Social service and disability in immigrant families: professionals views and strategies

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Abstract. Immigrant families with a member with disability represent a social group particularly at risk: their vulnerability, in fact, depends on both the disability and the migration experience. The paper presents a research work starting from a scoping study (Arksey & O'Malley, 2005), realized by analysing 94 scientific works collected through Scopus with the aim of highlighting the specific problems which immigrant families with disabilities have to deal with, what to do and the culturally sensitive intervention strategies effectively used by the services. Often, they lack informal support networks, they have social and/or economic disadvantages, they do not know how the educational, social and health institutions work. Therefore, they live in a multi-problem situation that requires health and social services to activate personalized assistance that takes into account cultural difference. Results from a quasi-qualitative research study conducted in the context of the Adult Disability Service in Padova will be also presented.

Keywords: Immigrants, Disability, Multi-problematic Contexts, Social Services, Intervention.

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Introduction

The theme of family care for immigrant families with a member with a disability is somewhat new in Italy. It is a virgin path due to a significant lack of scientific research and literature, especially in the fields of sociology, and in social sciences in general. Yet, in accomplishing their work, health- and socio-educational services are calling upon the link between disability and immigration ever more. As a result, they have been raising a number of issues concerning linguistic difficulties in communicating with immigrant families with regard to the diagnosis of both disability and its related therapy. Accordingly, Lepore pointed out «the perception of a limit or a relative effectiveness/fallacy in the instruments of diagnosis and nosographic categories. There is an exceedingly high number of functional diagnoses of foreign minors with a specific language impairment and a learning disability. One has also to consider the difficulty of producing medical protocols that families ought to respect, and the effort in giving meaning to other styles of care. Besides, it is hard to meet with some ideas of non-recognizable disabilities, “odd” magical interpretations, and supernatural and likewise “odd” therapy paths - which are not in compliance with medical expectations» (Lepore, 2010, p. 94).

If a disability can make individuals question the entire life cycle of any family (Valtolina, 2000), for immigrant families it can surely become a more complex event since they entangle in two heavy-laden stress conditions. On one hand, they suffer the separation from their native country; on the other hand, they have to handle the disability of their family member within a different social, cultural and relational context (Giuliani, Bellomira, & Borghetto, 2010).

Endowed with wide vulnerability that affects these families, such a scenario calls for the capability of institutions to understand a sui generis condition and of being able to accommodate them with appropriate tools. In fact, such families can hold with them a variety of problems that go beyond the mere condition of disability. They do require both a set of skills and a sensibility - partly to consolidate, and partly to renew. To begin with, social

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1 «the perception of a limit or a relative effectiveness / fallacy of diagnostic tools and nosographic categories, a very high number of functional diagnoses of foreign minors in terms of language and learning disorders, the difficulty of making medical protocols respected by families , the effort to make sense of other styles of care and, again, the comparison with the ideas of disability not recognizable, "strange" magical and supernatural interpretations and equally "strange" therapeutic itineraries, ways not conforming to the expectations of the doctors» (Lepore, 2010, p. 94).
service had better accompany the experience of caring for people with disability in a context of cultural diversity. It is clear how the meaning attributed to such a critical event (i.e., the disability in the family life cycle) is a pivotal matter with regard to its own managing and to a likely family crisis. To the would-be cultural difference in the interpretation of each case, one must add some other issues, which mainly cause stress. Among such issues, one finds the socio-economic conditions of the family, a basic knowledge to be able to understand more or less the diagnosis and its accompanying cure. There should also be an awareness of the social services available and of the rights which the individual with disability and their families can benefit from, the absence or the lack of family ties which may support in the managing of each issue, social isolation, the fear of social stigma, and so forth. Such families often live in environments of «oppression and marginalization», in a district with very limited local resources (Leidy, Guerra, & Toro, 2010), thus preventing meaningfully a family to access social service (Ceballos & Bratton, 2010). Such conditions create difficulties to the extent that (even) coping with a case of disability of a family member can become a complex and risky endeavor.

This essay will first consider a scoping study (Arksey & O’Malley, 2005), which aims at mapping out the core notions of this specific field of research by looking at sociological critical literature. The scoping review allowed highlighting both the complexity of the problems that immigrant families with a member with disability face out in their host country, and some specific categories of content. Qualitative research made possible to expand on the experience of a group of socio-educational workers in the Northeast of Italy. This was an attempt to identify both resources and limits in the approach used at present when dealing with such users.

