Social Inclusion of migrant families with disabilities: parents experience and future time perspectives

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Abstract. This study explores through the lenses of parents, the experience of inclusion in families raising children with multiple disabilities who migrated in Italy. Both challenges and supports to access and participation were analyzed. A future oriented perspective was also adopted insofar being engaged in and envisioning inclusive trajectories in future life designing fosters the development of a social identity, of an active role in community life thus contributing to participation and inclusion. Seventeen parents, 12 mothers and 5 fathers, of children with disabilities in school age were interviewed. Countries of origin were both Eastern Europe and, mainly, African countries. A qualitative analysis highlighted several themes, as well as supports and barriers these families face highlighting their experience of inclusion. By adopting a future time oriented perspective hopes and fears about inclusion emerged as well as resources and specific actions professionals and community members can undertake to support and promote inclusion.

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Introduction

After resettlement in a new country, when the difficulties and circumstances that have caused people to seek asylum or leave home country become less pressing, a new phase of life begins for migrant families.

Challenges and, hopefully, opportunities associated with migration processes are very complex and become even more multifaceted for families when their child has a disability. Parenting children with disabilities can in fact embed intense and chronic caregiving responsibilities. The experience can be both a stressful and a rewarding dimension of parenthood (Canary, 2008).

As reported in the literature, several factors may strongly condition families' perceptions and situations, such as the *culture of origin*, *circumstances* an*d reasons* underlying their migration, their *experience* in the country of arrival and their *expectations* from services. These challenges include perceptions fixed in advance (Berg, 2015). Ways of understanding disabilities are in some cases culturally specific and may contribute to social isolation and experienced guilt and shame. For example, a child's disability in one specific culture may be viewed as a punishment from God rather than an entirely medical condition, a more spiritual perspective rather than medical (Welterlin & LaRue 2007; Kramer-Roy, 2012). As a consequence, some immigrant parents are unwilling to accept the Western medical diagnosis of a condition, and see their child as mis-labelled (Daudji, Eby, Foo, Ladak, Sinclair, Landry, ... & Gibson, 2011). Moreover, Fellin and colleagues (Fellin, King, Esses, Lindsay, & Klassen, 2013) found that immigrant parents raising a child with disabilities face several barriers to accessing and using health and social services because their language barriers can lead to lack of knowledge of supports and service. This, in combination with limited economic resources and other risk variables, may contribute to greater needs and reduced supports. Additionally, limited language skills, lack of knowledge about the health-care system, limited social networks and fewer economic resources seem to contribute to increased mental distress (Berg, 2015).

While these families frequently lack information about the services' system, there is potentially also a lack of knowledge in the service system about the needs of these families (Canary, 2008) and they may encounter stereotyped assumptions or prejudice. If health-care workers are not aware of the specific cultural context in which the services are provided, they will miss out on the significance of both their own and the

service recipients' inherent perceptions and views (Söderström, 2014) making their actions at risk for a reduced efficacy and reduced satisfaction for both professionals and families.

As a result of the prolonged and complex transition experienced, challenges may in fact arise for participation and inclusion, that is for the possibility to exercise their rights and participate, in the ordinary activities as an equal citizen; to benefit from all the opportunities available, employment, education and other social and recreational activities; to take part in society and plan for their future life. But it is also about a community that cares for its members, makes them feel welcome and is willing to adjust to fit their various needs (Marino-Francis & Worrall-Davies, 2010).

Based on existing knowledge, we developed the following research questions: What are currently the barriers and supports immigrant parents experience in their inclusion and participation when a member of their family, i.e. their own child, has a disability? Is their experience still influenced by the cultural context of origin? And also, are they meaningful in current Italian context? Analyzing these themes in Italy is relevant insofar Italy is in a country where incoming migrants is a relatively recent phenomenon, dynamic and continuously changing.

