

Immigrant Youths with Disabilities and Caregivers from the Middle-East—Challenges and Needs During Transition to Adulthood

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Abstract

Background: Recent years of research have increased the knowledge about how to support the transition to adulthood for youths with disabilities. In today's multi-cultural societies knowledge about transitioning immigrant youths and their caregivers is still needed.

Objective: To describe the expectations and needs of immigrant youths with disabilities residing in Sweden during their transition into adulthood as well as the expectations and needs of their caregivers, all of whom come from Arabic-speaking countries.

Method: Structured interviews based on the Rotterdam Transition Profile (RTP) questionnaire were conducted with youths 16 to 24 years of age and with caregivers based on the Family Needs Survey (FNS).

Results: Findings of interest were the youths' dependence on parents for care demands and leisure activities, their need for information regarding future care and support and their concerns regarding future marriage. Caregivers' felt unfamiliar with the term 'intellectual disability' and had a need for information about their youths' condition and of available service for their children now and in the future.

Conclusion: To prepare immigrant youths for future support, health care and habilitation services, it is important to enhance their autonomy. Immigrant families need culturally sensitive support and information, provided by designated professionals in their language of preference during the youths' transition to adulthood.

Keywords

disability, transition, immigrants, youths, needs, recruiting

1. Introduction

Transition often refers to the transition from child- to adulthood, which involves leaving the parental home, examining relationships, enrolling in higher education or being employed (Arnett, 2000; Priestley, 2003). The transition of youths with long-term disabilities also involves transition from child- to adult-oriented support and health care systems (Gorter, Stewar, & Woodbury-Smith, 2011). These transitions are not always smooth, neither for the youths nor for their caregivers (Björquist, Nordmark, & Hallström, 2015, 2016; Donkervoort, Wiegerink, & Meeteren, 2009; Gorter & Roebroek, 2013), and they often need support to manage. Children with physical or/and intellectual disabilities receive structured health care and habilitation services, but as adults the continuity of service is found to be lacking (Donkervoort, Wiegerink, & Meeteren, 2009).

Among physical disabilities, Cerebral Palsy (CP) is one of the most common motor disorders and affects approximately 2-2.5/1000 children (Himmelmann & Uvebrant, 2014; Rosenbaum et al., 2007). Among children and youths with CP, it was estimated one in two have an Intellectual Disability (ID) (Novak et al., 2012). ID is defined as a disability characterized by limitations in intellectual functioning and adaptive behaviour, originating before the age of 18 years (American Association on Intellectual and Developmental Disabilities, 2017). In accordance with the Swedish disability legislation called the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), residents of Sweden with ID are entitled to support if they have the need (Proposition, 1992/1993:159). The support through LSS is regulated by specific measures and is most often provided by the municipality of residence. One of the measures, personal assistance, is intended for persons who have an extensive need of support in their daily lives and enables caregivers themselves to be the assistant for their child. Other measures of interest for transitioning youths are a “companion service” or a “contact person” aimed to provide support for their social life and leisure activities (Proposition, 1992/1993:159). Furthermore, anyone receiving support in accordance with LSS shall be offered an Individual Plan, meaning that measures are planned, drawn up, and approved in consultation with the youth, thus providing a useful tool for transition planning (Proposition, 1992/1993:159). For youths with ID living in Sweden, the transition often includes moving out of the parental home and into housing with special services and moving from special schools to disability day programs known as ‘daily activities’. This is also in accordance with Swedish Legislation (LSS) (Proposition, 1992/1993:159).

Recent years of global migration have resulted in diverse populations with individualized needs and expectations, entailing new challenges for health care, social work and habilitation service. Due to the conflicts in e.g. Syria a large number of Arab-speaking people have settled in other countries; hence, knowledge about multicultural experiences and needs requires development and incorporation into support and health-care services (O’Shaughnessy & Tilki, 2007). Today Sweden has approximately 10

million inhabitants, of whom around 16% were born abroad (Statistics Sweden, 2016). Knowledge about the needs of immigrants with disabilities living in Western countries is limited in general (Ali et al., 2001; Daudji et al., 2011; Leavitt, 2002; O'Shaughnessy & Tilki, 2007). Immigrants are rarely represented in disability research, especially in a Scandinavian context (Söder & Hugemark, 2016). In a recently published literature review it was found that ethnic minorities are not represented in healthcare research due to a lack of functional methods and time-consuming processes for all involved (Morville & Erlandsson, 2016).