**On immigrant families and disability**

The study of the main sources and database on Scopus and Sociological Abstracts (Pavesi, 2017) allowed selecting 94 articles out of 197 ranging

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3 Robert Hill first hypothesized that the interpretation of the critical event as reported by the family is a matter that marks the possibility to manage properly or not any situation. One should also relate the aforesaid critical to other issues – the event itself, as well as internal and external family resources which are already up and running or which are yet to be activated, see Hill R., *Generic features of families under stress*, in “Social Casework”, 49, 1958, pp. 139-150.
from 1980 and 2016. The articles were read the first time to find out any recurring categories, and a second time to improve their grouping. The resulting categories of content refer to two main macro-areas: (1) the problems foreign people with disability and their caregivers must specifically chance upon; (2) tested and successfully evaluated intervention strategies by social services in taking users into care.

Disability: a problem within a problem
The international critical literature has been pointing out for some time on how cultural specificities lead to different meanings ascribable to disability, as well as to illness in general. Yet, such an assumption does not seem to have completely entered the operational practice of those who work with people having a disability. As outlined by Welterlin & LaRue (2007), in Western society there is indeed a “western” way of reading and treating the disease and disability with regard to a “medical model” which is strongly influenced by technological progress, as well as social, economic and political factors.

There is also a close link between a religious vision or the belief in a spiritual system, and the likely reading of one’s disability as a form of punishment inflicted on the family due to some action committed in the past. Yet, in some cultures, the birth of a child disability is rather a “gift from God”. Accordingly, they believe that the care of the person with disability must be solely a right of the family since the intervention of an external professional might sound as an interference within the divine plan (Bennett, Zhang, & Hojinar, 1998).

A problematic issue concerns the network in which immigrant families are (or are not) included. The research carried out by Neufeld et al. (2002) emphasised how immigrant families (and especially women, as the main caregivers) make links with local social services because of their social networks. The latter include their relatives, friends, religious or community

4 It is worthy of note that the circulation of the bio-psycho-social model (Maturo, 2007) is ever more of help to sanitary professionals to look at illnesses and disability. There are outlined three interconnected dimensions: (a) a biological dimension (disease), as a diagnosed syndrome owing to a number of techniques and within a specific vocabulary, which is also subject to nosographic classification; (b) a psycho-personal dimension (illness), i.e. how this is present within the individual conscience, the disease the person is ill with, and both the pain and the distress which it may cause; (c) a social dimension (sickness), i.e. the disease/the disability of a member of society in the way in which it is perceived, understood interpreted and taken over by the community, by the social environment and by the social structures where the sick/the person with disability lives in and with which they interact.
associations, and professionals. Conversely, the lack of such a network is an obstacle to access social services. Informal support not only provides information, but it can also be a resource when it is essential to evaluate and choose between different options of cure and intervention, or between different social services (Neufeld et al., 2002).

Language is indeed an issue that can prevent the access to and use of social services on several levels. Accordingly, one should first notice the difficulty of mastering adequately the language of the host country both on a denotative and connotative level. Second, one should also consider the likely difficulty for immigrants to understand the technical language spoken by health personnel when properly interacting with them.

Scanty economic resources are higher than the number of immigrants. In fact, they left their own country where they had limited financial enterprise. The first generation of immigrants holds a lower socio-economic position than the one prevailing in Western countries. Their children, who grow up in the host countries, often continue to have less economic resources than their native peers, at least until they become young adults (Crul & Vermeulen, 2003).

Inadequate education represents an additional source of distress for immigrant families as to their relationship with social services. Jegatheesan’s research (2009) points out how less educated mothers showed uneasiness not only when they were struggling to understand clearly the diagnosis of their child, but also when social services asked them to express their opinion about the objectives concerning their child with disability being taken into care.

Besides, immigrant families often come from territorial realities where the possibilities to care for people with disability are somewhat limited. This aspect reduces access to social services owing to the lack of knowledge of the rights that families with members with disability have in other countries (Khanlou et al., 2015; Fellin et al., 2013; Rosenthal et al., 2010).