A future oriented perspective was also adopted by looking to their future hopes and fears, to goals they set in personal and social domains of their future life, to the space inclusion and participation have in their future designing. Experiencing complex life conditions, vulnerabilities or disabilities, may limit in fact life trajectories; influence goals' setting, personal and social future goals exploration, and the perception of supports and barriers towards future (Sgaramella, Ferrari, & Ginevra, 2015; Stommen, Verbunt, & Goossens, 2016). Research has in turn shown that a positively future oriented perspective predicts well-being and plays an important role in individual attitudes and behaviors (Adams, 2009; Kirby & Petry, 2004; Reynolds et al., 2004; Sgaramella, Ferrari, & Ginevra, 2015). More particularly, when future time perspective extends beyond the boundaries of the personal sphere, it becomes *a resource for building communities* (Morselli, 2013).

Being engaged in and envisioning future trajectories including both personal and social future goals can be seen as fostering the development of a social identity, of an active role in community life (Taber, 2015) thus contributing to participation and the experience of inclusion of immigrant families experiencing disability in their everyday life.

Study participants

Twelve mothers and 5 fathers of immigrant families were interviewed. They came from three different cultural background: Romania (n=6), North (5) and Central Africa (6). Their age ranged from 30 to 45 years. Children age ranged from 5 to 12 years old.

Parents were informed of the study aims and procedures. Participation was voluntary. A language interpreter was available, if needed and involved for three interviews.

An interview on current participation and future perspectives

Interviewing is an effective method for exploring experiences, opinions, wishes and concerns and to achieve a deeper understanding of how people feel and think about a specific issue in their own words. Both objective and subjective indices were used in analysing conditions posed by life contexts and participants perceptions (Sgaramella & Scorgie, 2017) in order to describe their experience of participation and inclusion.

The interview proposed is structured along four sections, as summarized in Table 1.

Table 1. *Interview structure*

Section	Issues
I. *General information*	Country of origin, Migration details, Family characteristics
II. *Experience of disability*	Type of disability experienced in the family, Past and current ideas on disability
III. *Challenges and supports experienced*	Supports and difficulties experienced when dealing with services and interacting with community members
IV. *Future perspectives*	Family future goals, Supports and difficulties foreseen to their participation and inclusion

In more details, questions in the general information section referred to Length of stay in Italy, Reasons to come to Italy, Members of their families, first experiences in the new context.

As   regards attitudes and ideas about disability, in section two participants were asked to describe their past and current idea of disability,

type and severity of disability of their son or daughter.

In section three, to address challenges and supports experienced, parents were asked about their access to support programs; opportunity to socialize, characteristics of people with whom they relate in terms of nationality, ethnicity or spoken language; context in which these interactions take place; supports on which they thinks can count in emergency situations and to deal with the difficulties in everyday life.

In section four, participants were asked to identify and list main future goals and afterwards choose the three most important goals for them, that is their priorities.

Clues provided to facilitate thinking and answering were: Think to yourself and to your family members; think to your personal life and to your family life, think to people living near your house, to the community groups with whom you interact.

Each interview lasted 45 to 60 minutes. Written narratives collected were analyzed according to Domains (*health, family, friends, free time, personal growth and work related goals*), Perspectives (*personal, family related and social*) and Priorities, Expected Challenges (*Personal or contextual*).

Two independent researchers read and coded answers provided during the interview and reached afterwards a consensus on themes highlighted.

Results

Families under the attention in this study were characterized by a permanence in Italy for a period ranging approximately from 2 to 6 years, with a mean duration of 3.7 years (s.d. 2.3). Severity of their children disability ranged from mild to moderate and, based on families narratives and service reports, it could be characterized as developmental intellectual disability for 11 children and learning difficulties for 6 of them.

Some of the families endured strenuous lives even before the birth of their children. Many had a challenging background as refugees or asylum seekers and had experienced danger, fear, and extreme uncertainty. Some families had lived in a centre for asylum seekers and had experienced this as a destructive both to their self-confidence and family relations.

