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Ethnicity and Disability: Minority families with disabled children

Abstract

Research on families with disabled children describes how these families face many challenges in their daily lives; lack of information, practical and emotional stress, and struggles with the service system. Families from non-western countries are for various reasons seldom included in such studies, and there are few separate studies about families with “double” minority background. Thus we have little research based knowledge about ethnicity and disability, professionals, user organisations, and bureaucrats indicate severe challenges. They talk about language problems, culture differences, lack of information about the welfare system etc. International studies indicate that communication problems and poverty explain more than culture differences and religion. In this paper we will discuss how families with disabled children understand disability and how they cope with their situation. Do disabled people from ethnic minority groups face the same type of challenges as the majority population in their daily lives, or if they meet special barriers due to their minority status. Or do they meet special barriers due to factors as culture, religion, language, prejudice or racism? Do they have other or additional problems because of their status as ethnic minorities? What are their experiences from interaction with the service system?

Introduction

In one generation the immigrant population in Norway has increased from about 3 per cent to almost 10 per cent of the total population (in numbers: about 480.000). In spite of the increasing immigration to Norway, the immigrant population is still relatively small compared to most other European countries. About 7,5 per cent of the immigrants have non-western background, and about 3 per cent have refugee background (SSB 2009). In Oslo every fourth inhabitant has an ethnic minority background. In smaller cities and municipalities, the proportion of migrants is considerably smaller, but nevertheless – ethnic diversity is a reality in all Norwegian municipalities. Immigrants in Norway come from more than 200 different countries, and they have different religions and political opinions. In average immigrants have almost the same level of education as ethnic Norwegians, but behind this “average” we find huge differences – both between and within the different ethnic groups, between men and women and between first generation and descendants. Immigrants also represent a huge variety when it comes to modes of living and life stiles. In short – immigrants in Norway is a heterogeneous category of people. We can hardly speak of them as a group, if we by group mean people with common characteristics. On the other hand – they have their minority status in common, and as a society we still have a way to go to accept immigrants as adequate members.
A more diverse society means new possibilities and new challenges. The Norwegian society aims to include migrants on all societal arenas such as labour market, education, welfare system etc. However, research shows that the unemployment rate among non-western immigrants is 3-4 times higher than for ethnic Norwegians, they have lower income, lower living conditions, higher frequency of all sorts of decease etc. Studies about posttraumatic stress and psychological strain among refugees indicate that living in exile influences on mental health. There are a few studies about somatic and mental health in the minority ethnic population in Norway, but there has been little attention on the situation of disabled people and families with disabled children. Moreover, disability research in the Nordic countries has to a very limited degree focused on questions about ethnic minorities or immigration. This may mean that there are unmet challenges, in research as well as in adequate and sufficient service provision.

This paper is divided into two parts: the first part present presents a review of the literature in this field in order to shed light on the above questions. The literature is roughly sorted in three areas: family attitudes towards disability, encounters with the service system and experiences of children and youth about living with a disability when one is a member of a minority ethnic family. The second part presents an ongoing study of minority families with disabled children in six Norwegian municipalities, based on qualitative interviews with families and professionals, observation of children in day care and school, and participation in meetings with parents and professionals. The parents are first generation migrants from Sri Lanka, Pakistan, Somalia, Iraq, Iran and Vietnam. Main issues to be discussed: interaction with service providers, understanding of disability, intersectionality, cultural barriers, language difficulties and discrimination.