One can certainly apply to disability Augè’s words on the condition of illness: «The paradox resides in the fact that the disease is, at the same time, both the most private and the most social of events» (Augè, 1986). One experience disability in an interweaving of relationships, be they personal, organizational, and institutional. Among the aforesaid relationships, each of them puts forward a proper interpretation of the situation; they refer to symbolic and normative codes that are never to be denied. Yet, if the person with disability is the real core of what the
intervention aims at, the latter codes must rather be explained, made known and be discussed.

Garcia, Mendez-Perez & Ortiz (2000) noticed that cultural differences are not a problem, but the chance that such differences are not considered does - either when one inflexibly refers to some undiscussed assumptions which create a misunderstanding, or even when the prevalence of a culturalist reading of the issue makes one lose sight of the individuality of human experience.

Professional intervention

As already said, one of the crucial themes dealt with in international literature is the proof that there lacks a support network. Such a network should consist of both informal and formal actors able to support families as they are often isolated in providing to their multiple problems. Thus, one should favour and support the creation of a varied coping network able to add the informal dimension (relatives, if available, neighbours, friends, etc.) to the formal one (public and private social services) according to an et-et logic (Cesareo, 2017). By so doing, one can also integrate specific methods of communication and support - thus enhancing both the professional knowledge of educational, health, social professionals, as well as the experiential competence and the relational ‘closeness’ of those around an immigrant family. Helping such families in developing their social network to identify likely support resources can thus be a task for social services (Reyes-Blanes, 2001). The ethnic community users belong to can be a significant resource for social services. Such communities can represent a place where families share their struggle, find resources and, at the same time, feel understood and accepted within their own cultural environment. Since these families are sometimes isolated even within their community, professionals could invest in promoting the network there, identifying and fostering resources in the communities themselves. Strengthening ethnic family networks can certainly be a goal and a tool for managing any critical issue about immigrant families with a member with disability. Yet, reducing relationships to the ethnic community alone can be a constraint that prevents access to a wider information and social services. It is then essential to add some other external links to the ethnic network. The same social services immigrant families are in contact with can encourage broadening the network to social and health services, language schools, vocational training programs, educational institutions, third sector present in the area, churches, recreational activities, one’s workplace, etc. Hence, it is essential to take into consideration the number of areas of life immigrants live in and consider them as likely places to create meaningful
bonds, which can convey information, offer both practical and emotional support, help in understanding the cultural heritage of the host country. To build a social space of closeness representing for the promotion of well-being, it is mandatory to call the different actors within the territory to their own responsibility (Cesareo, 2017).

Fong (2004) suggests to working on the strengths and resources of immigrants. The core idea of this approach is to mobilize immigrants’ knowledge, skills, aspirations and resources to withstand the stress the complex situation they live in causes them by giving space to resilience. Some values such as family ties, work ethic, educational goals, membership (if present) to a cohesive community can all be included in the initial evaluation and in the care project for the person with disability, in an exchange model perspective of defined assessment (Milner & O’Byrne, 2005).

Immigrants then need support in knowing and understanding the rights of which they are entitled. The task for social service professionals is also to direct families to receive adequate support and to have their rights recognized.

Furthermore, promoting the creation of self-help groups can be useful (Hernández-Plaza et al., 2005). This focuses on starting small voluntary groups, made up of people who have common needs, interests and objectives, whose main purpose is to provide mutual help and face shared problems. This strategy can encourage building supportive links, increase resources by putting them in the network, among people who share the same situation and contribute to the awareness of the need to develop abilities, competences and skills in the people who are part of it. Besides, such experiences often allow the main caregivers to get out of the isolation they often live in (Hernández-Plaza et al., 2005).

For professionals, it is obviously necessary to invest first in the training of health, social and educational professionals who work with immigrant families with a member having a disability. A vast corpus of literature highlights the need for training on multicultural-oriented intervention practices. For instance, in the USA, an approach to the treatment of disability is increasingly developing in a so-called eco-cultural perspective (Brookman-Frazee & Koegle, 2004). This aims at integrating the social and cultural context of the immigrant family in order to create the best intervention, to make the intervention itself more effective, and to increase meaningfully one’s participation to the project as to taking into care the person with disability.