Additionally, families involved in the study frequently reported difficulties in the first steps, in the initial periods of their life in Italy which

they perceived more impacting on wellbeing and in dealing with values different from native ones**.**

Attitudes and ideas about disability

Several participants (13; 76.5%) referred   that one of the main reasons to choose to migrate was the awareness that their home countries are stigmatising and not inclusive for people with disability. Main purpose of their migration was to guarantee both health support and educational and learning opportunities for their children. And this was true for families coming from different cultural contexts.

Most parents hoped to take care of their children with the occidental medicine although some of them (4; 23.5%) referred that at the beginning they were unwilling to accept the medical diagnosis given to their child and as 'mis-labelling' and not describing in full their child.

Four parents (23.5%) reported a sense of social stigma and lack of leisure time. Some of the parents reported that taking care of their ill child impacted their marital relationship (2; 11.8%).

Supports and challenges

Mothers participating in the study were mainly satisfied with the support received from health services but less satisfied with their social services. Fathers reported being generally satisfied for their health, but two of them also expressed worry about the health of both their wife and child.

Several themes emerged after coding the answers provided.

Communication. Despite the use of linguistic mediators, language barrier was perceived as one of the main obstacles (13; 76.5%) in accessing, receiving, and utilizing health care services for these parents. Some parents reported difficulties in understanding the language of the clinicians (7; 41.2%), and this was particularly relevant for families coming from central Africa. Language problems, difficulty in understanding and accessing information related to their son disability (2, 11.8%) were still reported. Some still felt uncomfortable and frustrated trying to obtain information about their child's DD (6; 35.2%) and this was mentioned as particularly relevant by mothers coming from African cultures.

Socio-economic conditions Precarious, unstable, and low paid jobs were referred by 14 (82.3%) participants. Due to transportation limitations basic practical tasks such as attending medical visits and doctor appointments were often seen as an economic challenge, as an obstacle (7 %). Most of them (82.3%), in fact, resettled in peripheral areas of the city ans services

were far from their house. A fear of loss of employment and financial support creates worry and guilt for them because health care expenses have negative impacts on immigrant families on their psychological, material, and physical health and well-being (12; 70.6%).

Social participation

Parents reported they frequently socialize with people of different nationality, ethnicity and mother tongue: 82.3% declare that they frequently (several times in a week) interact with people of different ethnicity and nationality, but 43.2% of them reported they never socialize with non-immigrant people outside their child school context. A perception of a more limited social networks (i.e., close family members and friends) with respect to their country of origin was reported by 14/17 families. And for these parents this was true also for their children.

Additionally, when answering to the question on sources of supports they think they can count on, they first of all mention family members friends (82.3%), secondly persons living in the close context (70.6%). A limited number of participants mentioned services (43.2%). They rarely or never think can refer to persons in the work environments.

Future time perspectives

When asked to list goals which they foresee in future life, a list of themes emerged as well as priorities. Goals listed referred to the economic domain (37; 43.5%), followed by health issues (34; 40%), housing issues (10; 11.8%), free time and leisure activities (4; 4.7%).

Family future goals mentioned (55; 64.7%) largely outset personal goals, such as more satisfying work or personal education (25; 29.4%), and goals related with their large social context (5; 5.9%) which consisted mainly in taking actions for the close neighbourhood.

Internal attitudes and knowledge (lack of confidence and skills) were mentioned as the most powerful barrier to reach their goals by 23.5% (4) participants while a challenging context was mentioned by the other 13 participants. The high level of competence requested and the unpredictability of the current situation were the reasons more frequently mentioned.

Discussion

In this study, we examined the experience of access and participation, which can be considered as central components of inclusion experienced by immigrant families of children with disability.

Inclusion in the view adopted here incorporates an integrated perspective involving Equitable Access, the Development of Human Potential, and Engaged Participation (Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010). It aims to facilitate access to needed supports, the development of a sense of belonging to a community, and opportunity to expand knowledge and engage significant experiences as a member of the community (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012). A future oriented perspective has been also adopted for the first time, to our knowledge, to examine inclusion.