**Part I: Literature review**

We have been doing systematic search in relevant databases for books and articles and have been in contact with researchers in the fields of immigration and disabilities. So far, we have roughly sorted the literature in three areas:

- family attitudes towards disability
- encounters with the service system
- experiences of children and youth about living with a disability when one is a member of a minority ethnic family

Most of the studies in this review are based on qualitative interviews. As expected, we have found only few studies about minority ethnic families with disabled children. This confirms our assumptions that researchers in the disability field have been “colour blind” and that researchers in the field of immigration have overlooked that disability is a fact also for minority ethnic persons and families. Most of the literature is from UK and USA. The studies from Great Britain mostly deal with people from South Asian countries while the North American studies mainly study the situations of people from Mexico and Puerto Rico. Three Scandinavian studies are found. One is Danish (Poulsen, 2005) and deals with ethnic minority families with children with rare disabilities. The two others are Norwegian. Sørheim (2000) has studied immigrants from Pakistan with disabled children. The study of Fladstad & Berg (2008) is the pilot study of our project. It is conducted in one district in Oslo and is about families from minority ethnic families with disabled children and their relations to the service system.
Social deprivation, inequalities and discrimination

Studies from UK show that British families with disabled children face relative social and economic deprivation and also discrimination because of the disabled family member (Beresford, 1995, Beresford et al. 1996 quoted in Bywaters, Ali, Fazil, Wallace, & Singh, 2003). Families from South Asian communities in general experience deprivation, discrimination and racism. Thus, the combination of being South Asian and having a disabled child will imply that: “The experience of being disadvantaged is magnified for South Asian families with a child with disabilities” (Hatton, Akram, Shah, Robertson, & Emerson, 2004: 12).

Fujiura & Yamaki (1997) found that families in the US with a member with intellectual disability had lower income and higher benefit receipts than other families and that these inequalities existed to a greater degree in Black and Latino families (in Hatton, 2002). A longitudinal study of 200 Mexican and Puerto Rican families with disabled children living in the USA showed that 82% of the Mexican families and 66% of the Puerto Rican families were living on public services such as food stamps or public housing (Bailey et al., 1999a).

Emerson et al. (1997) have found higher prevalence of persons with intellectual disabilities in South Asian families in Great Britain than in families of other origin. Among possible explanations are social and educational deprivation and possible inequalities in access to maternal health care. Hatton (2002) points to the fact that there is a well-established link between poverty and higher rates of intellectual disability, and he states that minority ethnic families continuously have been shown to be disadvantaged in terms of low income and higher degree of welfare benefits. Hatton (2002) concludes that throughout the research literature there is substantial evidence that people with intellectual disabilities experience material deprivation and that the deprivation is more extensive for persons and families from minority ethnic communities. Members of minority ethnic communities, especially people with dark skin colour, are also subjects to racism and discrimination.

Non-western families with disabled children often report lack of information about the disability of their child and about their rights. Lack of information may lead to lower uptake of services (Bailey, Skinner, Rodriguez, Gut, & Correra, 1999b) or to problems with accepting their child (Hatton, Akram, Robertson, Shah, & Emerson, 2003). Insufficient information may be connected to structural discrimination as information only being given in the language of the majority population, infrequent use of interpreters or being met with prejudice from professionals. Factors as language barriers, limited knowledge of the service system and experienced discrimination in combination with poverty and other risk variables may contribute to greater needs and reduced access to services (Bailey et al., 1999a). There are indications that there in fact may be an inverse relationship between needs perceived by the families with disabled children and available support. Reyes-Blanes, Correra & Bailey (1999) report that Latino families who experienced higher needs reported less support. On the other hand, families with fewer needs reported more support. While minority ethnic families with disabled children lack information about the service system, there is also a lack of knowledge in the service system of the needs of these families (Fazil, Bywaters, Ali, Wallace, & Singh, 2002) or they may be met with stereotype assumptions or prejudice (Bailey et al., 1999b; Hatton, Azmi, Caine, & Emerson, 1998; Poulsen, 2005).
The importance of the disclosure process