To deal with them properly, Fong (2004) believes that any professional ought to become increasingly aware of their personal cultural background,
beliefs, and values, and realize how the latter can influence the understanding and conceptualization of the behaviour of a foreigner with disability, as well as the purposes of the intervention project. In short, one needs to put into question their own vision of the world to avoid thinking that it will subtly stop its inclination to understand (Welterlin & LaRue, 2007).

It is often necessary to integrate any professional team with real cultural mediators, not simply interpreters but experts who act as socio-cultural bridges between professional intentions and the expectations of users, their family, and of the ethnic group (Jegatheesan et al., 2010). Accordingly, they should not only interpret the meanings of words from different languages and cultures, but they should also be able to mediate between organizations and users to provide adequate, meaningful and sensitive attention from social services.

The figure of a cultural mediator is complicated since they are often immigrants themselves. They have the task of assisting educational-, health- and social-professionals, and psychologists in quasi-professional interventions, for which they have not received an adequate training or supervision - thus putting the success of the intervention at risk.

**From literature to practice: a research project in Padova**

The research aimed at investigating disability in the population of foreign adults, and collecting organizational and operational strategies used by professionals (social workers and educators) trying to spot out new needs and new practices as they dealt with such users.

**Immigration in Padova**

From the Statistical Annual Publication of the City of Padova emerge that resident population, from 1994 to 2014, fell by 1.25%, while the number of foreigners increased almost tenfold. Over the past twenty years, the percentage of foreigners recorded a progressive increase. Yet, it has intensified since 2002.

With regard to the origin of immigrants, over the last three years, there has been a slight decrease of foreigners coming from all continents, albeit with a slight recovery in 2014, with the exception of Asian immigrants, who marked a progressive increase. Among European citizens, Romanians

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6 We want to thank Anna Pagnin who collected the interviews during her supervised traineeship as social worker at the Padova Adult Disability Service

7 [http://www.padovanet.it/informazione/storico-statistiche-sulla-citt%C3%A0](http://www.padovanet.it/informazione/storico-statistiche-sulla-citt%C3%A0)
and Moldavians are the two most represented. In the last two years, European Union citizens have increased, while the number of those coming from non-EU countries has remained almost unchanged.

Immigration and disability service

A wider analysis of the features of foreign users who accessed disability social services in the area of Padova in the last 10 years reveals that over half of them (57%) is from Eastern Europe, followed by Africa (34%) and, finally, a minor part from Asian countries (9%). Specifically, the majority of people come from Moldova and Albania (18%), followed by Nigeria (9%) and Morocco (9%). As to Asian immigrants, they are from the Philippines (5%), China (2%) and Vietnam (2%). Users between 18 and 35 years of age represent 66% of users. Most of them have a disability since their birth, and live in their original families together with other siblings, as well as with their parents (there are very few cases of single-parent nuclei). Users over the age of 35 represent 34% of users assisted by social services; they are affected more by acquired disabilities or neurodegenerative diseases. They are mostly men with a spouse and some dependent children (rarely they are lonely and without family ties).

Participants

The research sample consists of 11 professionals, specifically 6 social workers and 5 educators operating in the Adult Disability Service of Padova. Even though data collection counts only 4% of the users benefitting from social services, it is central to underline that these were different groups, with different needs, coming from different countries, with different stories. Due to such a high degree of variability, interviewed professionals were not able to generalize some reflections.

Instruments

A semi-structured interview explicitly prepared for them intended to investigate their experience in the care of immigrant users with disability, the implementation of new operational practices, the likely emerging training needs along with any possible organizational changes. The main questions were: (1) Do you remember the first immigrant user you met?

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8 The data were collected from the Padova Local Health Service database.
Results: The words of professionals

From a first analysis of the answers given by the interviewees, professionals have been divided into two groups. Some consider the differences as related only to the individual case and to the single family as a “unique and unrepeatable” universe. They do not give value to the cultural difference, not detecting either specific needs, or different ways in the care they give to the person with disability, or their taking into care by social services. There are also other professionals, the majority of them, who claim instead the need to recognize the differences related both to contrasting cultures and to the shared status of an immigrant.

Among professionals who have not felt the need to make changes in their practice, there is the awareness that, as a residual phenomenon, they may not have fully experienced the complexity that is part of such cases. On the other hand, other professionals highlight «the fact that having a disability means that there are so many differences that make foreigners just one more difference» (E3). They underline how the approach normally used in taking into care a user by social services stands on the subjectivity, it allows even immigrant users to find some space for their specific needs. One said that «some showed how in this country their son, their brother, a person with disability, are welcomed in a way that in their native land
would not be possible ... here there is an interest for a person as a whole, not only just about their health aspect, but also about their social and a relational dimension» (E4).