Many immigrants in Sweden are from countries where Arabic is spoken, such as Iraq and Syria (Statistics Sweden, 2016). Swedish services and healthcare registers do not record the immigrant's country of origin; thus, there are no data related to disabilities among this group. However, a total population study showed that the prevalence of CP was higher amongst children born abroad, with more functional limitations than their peers who were born in Sweden (Westbom, Hagglund, & Nordmark, 2007). Broberg et al. (2014) found that immigrant parents of children with disabilities residing in Sweden lacked information about available support and access to habilitation services for their children.

The Scandinavian countries, like many other countries, have no reported national policy to guide transition from paediatric to adult care (Hepburn et al., 2015); however, local interventions aimed at supporting youths during the transition are used in habilitation services (The Swedish Association of Rehabilitation Managers, 2007, 2015; Karlsson et al., 2011). Due to the high number of immigrants who come from countries where Arabic is spoken and are now residing in Europe, it is important to obtain more knowledge about the youths with disabilities and their support needs (Nilgert, 2009). A literature review showed that information from a multicultural perspective about how adolescents with disabilities in Sweden access services in general was limited (Björngren, 2016). More research is still needed, and an extension of international research could provide more knowledge about the needs of transitioning immigrant youths and their caregivers. The aim of this study was therefore to describe the expectations and needs of immigrant youths with disabilities residing in Sweden during their transition into adulthood as well as the expectations and needs of their caregivers, all of whom come from Arabic-speaking countries.

2. Methodology

The study was a prospective interview study based on English-language questionnaires translated and adapted to Swedish and Arabic for structured interviews in Swedish and Arabic.

2.1 Recruitment Process

The study was conducted in three counties in the south and the west of Sweden representing areas with high populations of immigrants. A three-step recruitment process was conducted. Initially, habilitation units in three counties and two schools with access to habilitation services were contacted and asked to invite participants. A total of 33 youths and their caregivers were invited to participate by habilitation

units in two of the counties and the schools. Invitation letters were addressed to the youths, including two envelopes addressed to the youth and his/her caregivers respectively, both containing easy-to-read-information about the study in Swedish and Arabic. Subsequently, 200 posters and virtual posters were distributed through websites in the Swedish and Arabic languages and were displayed at habilitation units, schools, associations for people with disabilities, national and community based programmes and other associations, such as mosques, in all three counties. This resulted in the participation of two youths and two caregivers.

In the second step, 130 persons including teachers, social workers, physio- and occupational therapists, personal assistance companies and directors of local social services and leisure activities in all three counties were involved in recruiting participants. This resulted in contact with 20 youths and 45 caregivers of whom 12 youths and 11 caregivers participated.

The third step involved a “snowball technique” (Taylor & Bogdan, 1998), meaning that when conducting interviews the interviewee suggested others that might be interested in participating in the study. This resulted in the participation of two youths and two caregivers. In total, the recruitment process resulted in 16 youths and 15 caregivers who chose to participate.

2.2 Questionnaires

Two study-specific questionnaires for obtaining information about background characteristics were used: one for youths and one for caregivers, both of which contained questions about the characteristics of the youth’s disability. Both questionnaires asked about the youths’ current LSS-related support and their contacts with habilitation services and experiences, as well as their preferences regarding information about the transition to adult support and habilitation services. The questionnaires further contained two additional open-ended questions: “What do you experience as challenging in your transition/the youth’s transition to adulthood?” and “What kind of support do you think could be helpful to you?”.

The Rotterdam Transition Profile (RTP) (Wiegerink, Donkervoort, & Roebroek, 2007) is a questionnaire comprising seven domains of participation and three sections about healthcare for use in interviews with youths during their transition to adulthood. RTP has been developed and tested for validity and reliability by the Transition Research Group South West Netherlands. It is intended for use in clinical practice to identify individual stages that youths with CP pass through in their transition to adulthood. The stages are defined as: 1) Dependent on parents, 2) Experimenting and orientating with the future, and 3) Independent life. Participation involves education and employment, finance, housing, leisure and social activities, intimate relationships, sexuality, and transportation. Healthcare involves care demands, service, aids, and rehabilitation services.