In an article about how families cope with having a child with sickle cell disorder or thalassemia, Atkin & Ahmad (2000: 58) underline that coping strategies are dependent on the circumstances of the family. They define key factors for coping as including: early diagnosis and appropriate information, availability of material and social support as well as family dynamics. The importance of the disclosure process for how parents accept their disabled child and how they cope with everyday stress is described by Hatton et al. (2003; Hatton et al., 2004) in a study about South Asian families with a disabled child. Hatton et al. (ibid) firstly point to the fact that in studies of White parents the process of disclosure is described as crucial. At that moment parents are for the first time faced with the challenges of adapting to the fact that their child has a disability. Floyd et al. (1996 in Hatton et al., 2003: 178) categorise these challenges into two broad categories: problems of meaning and acceptance and practical everyday adaption to the disability of the child. What has been described as important in order to address parents’ existential challenges include that both parents and the child should be present, that there is enough time for consultation, that emotional support is given and that the child is spoken about as a person of worth. Information should also be linked to the provision of services. Hatton et al. (2003) conclude that for the South Asian families, the preferred practice of disclosure were essentially the same as for White parents, but with one exception: that the disclosure should be conducted in their preferred language. In addition, Shah (1997) highlights the parents’ need of support at the time of disclosure. She writes that if parents are not given appropriate advice and counselling, or do not have early intervention support, the welfare of their child will be at risk.

For the South Asian parents the disclosure process had a huge effect on their understanding of the condition of their child. Parents who had a shared understanding of their child’s disability proved to be more able to mobilise informal networks through sharing their new “medical” understandings with “lay” understandings that could be held by family or friends. On the other hand, lack of shared understanding could lead to experience of distress, lack of mutual emotional support among partners and lack of support from informal networks. The disclosure process also had impact on how the parents faced the practical challenges in their daily experience with a disabled child and how they accessed benefits and formal services. There proved to be evidence that parental satisfaction with the information received during the disclosure process predicted receiving greater support from formal services. Such strong relationships between the disclosure process and practical gains for parents are not found in research with White families. According to Hatton (2002) it seems like White parents are able to access the service system despite of the disclosure process while a negatively experienced disclosure process may be a barrier against gaining formal support beyond special education for South Asian families.

Family attitudes towards disability

Fladstad & Berg (2008) found that most of the non-western families had little knowledge about disability and disability issues before the birth of their disabled child. Many parents need time to accept the child’s diagnose and some will experience that it is not possible to give the exact diagnose at once. Thus, families may have to deal with uncertainty about what the implications of the disability will be. The dimension of time is highlighted in research as important when it comes to explanation, diagnosis, accept and a re-orientation in one’s life.
(Tøssebro & Lundeby, 2002; Sørheim, 2000; Poulsen, 2005). Bringing up a child with a disability means that the families have to face many challenges: a strenuous daily life, relations to siblings and other family members, collaboration with the service system, and often struggles to achieve necessary services.

In a study about minority ethnic families with children with rare disabilities Poulsen (2005) described the situation of the families as simultaneously equal and different from the situation of other Danish families. The families primarily accept western medical explanations and treatment. At the same time, many families find consolation in their religion. This is supported by Raghavan & Small (2004) who in a literature review found that families find support in their religion, but more in their faith than in the formal religious system. There is also little evidence in research that families seek alternative treatment of their children instead of medical treatment (Bywaters et al., 2003; Poulsen, 2005; Bailey et al., 1999a), but some seek alternative treatments in addition to medical ones. Bailey et al. (1999a) in their study of Latino parents found that the families chose to accept “western” services and that few made use of religious or alternative treatments, but some used prayers or pilgrimages together with medical and social services. Examples of the use of amulets and traditional healers are also given by Sorheim (2000) in her study about Pakistani families with disabled children living in Norway.

According to Bywaters et al. (2003) there is a complex relationship between religion and medical treatment. Some parents will say that the disability of their child is because of the will of God. Some also will refer to the disability as a way they are tested by God. In a study of Pakistani families with disabled children Croot, Grant, Cooper & Mathers (2008) found two theological explanations about disability; either that the child is a gift from God or that to have a disabled child is a way God is testing the family. Ahmad & Atkin (1996) found that religion could act as consolation for the families, but this could not be defined as fatalism, because the families, both muslims and catholics, simultaneously accepted biomedical explanations for the disability of their child and were actively engaged in the treatment of their children. Skinner, Correra & Rodriguez (1999) in a study of Mexican and Puerto Rican families with disabled children found that mothers tended to tie their construction of meaning to catholic understandings of motherhood. As mothers of disabled children they were given a special responsibility by God, and most mothers rejected that the child could be seen as a punishment. In a study about Bangladeshi and Pakistani families Bywaters et al. (2003) indicated that it seemed like religious explanations were more commonly used when the families were not well informed about the disability.