Among those who draw attention on the differences between the native population and immigrants, we emphasize an across-the-board need for this as regards the orientation and accompaniment amid social services. Regardless of any specific geographic provenance, being a foreigner would make it more difficult to move amid social services, administrative practices and offices. This requires a more extensive management for a professional. It is still clear how immigrants must first deal with economic issues: «to start with, they are families who clash with the general problems of immigration, such as temporary work; therefore, economic aspects matter indeed» (SW3). And besides, «they are still a source of income for their families» (SW1). For instance, this occurs with the failure in the request of their institutionalization as «it is a paid service that would result in a decrease – the loss of the income out of which the whole extended family benefit from» (SW1).

Then, there are those who emphasize the impact of the cultural dimension on the meaning attributed to disability. Those who talk about it mainly refer to users coming from Africa. An interviewee in particular stressed that African people have «a different concept of illness ... linked to the figure of the shaman» (SW3). A person with disability is considered possessed by spirits; therefore, as a person who is chosen due to their sensibility, «as a bridge with the world to explain us something». Conversely, «there are those who understand it as a misfortune inflicted by the God they believe in. Others take it as a fault.» (SW1).

In evaluating the practices of social services with regard to taking users into care, we first investigated the use and usefulness of cultural and linguistic mediation social service. Data analysis on the activation of linguistic mediation reveals a high percentage of this tool not being used (66%). Yet, it is worthy to note that 5 of professionals have used it mainly with Asians (who are actually present in a residual percentage both in the territory and within the assistance of social services), followed by the Africans and finally the Europeans. Whenever the topic concerning a cultural mediator is dealt with in interviews, half of the interviewees utter that mediation is an effective tool when there is a problem of linguistic communication. Its reduced use compared to its real need is due to some critical issues. One of these lies in the impossibility of having a mediator in real time, one must wait a few days for them to be assigned. Besides, there is almost no possibility of having the presence of the same mediator every time for the same user «since they always send different professionals. This
does not allow me to give continuity to my interventions, even on a communicative level. By so doing, the users’ emotional part is lost, and so do both their emotive charge and relationship of trust – which is vital» (SW1).

Furthermore, the approach and preparation of an appointed mediator is not always adequate, thus undermining the success of the interviews. The role of a mediator can be quite emblematic. In fact, it is a weak professional figure; it is even recognised in different ways on a regional level. Mediators do suffer a general lack of training (Luatti, 2006; Luatti & Torre, 2012).

In addition, on a European level, and for the SPRAR (Sistema di Protezione per Richiedenti Asilo e Rifugiati; Protection system for asylum seekers and refugees), research on mediators drew attention on some difficult issues such as its acknowledgement as a profession (Casadei & Franceschetti, 2009; SPRAR, Cies, 2010). Since it is not a job recognized on a national level, mediators are often chosen just because they are foreigner and they share linguistic commonality with users (natural mediators). Without some specific training requirements, mediators function as general professionals or they just take part in emergency actions. They are rarely permanent members of a team of professionals (Luatti & Torre, 2012). Hence, the role of a mediator can be endowed with multifaceted connotations, though they might not be always aware or adequate to the various contexts, and reveal different cultural assumptions concerning their translation choices. This recalls the importance of recognizing and re-elaborating both stereotypes and prejudices within interpersonal relationships; thus identifying a dynamic notion of culture, negotiating meanings and actions, considering the peculiarities of intercultural communication and inter-ethnic conflict (Esposito & Vezzadini, 2011).

Though it has not yet been done so far, it too would be of great help «to have mediators who are a bit more connected to the reality of local territory and, therefore, capable to help you find out how to get in touch with forms of community support that these families may have anyway » (SW5).

The creativity of the interviewees emerges when they face the issue of communication difficulties between a user who does not always speak our language and a professional who rarely speaks a second language. They express the importance of building a strategy together with the user to understand each other. This fosters the success of the taking one into care by social services and the formulation of a shared project. Some of them talk about simplifying language and information; an interviewee states that he also relied on some written communication delivered to the user or to
their caregiver, either as a reminder or as a mean of conveying a message to another professional (be they in a health or administrative department). Other interviewees have also spoken of both dictionaries and translation services online.