Following this view and related suggestions from the literature our main findings on inclusion can be effectively described in terms of experience of being, belonging and becoming active member of the community.

Being immigrant family experiencing and dealing with disability

For families who migrate to a new country the process of migration comes with challenges in terms of adaptation to a set of differing beliefs, ideologies, and practices.

Communication and socioeconomic factors are frequently mentioned by parents interviewed as relevant variables in the well-*being* experienced by their families, underlining the role of language as a significant language barrier in understanding information or expressing feelings and needs. Lack of knowledge and need for supports from professionals also emerged. These results are consistent with previous research (Greenwood et al., 2015).

According to Bywaters et al. (2016), there are still stereotypes about how ethnic minority families react to having a child with disability. One is that they usually have religious explanations for a child's disability. Another is that they feel shame and therefore do not seek help, and a third is that they have low expectations for the future of their child. These stereotypes are also encountered among professionals in the service system and might result in a failure to seek professional assistance. We did not find these stereotypes among answers provided by families interviewed. A possible explanation might be the length of permanence in the host country, that is in Italy.

The situation of immigrant families foreseen in the study does not seem so 'special' with respect to other non-immigrant families dealing everyday with their child disability (Amado, Stancliffe, McCarron, & McCallion, 2013). What may differ is the role that additional variables, external to disability itself and more linked to the

migration experience may play such as language difficulties, the need for information about both disability and welfare arrangements, and an awareness of refugee-related problems in professionals.

Becoming part of the community: Challenges and Supports to participation

Some of the parents interviewed reported difficulties in dealing with health services. Experience with health care professionals can be seen as a barrier to care for immigrant parents. But its influence extends beyond the degree of satisfaction and wellbeing experienced and may also increase the distance between these families and the context (Fellin et al. 2013; Kramer-Roy, 2012).

Additionally, parents participating in the study seem to be aware of changes in their social networks. In line with the literature, most of them reported in fact that they left strong and large social networks in their home countries, and now experience smaller ones in the host country. Here work context is not felt as a source of support thus increasing their feeling isolated and alone in navigating through a new environment (Tarricone et al., 2012). Social supports mentioned come from family, friends and neighbours and social support is seen as an important factor in reducing their strain on parents (Berg, 2015; Tsai & Wang, 2009). Support they receive from their families vary among our participants. For instance, immigrant parents' contact with friends as a coping method (Croot, Grant, Mathers, & Cooper, 2012).

Social networks seem limited not only in the number of persons to which they can refer to but also in the range of contexts in which they think they can find it. A very limited number of parents mentioned the possibility of searching for supports in the workplace. Parents still feel this strong stigma of their child disability (Daudji et al. 2011; Kramer-Roy, 2012) therefore, they are hesitant to readily seek out support to persons in the work context where in most cases no one is informed about the family member with disability.

Following House's conceptualization of social support (House et al., 1988), the study suggests that attention should be paid to *instrumental support*, that is financial received as well as the availability of other forms of tangible/care giving services and programs); s*tructural support* (the ease with which parents can access, utilize, and gain information about their child's DD.); *emotional support* focusing on the social networks (for

example, family and friends) present to help reduce caregiving demands; *Perceptive support* referring to the adequacy and helpfulness of support the individual feels they are receiving, particularly regarding the social, cultural and economic barriers.

Belonging to the community: future goals and participation

Future goals described by parents more frequently referred to the economic domain and to the relationships amongst family members. Data collected involving non-immigrant parents showed similar patterns (Sgaramella, Ferrari, & Ginevra, 2015). Similarly, intraindividual barriers toward future goals were described but more frequently they were ascribed to the context. Current experience, their actual perception of the living context as challenging seem then to influence future orientation and expectations about their inclusion and participation.

As regards the space and the priority given to personal, family or socially relevant future goals, in this study participants give personal growth have a limited space among priorities. They seem less interested in improving their educational or job matches, with the consequence that their occupational segregation may persist (Sgaramella, Ferrari, Ginevra, Santilli, & Nota, 2017) and give instead priority to family relevant goals.