However, families risk meeting negative attitudes and different explanations in their extended families and social networks. McHatton 6 Correra (2005) report that some fathers in Latino families blamed their partner for giving birth to a disabled child and some left the family. Blaming the mothers and demanding divorce is also reported by Fazil et al. (2002) in their study about families from Pakistan and Bangladesh. Bywaters (2003) argue that negative attitudes from the extended family or people from one’s own ethnic community may lead to isolation and fear of bringing their child to family, religious or social events (Poulsen, 2005; Hatton et al., 2003; Bailey et al., 1999a; Atkin, Ahmad, & Jones, 2002). According to Poulsen (ibid) some families report that in their home countries disabled people are not accepted and this lack of acceptance can be found also in the minority ethnic communities in their new countries. To be met with such attitudes may lead to withdrawal and isolation. Sometimes the parents felt shame because of the child’s appearance or behaviour, and this could be another explanation for choosing to keep their child away from social events (Bywaters et al., 2003).
McHatton & Correra (2005) found that the mothers in their study were discriminated by family, professionals and strangers and for several reasons: because of the disabled child, because of their culture and because of a combination of culture and disability.

Families who are given relevant and satisfactory information about the disability during the disclosure process find it more simple to inform the rest of their families and this may lead to more understanding and support (Hatton et al., 2003). But to give information to others is more difficult when the condition of the child is uncertain or has no name (Bywaters et al., 2003). It is also difficult to inform others when the information has not been properly understood. Sørheim (2000) found that some parents understood the given information differently from what the professionals had intended. Bywaters et al. (ibid) explain, there was evidence that the Pakistani and Bangladeshi parents in their study had poor information about the disability of their child and of the services available. This is referred to as language barriers due to the use of English language and lack of interpreters available in medical consultations.

Meeting the service system

According to Bywaters et al. (2003) there are stereotypes in the majority community about how families from ethnic minorities react to having a disabled child, and these stereotypes are also reflected among professionals in the service system. Four different stereotypes are identified. The first is that the families have religious explanations about disability; the other is that they feel shame and as a consequence do not seek help and the last one is that they have low expectations about the future of their child. This is supported by Poulsen (2005) who writes that Muslims are perceived by doctors and social workers to believe that disability is God’s punishment. However, Bywaters et al. (ibid) that there were other and complex reasons for low service uptake than religious beliefs. They found strong evidence that the primary problems for the parents in bringing up their disabled children resulted from institutional racism, poor material circumstances, less access to services and lack of information due to language barriers and poorly arranged services.

Minority ethnic families also have to face the stereotype that they all have an available and supportive extended family (Fazil et al., 2002). Hatton et al. (2003) show that on the contrary, most minority ethnic families lack support from a social network and are in need of support from the service system. Need of respite care and coordination increases due to lack of social network (Fladstad & Berg, 2008). Latino families in the USA reported a high degree of support from their extended family but nevertheless, most support was received from the formal service system. According to Bailey et al. (1999a) this means that Latino families who have left their country of origin, may lack family network. This is supported in a study about Puerto Rican families with disabled children living in Puerto Rico and in Florida respectively (Reyes-Blanes, Correra, & Bailey, 1999). Families who lived in Puerto Rico received more informal support from family and friends than the families who lived in Florida. However, this was also due to lack of formal services in Puerto Rico.