In general, people believe that the mediator is useful above all, or solely, in a first phase. This allows a user to understand the elements that underlie social services, express their needs, and feel understood without adding tension to a delicate moment: «I always prefer to call upon a mediator for the first time because it is important to know and understand what is needed» (SW5). Instead, in the next phases, most professionals believe that it is worthwhile to do it without a mediator to stimulate the responsibility and autonomy of users and their family, and to prevent the condition of trust which creates a true relationship of exchange between professionals and family members. Among the interviewees, a social assistant recognises the useful and necessary role of a linguistic mediator. Yet, he emphasizes to favour, whenever possible, the use of a family member who knows Italian and can act both as a link and as a main interlocutor: «A mediator only mediates for me at that moment, he cannot link up extensively. Therefore, if a family member is available, I go after them – be they another child who is able to build a communication bridge maybe with the parents of the person with disability» (SW3). Relying on a person in the family makes the context «less formal and less cold», helping the establishment of a relationship with the nucleus.

At the end of the interview, we collected many change proposals as to the organization of social services and their relationship with their users. Besides the need to increase the number of cultural-linguistic mediators and to introduce a new professional figure, there has been proposed a profile of the ethno-psychiatrist. Such suggestions ought to imply greater political attention as to the issue of immigration, as well as its relative allocation of additional funds for social needs. Whereas other proposals can be realized even within the extant organization, as it is for:

a. Creating a listening point or a helpline or an AMA group. It could be very useful to set up a free and open space where an immigrant can go without an appointment, and without the mediation of social services, not only at the onset of a problem related to their disability but also to be able to meet up and feel supported in case of need.

b. Prepare a written information sheet in several languages aimed at improving the knowledge of the welfare offer present in the territory and distributed throughout municipal social services or
where one can apply for a health insurance card, or in other strategic places where immigrants can benefit from social services.

c. Work on the sense of a community of immigrants, to be capable to expand the network to which foreign families with a member having a disability can refer to. Thus, it would be essential to understand what are the actual community immigrants live in. Beyond their possibility of having close relatives or not, «there is a possible network of relationships I think it would be useful to know» and use.

d. Create informative and training courses for the professionals working in socio-educational services. This will allow both to increase the knowledge on the reference cultures of the immigrant population, mainly regarding the meaning of disability, and to share the reflections and concerns of professionals as to their daily work and to those topics considered somehow ‘thorny’ such as religion and sexuality. The effort of many interviewees to consider the immigrant user as a bearer of their own experience, an expert of their own world, to whom one can ask non-judgmental questions to allow a better understanding of each other was quite evident.

Conclusions

The research carried out in the territory of Padova has helped to recognize many of the themes mentioned in literature. Before moving to contents, it is worthy to note how all the interviewees have repeatedly highlighted their awareness of not being able to generalize what they experienced. They repeated several times the words «this is my experience» due to the residual numbers of users taken into care so far by social services. Nonetheless, they attempted to recount their experiences, ideas, critical issues, challenges and strategies, making it possible to detect the appropriateness of a user-centred method used across-the-board within Italian social services, which makes possible not only to follow a too standardized pattern, but also to adjust interventions on the specificities of any individual. In this sense, despite some complaints, the availability of professionals to accommodate as much as possible the need to support of foreign immigrant families with a disable member is high.

Additionally, it is vital to highlight the little attention interviewees paid on the cultural aspects, unless it is a radical difference with the local culture which might threaten the results of the intervention project. The need to become acquainted with these cultural aspects allow us to be more aware of the specificity of others to favour better communication and taking users
into care in a more efficient way, thus making social services more welcoming.

On one side, the aspect of communication is most mentioned for the need to receive support from professional figures, such as mediators or users’ family members who speak Italian from their first interactions. On the other side, one finds a variety of strategies experimented in order to communicate in a direct way with the member disability and their family, to help them build relationships of trust. Finally, one cannot but mention the urge to intervene in the near future to improve the knowledge of social services among immigrant disable users. Besides, there must be built some informal support environments by organizing self-help groups, launching helplines and, yet again, through collaboration with the communities of interest.

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