The space to future goals involving a larger community context was limited and lower than in non-immigrant adults dealing with a disability (Sgaramella, 2018). This can be seen as evidence of a more limited sense of belonging, of a social and civic identity (Taber, 2015) still under development.

Some preliminary conclusions

Generalization is not the aim of qualitative research. Some cautions are needed in thinking to results of this study. One of the reason is because it mostly included mothers who were easier to recruit and involve.

It is also important to emphasize that parents with an ethnic minority background are not a homogeneous group. A great variation emerged, in fact, with respect to language proficiency, cultural background, migrant history, and most other characteristics. Some parents have huge problems understanding both the service system and their legal rights, while others may have no difficulties integrating into the new society. However, there is no doubt that participants to this study are characterized by a double

burden and a double challenge, due to unique stressors and barriers related to their immigrant status and the care needed by their child.

Themes emerged are in line recent narrative review of research on the experiences of immigrant fathers raising children with developmental disabilities (Khanlou, Mustaf, Vazquez, Haque, & Yoshida, 2015; Kvarme, Albertini Früh, Brekke, Gardsjord, Halvorsrud, & Liden, 2016). However, looking to the inclusion experience of these families through the lenses of parents, one of the lessons learned with this study is, first and foremost, that ethnic minority families with children diagnosed a disability often face challenges very similar to those of the majority of local families with children having a disability, thus giving less room to stereotyped visions. We can then think of massively using knowledge already developed.

Moreover, the future orientation perspective adopted, in line with recent theoretical approaches in counseling (Savickas et al., 2009), and the distinction between personal and social future time perspective, suggest some reflections on preventive actions that professionals and those interested in studying and fostering inclusion can undertake. First of all, a social future perspective can be seen as an index for analyzing and improving intergroup and interpersonal relations, a change of sign of the future and the implications of future time perspective as an educational strategy in multicultural context (Morselli, 2013; Taber, 2015).

Although healthcare and community service providers encounter several challenges in providing care to immigrant families raising a child with a disability (Lindsay, King, Klassen, Esses, & Stachel, 2012), this study underlines the important role played by individuals who mediate in educational and work context their attitudes and beliefs is underlined by this study. Training and educational activities should focus on inclusion together with cultural competence training aimed at developing awareness, sensitivity, and effective behaviors should be proposed for enhancing culturally competent care and increase social and work inclusion of migrants. Additionally, inclusion of migrants requires professionals to develop knowledge, skills and competencies not only to work with individuals for empowering migrants and refugees but also to work with the contexts. More efforts should be devoted to preparing professionals in assuming an active role as changing agents in promoting inclusive attitudes in schools, work and social contexts and make feasible concrete actions involving people living in Italy, that is Italians and foreigners, either

migrants and refugees or not.

A message for professionals

Several levels of actions derive from the definition of inclusion adopted in this study: actions focused on supporting access, thus fostering the dimension of *being* in the community; actions fostering a *becoming* dimension, that is constructing a context applying culturally sensitive communication and providing flexible and tailored health-care services, contexts where these families have the opportunity to expand knowledge and experiences as members of the community; actions tailored to the development of a sense of *belonging* to a community, both in the present and in the future, to an active role in community life.

Along these dimensions, professionals are required at least two types of actions aimed at *looking inward and looking outward* (Sgaramella & Scorgie, 2017). The first refers to *self-reflection and transformation* of attitudes and dispositions foundational to equity and inclusion, such as open-mindedness, respect for others, empathy, sensitivity, courage, responsibility, and a purposive commitment to one's values, identify personal biases. The second implies going *beyond diversities promoting inclusive relationships and acting to support human rights* thus reducing the risk of segregation and marginalization.

The value of these actions goes beyond professional ethics because supporting inclusion is a function of one's *"civic responsibilities, not a favour to the less fortunate"* (Asante, 2002, p. 1).

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