Several authors discuss the cultural underpinnings of the service system as barriers for people from minority ethnic families. Such underpinnings are often understood by professionals as universal, and if professionals are not sensitive to cultural diversity their attitudes may create a distance between the services and people with minority ethnic and cultural backgrounds (Kalyanpur & Rao, 1991; Kalyanpur, 1998; Kalyanpur, Harry, & Skrtic, 2000; Harry &
Disregard of cultural diversity or lack of cultural awareness may result in cultural inappropriate services (Hatton et al., 2004; Ali, Fazil, Bywaters, Wallace, & Singh, 2001; Fazil et al., 2002). Caton, Starling, Burton, Azmi & Chapman (2007) advertise for services that are sensitive to cultural diversity and flexible enough to meet the needs of the families.

In their review of literature about cultural diversity and intellectual disability from 2001 to 2004 Raghavan & Small (2004) conclude that language and communication are the biggest barriers to the access and uptake of services in the UK (see also Bywaters et al., 2003). This is also documented in other countries such as in Denmark (Poulsen, 2005), in Norway (Sørheim, 2000) and in USA (Bailey et al., 1999a; Bailey et al., 1999b; Reyes-Blanes et al., 1999). Bailey et al. (1999a) report that English fluency was the only factor to determine differences in needs and support between families from Mexico and Puerto Rico. Families who were able to communicate in English received more services and experienced less needs than non-English speaking families. Ability to speak the majority language as a prerequisite for getting access to services is also documented by authors in other countries (Hatton et al., 2004; Fazil et al., 2002). This raises questions about the use of interpreters. According to Fazil et al. (ibid) there is evidence of lack of interpreters or interpreters who are not well qualified (see also Caton, Starling, Burton, Azmi, & Chapman, 2007). Shah (1997) discuss the role of interpreters and claim that they should be professionally trained. Fladstad & Berg (2008) refer that the quality of interpreters may vary and that communication can be experienced as difficult even with the presence of an interpreter. According to Sørheim (2000) some families may have problems understanding how to make use of an interpreter.

Most studies in this literature review document that there is lower uptake of services among families from minority ethnic backgrounds than by the majority population. However, this is not due to characteristics of the families, but has to do with characteristics of the service system (Bailey et al., 1999b). Fazil et al. (2002) refer to studies of White families with disabled children and write that minority ethnic families have similar difficulties in accessing and receiving services. However, the minority ethnic families have additional difficulties. One problem is that they may have knowledge about more general services as doctors and dentists, but many are not familiar with more specialised services as speech therapists, psychologists or psychiatrists (Hatton et al., 2004). They may have little contact with professionals and not be aware of their role and responsibilities. They may also have little knowledge about special services such as respite care.

From research about families with disabled children in general it is well documented that the families experience lack of co-ordination of services, lack of availability, quality and timeliness (Beresford 1995 in Fazil et al., 2002; Tøssebro et al., 2002; Fladstad et al., 2008). Hatton (2002) advertise for the role of a keyworker or case manager. Minority ethnic families who were in contact with a keyworker were provided with more information about services, and the families also experienced fewer problems with the service system. What the parents want from the service system is according to Hatton (2004) more information of the services in relevant languages, services that are culturally sensitive and more professionals from South Asian countries.
Living with a disability when one is a member of a minority ethnic family

Ali et al. (2001) argue that there is a growing awareness about listening to the perspectives of disabled children and youth, but that the voices of minority ethnic children and youth with disabilities are seldom heard. In a literature review about disability, ethnicity and childhood they identified 23 studies from USA and Great Britain, but only 8 of these included the perspectives of children and youth from minority ethnic communities. Seven of the eight studies focused on children and youth from South Asian families. The main topics of the studies seem to be questions of identity and how to cope with a disability in family and society.

According to Ali et al. (ibid) many disabled children have experienced being bullied because of their disability while disabled children from minority ethnic communities have experienced discrimination because of their ethnicity as well. Both Ali et al. (ibid) and Azmi, Hatton, Emerson & Caine (1997; Islam, 2008) utilise the concept “double discrimination” to describe such experiences. Discrimination and racism take place in a whole range of settings; from people in the neighbourhoods, other service users and staff in service settings. One additional problem is that teachers seldom address issues as identity and culture (Ali et al., 2001).

