du Rapport alternatif concernant la CDPH : la Suisse « handicapé ». *Revue suisse de pédagogie spécialisée*, 4, 68.
- Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention*, 5(3), 93–107.
- OECD. (2017). *International Migration Outlook 2017*. Paris: OECD Publishing. http://dx.doi.org/10.1787/migr_outlook-2017-en. Retrieved May 2018

- OECD. (2018). *International Migration Outlook 2017*. Paris: OECD Publishing. http://dx.doi.org/10.1787/migr_outlook-2018-en. Retrieved May 2018
- OFS. (2018a). *École obligatoire*.. Retrieved May 2018 from <https://www.bfs.admin.ch/bfs/fr/home/statistiques/education-science/personnes-formation/ecole-obligatoire.html>
- OFS. (2018b). *Migration et intégration*.. Retrieved May 2018 from <https://www.bfs.admin.ch/bfs/fr/home/statistiques/population/migration-integration.html>
- Pelchat, D. (2012). *Reconstruire la vie. Défi et espoir pour les pères et les mères d'un enfant ayant un problème de santé*. Montréal: Guérin.
- Piéart, G. (2013). *Familles, handicap et migration. Enjeux et intervention interculturelle*. Genève: Editions IES.
- Piéart, G., Gulfi, A., Scozzari, E., Tétreault, S., & Lindsay, S. (2020). Trajectoires de vie, ressources et soutiens de familles migrantes ayant un enfant en situation de handicap. Une recherche action dans un canton suisse. *Éducation comparée, Nouvelle série*, 20, 133–148.
- Pondé, M. P., & Rousseau, C. (2013). Immigrant children with autism spectrum disorder: The relationship between the perspective of the professionals and the parents' point of view. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 22(2), 131–138.
- Public Defender of Georgia. (2015). *Annual Report – The Situation of Human Rights and Freedoms in Georgia*.. Retrieved May 2018 from <http://www.ombudsman.ge/uploads/other/3/3512.pdf>
- Rekhviashvili, E. (2017). *Social support to enhance development and inclusion of children with disabilities in multi-ethnic context in Georgia*.
- Sajjad, T. A. (2012). Pakistansk norske familier med funksjonshemmede barn. In B. Berg (Ed.), *Innvandring og funksjonshemming* (pp. 57–73). Oslo: Universitetsforlaget.
- Sandri, P. (2014). Integration and inclusion in Italy. Towards a special pedagogy for inclusion. *Alter*, 14(8), 92–104.
- Selod, S., Grima, M. A., Brandibas, J., M'Roivili, K., Chatel, L., Foubert, R., et al. (2010). Des écoliers issus de la migration mahoraise et comorienne à la Réunion. *L'Autre*, 11, 79–93.
- SEM. (2018). *Politique suisse en matière d'intégration*.. Retrieved May 2018 from <https://www.sem.admin.ch/sem/fr/home/themen/integration/politik.html>
- Siar, S., Chindea, A., Majkowska-Tomkin, M., Mattila, H., & Pastor, I. (2008). *Migration in Georgia: a country profile 20p08*. Geneva: IOM.
- Simon, P. (2010). Statistics, French Social Sciences and Ethnic and Racial Social Relations. *Revue française de sociologie*, 51, 159–174.
- Slocum, N., Elliott, J., Heesterbeek, S., & Lukenmeyer, C. J. (2006). *Méthodes participatives. Un guide pour l'utilisateur*. Bruxelles: Fondation du Roi Baudoin.
- Söderström, S. (2012). Kultursensitiv kommunikasjon. In B. Berg (Ed.), *Innvandring og funksjonshemming* (pp. 129–150). Oslo: Universitetsforlaget.
- Sumbadze, N., Makharadze, T., Abashidze, T., & Zhvania, I. (2015). *Research Report: Impact of micro and macro factors on working environment adaptation and the work efficiency of people with disabilities*. Ivane Javakishvili Tbilisi State University.
- Tabin, J.-P. (2017). Quand l'Etat social profite des immigrés. *Reiso, revue d'information sociale*.. Retrieved May 2018 from <https://www.reiso.org/articles/themes/migrations/1755-quand-l-etat-social-profite-des-immigres>
- Vandentorren, S., Bois, C., Pirus, C., Sarter, H., Salines, G., Leridon, H., & Elfe Team. (2009). Rationales, design and recruitment for the Elfe longitudinal study. *BMC Pediatrics*, 9–58.
- Vatz Laaroussi, M., Bolzman, C., & Lahlou, M. (Eds.). (2008). *Familles migrantes au gré des ruptures. Tisser la transmission*. Lyon: Éditions l'interdisciplinaire-Psychologie.
- Wang, S. (2013). « Handicapé ? C'est insulter ma descendance et aussi mes ancêtres ! » : Négociations autour de l'inscription de l'enfant d'origine chinoise à la MDPH. *Terrains & travaux*, 23, 2.
- Wiefferink, C. H., Vermeij, B. A. M., & Uilenburg, N. (2012). Family counseling in the Netherlands for Turkish-origin parents of deaf children with a cochlear implant. *American Annals of the Deaf*, 156(5), 459–468.
- WHO (s.d.) Disability. Retrieved May 2018, from <http://www.who.int/topics/disabilities/en/>.
- Ytterhus, B., Egilson, S. T., Traustadóttir, R., & Berg, B. (2015). Perspectives on childhood and disability. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 15–33). Basingstoke, UK: Palgrave Macmillan.