In their study about young people with intellectual disabilities Azmi et al. (ibid) found that most of the participants had a strong and positive sense about their ethnic and racial identities. Simultaneously they wanted to adopt a more western life style in some areas: for instance some wanted more independent living. In order to avoid conflicts, many young persons tried to balance between traditional and religious values and the way other young people are leading their lives (Azmi, Hatton, Emerson, & Caine, 1997; Atkin & Hussain, 2003). Islam (2008) describes how the young persons were able to negotiate the value system of their parents without totally adopting them. Azmi et al. (ibid) quoting Ahmad (1996) concluded that their informants with intellectual disabilities experienced a complexity of inter-generational change in their ethnic identities and personal behaviour.

How the parents react to the impairment of their child is affecting the young persons’ experience their disability (Atkin et al., 2003). According to Atkin et al. (ibid) most parental reactions about their disabled children are the same as is described for White families: to have a disabled child may be seen as a tragedy, but simultaneously there are many examples of loving and caring relationships in the families. Some young persons sometimes experience lack of respect in their families and others regard their parents as their best allies. Most children and youth felt supported and accepted in their homes, even if some reported being overprotected (Islam, 2008; Azmi et al., 1997). However, as Atkin et al. (2003) comment: to be overprotective is a common trait in families and not always because of the child’s impairment. And as in many families girls experience having less liberty than boys.

According to Islam (2008) religion seemed to be a key factor for the young persons in shaping their identity. However, “disablist” attitudes among peers and adults, for instance religious teachers might put limits to their religious practice. Atkin et al. (2003) exemplifies how young disabled persons were not socialised into religious practice and had less knowledge about their religion than their siblings. This may lead to ambivalence about one’s religious identity. At the same time there is also ambivalence about one’s ethnic identity. Children and youth who grow up with immigrant parents often have to struggle hard to come to terms with who they are: whether for instance British or Asian. For young disabled persons being British could be experienced as more favourable because of the more positive attitudes towards...
disability in the British society (Atkin et al., 2003). This struggle about identity is even more complex for young people who are deaf (Jones, Atkin, & Ahmad, 2001). Being deaf may be seen as a threat for the person to have full membership in family and society (Atkin et al., 2002). Being deaf and belonging to an ethnic minority family may be experienced as even more of a threat. This is because of the need for communicating in sign language, a language that can be understood as a White language. Thus, a Deaf identity may be experienced as a White identity. This may lead to ambivalence for the young person and the family. In addition, the Deaf society has so far been reluctant to include people from minority ethnic communities (Jones et al., 2001). Identification as Deaf is therefore extremely complicated for a young person from a minority ethnic background.

For most young people their disability was not seen as something that dominated their whole lives (Atkin & Ahmad, 2001). Instead, the young persons tried to reduce the influence of their condition on their everyday life. They tried to live like anybody else and maintain a positive self-image. Islam (2008) did not find evidence that the young disabled persons in her study experienced having an identity as disabled. The young persons regarded themselves as normal and described people with more needs for help as the real disabled ones. Such attitudes are also documented in studies of disabled people in the majority population (see for instance Watson, 2002).

Atkin et al. (2003) conclude that the informants in their study held multiple identifications and used them flexible in different situations. They also tried not to choose between Western and Asian identities, but tried to find space for various identity claims. In their identities they also had to include both disablist and racist attitudes from their environments and society as such. Islam (2008) did not find evidence of a unitary identity for instance as disabled. Other aspects of their self-identity as religion and ethnicity played an equally important role. Conclusively, Islam (ibid) with reference to Giddens (1991) describes identity formation as a dynamic process that is always negotiated in context. Young persons with disabilities from minority ethnic backgrounds negotiate their identities against a backdrop of ethnicity, religion, gender and race and make sense of the values of their families within the contexts of their own lives (Islam, 2008).

Part II: Immigrant families with disabled children in Norway

The literature review shows that we have limited knowledge about the intersection between ethnicity and disability within a Norwegian (and Scandinavian) context. At least, the research based knowledge is limited. A dominant understanding among professionals has been that culture differences is a major challenge, but this understanding has only limited support in the literature. Even if international studies discuss culture differences between minority groups and the majority (and within the minority groups), they conclude that differences in living conditions, level of education, health status and differences in housing standards explain more than culture differences. It has also been a tendency to overlook the diversity within the immigrant population. We have for instance studies on disability focusing on immigrants from Pakistan (Sørhaug 2000), but there is no evidence for transferring these experiences to other immigrant groups. Education and social class might also influence on both attitudes and experiences. It has also been a tendency to overlook the time factor. Newly resettled immigrants and refugees will most likely face other problems than immigrants with a long period of residence.
The risk of drawing an oversimplified picture of the situation was one of the main reasons why we applied for research funding on the intersection between ethnicity and disability. The project “Ethnicity and disability: immigrant families with disabled children” is funded by the foundation “Health and Rehabilitation” for a period of three years (2008-2010) and is built on the results from the pilot study, carried out in 2006/2007 in a suburb of Oslo (Fladstad & Berg 2007). The aim of the project is to gain more knowledge about challenges for immigrant families and to develop strategies for better collaboration between the service system and the families. Main topics:

- Understanding of disease or disability
- Treatment – experiences
- Potential for learning
- Experience with the service system
- Expectations towards the service system
- He transitional stage between day care and school
- Network and family support

The focus of the project is on the informants’ experiences and reflections. We have chosen a qualitative design with semi-structured interviews with the parents and with professionals from the health and social services and from kindergarten and schools. In the interviews, we use interpreters when necessary. We also observe the children in kindergartens and schools.

The project is now half way, which indicates that we still are in the process of collecting data and in an early stage of analysing the data. Nevertheless – we are at this stage able to present a picture and to draw some preliminary conclusions. (In a final version of this paper, we will of course add more to this empirical part of the article.)

Data collection and sample

The families in this project are recruited from three Norwegian cities (Oslo, Trondheim and Kristiansand) and five smaller municipalities in the same regions as the cities. In all we are interviewing between 50 and 60 families and more than 100 professionals working close to the children with disabilities. The disabilities represent a wide range. The children are from 2 to 12 years old. Most of the children have intellectual disabilities/severe learning difficulties, often in a combination with physical impairments. Most of the children have multi diagnoses. The families have different backgrounds both with respect to nationality and language, period of residence in Norway, migration history, family and network - and with respect to education, labour market participation, living conditions etc.

The recruiting process has been both challenging and time consuming. The researchers involved in this project have extensive experience both on immigrants and people with disabilities. Nevertheless (or perhaps because of this) we were fully aware of the methodological challenges in this project. In addition to take into account that the families are in a vulnerable situation having disabled children, we have to be aware of culture differences, language problems and problems connected to migration and exile. Trust has been a key concept both in the process of recruiting families to the project and in the data collection. All information about the project has been translated into the mother tongue of the families to ensure that the information about the project is understood. The information letter is translated into 17 languages, which indicate the variety of national and cultural background in this
The recruiting process has been in collaboration with professionals who know the children and their families. The criteria for participating in the project have been discussed with the professionals, but finally decided by the research team.

Some preliminary results and experiences

As mentioned already, this paper is based in preliminary results. Nevertheless – after having finished most of the field work, we are able to see a picture. In many ways this picture confirms the results from the pilot study we carried out a couple of years ago. A main conclusion from the pilot study was that parents with an ethnic minority background describe their situation very similar to native parents with disabled children. Very few parents think of the possibility having a child with a disease or disability. You just don’t think about it and are not prepared for the situation. This is the reality for most parents – regardless of ethnic background. You hope to have a healthy child and plan for the future in accordance with that. When you realise, either by birth or later, that your child is different, you have to re-think a lot of things. New questions occur, and you have to face both uncertainty and new challenges. Immigrant parents are like most other parents. This does not mean that all parents react the same way, but we see no systematic differences between ethnic minorities and majority with respect to reactions to and understanding of disease or disability. Even if some parents talk about destiny and fate, this goes hand in hand with “a modern understanding” of disability. We have met parents who tell us about relatives who represent a more “traditional thinking”, but they themselves do not believe their child has become disabled because of “black cats”, “wrong moon positions”, “evil spirits” etc – and they do not believe in “black magic”.

When parents talk about their everyday life, it is not at all wrapped in mystery. They talk about strenuous days, hard work and struggle for treatment and special education. At the same time most of the parents also express hope, optimism and gratitude towards the service providers. This “both –and” attitude, is quite typical for the parents of the youngest children. As time pass, some of optimism and gratitude seem to be replaced by more resignation. You realise that treatment and special education will never cure your child, and the difference between your child and other children is increasing. These are experiences most parents with disabled children have in common – regardless of ethnic background. What strengthens the challenges for many ethnic minority parents, are problems connected to language and communication. Language problems also influence the ability to receive and understand information about both the disability and the welfare system.

Realising that your child is different, you need a lot of information. You have to learn about the disability, you have to learn about methods of treatment, the potential for learning etc. You also have to cope with the treatment systems, the bureaucracy, and you have to learn about your legal rights. If you are not native spoken, this might be challenging. Service providers seldom use professional interpreters - even if the language difficulties are obvious. This is a well documented fact all over the service system – in child welfare, in hospitals and other welfare institutions (ref…). The experiences in our project are the same. Even if service providers have an ambition of using professional interpreters in official meetings, interpreters are never available in more informal situations. A consequence of this is that parents with poor understanding of Norwegian miss a lot of “informal information”. An example is what is happening every day when you pick up your child from the kindergarten. This might be an important situation for exchange of information – about the child, about how the day has passed, reminder on activities the next days etc. This is important for all parents, but even
more important when having a child with a disability. If you are not able to understand more
then bits and pieces of what is communicated, you lose a lot of information. There will of
course also be a huge risk for misunderstanding, which might cause further frustrations.

It is important to emphasise that parents with ethnic minority background are not a
homogeneous group. Both with respect to language abilities and most other characteristics,
they are different. Some parents will have huge problems understanding both the treatment
system and your legal rights, while other parents have no problems connected to language and
ethnic background. There might be other differences within the minority population as well.
Some families have lived here for a long time. They have their networks – both within the
different societies and within the Norwegian society. Some families do not. And even if you
have a big social network, this does not necessarily mean that you receive support and help to
cope with your disabled child. There is a persistent misunderstanding that ethnic minorities
receive more family and network support than families with majority background. In our
sample we have ethnic minority families with little or no support (even if they have most of
their extended family in Norway), and we find families with much support. This is also the
case in Norwegian families with disabled children. There is also a misunderstanding that
families think regard family and support from the network as a substitute for professional
help. Most families – both ethnic minorities and majority families – receive both, but there is
a tendency that the professional support is more important as the child grow up. It is also a
tendency that families receive less help from the family as the child is getting older.

Conclusion

Minority ethnic families with disabled children face the same challenges as families from the
majority population. In addition, they have to face other challenges as discrimination, lack of
information, poor access to services and prejudice from professionals in the service system. In
this literature review, however, most families are immigrants. This is not the case for minority
ethnic families in the Norwegian society. Many minority ethnic families in our country are
refugees and asylum seekers. They may have experienced traumatic situations and uncertainty
on their way into the Norwegian society. This may have caused additional problems.
Description of this kind of problems has not been found in the literature so far, but is
something we have to take into consideration in our study.

Reference list


cope with at child with a sickle cell disorder or thalassaemia. *Health and Social Care
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