The Family Needs Survey (FNS) (Bailey & Simeonsson, 1988) is a parent-report questionnaire containing statements grouped into six types of needs described by caregivers of children with disabilities: a) information, b) support, c) explaining to others, d) community services, e) financial needs, and f) family functioning. Caregivers choose from the answers, “definitely do not need help”,

“not sure” or “definitely need help”. The statements in the FNS (Bailey & Simeonsson, 1988) may not cover the specific needs of immigrant caregivers to youths in transition, and so, we also used open-ended questions specifically linked to the youths’ transition.

2.3 Translation and Adaption process

The two study-specific questionnaires were prepared in Swedish and Arabic. RTP and FNS were translated and adapted from English to Swedish and Arabic with the permission of the authors and in accordance with international guidelines for translation and adaptation of instruments (WHO, 2013). The translation process was conducted by the study team and three external translators. All translations emphasized conceptual rather than literal translation, using natural and relevant language for the target group and involved discussing and adjusting terms in order to customize the questionnaires to fit a Swedish context (WHO, 2013).

The adaptation of the English version of RTP (0, 2) (Wiegerink, Donkervoort, & Roebroek, 2007) into a Swedish concept involved adjustments that took into account youths receiving support in accordance with the Swedish legislation (Proposition, 1992/1993:159). The RTP has been used in earlier research involving youths with CP, with or without mild ID (Donkervoort, Wiegerink, & Meeteren, 2009). The description of the phases in the adapted and modified version of the RTP is provided in Appendix 1.

All questionnaires were pre-tested for face validity with five Swedish-speaking youths, aged 16-21, who had various types of disabilities and their caregivers, and with five Arabic-speaking youths without disabilities/caregivers (WHO, 2013).

2.4 Participants

The inclusion criteria for participants were: 1) youths aged 13-25 years of age with disabilities, and 2) their caregivers, from Arabic-speaking countries residing in Sweden. “Disability” was defined as any disability for which the youths receive or desire support from the community and/or habilitation services. “Caregiver” was defined as parent, sibling or other close relative involved in the youths’ care. Sixteen youths between the ages 16 and 24 years, ten mothers, four fathers and one sibling participated in interviews. Two were caregivers of youths who did not participate in the study. Fourteen of the youths and all except one of their caregivers were born in Middle Eastern countries. The majority had been living in Sweden for more than five years. All but one of the youths had an ID but different types of other disabilities were represented. Characteristics of the youths are presented in Table 1 and those of the caregivers in Table 2.

Table 1. Characteristics of Participating Youth, Their Rehabilitation Contacts and Support in Accordance with Swedish Disability Legislation

	n 15
Gender	
Male/Female	9/7
Age	
16-17/18-19/21-24	5/4/7
Country of birth	
Sweden/Iraq/other	3/7/6
Their parents' country of birth	
Iraq/Palestine/other Middle Eastern country/other country outside Europe	8/3/4/1
Living with/in	
Both parents/mother/own household/ housing with special service	12/1/2/1
Education/employment	
Elementary special school/secondary special school/Daily activity/nothing	1/9/5/1
Type of disability**	
CP*/moderate or severe ID*/mild ID*/Autism*/visual impairment/hearing impairment/Epilepsy*/do not know or use other explanation	3/4/11/1/5/1/1/15
Rehabilitation contacts**	
Physiotherapist/occupational therapist/counselor/speech therapist/doctor/nurse/psychologist/other/do not know	1/0/4/2/6/3/2/5/6
Support in accordance with Swedish disability legislation**	
Personal assistance, daily activity/companion service/contact person/relief services/short stay away from home/after school activity/do not know	3/3/4/0/1/0/5

*Disability diagnoses were identified based on information from professionals mediating contact or by medical documents shown by caregivers.

**Multiple response options.

Table 2. Characteristics of Participating Caregivers

	n = 15
Gender	
Male/Female	4/11
Age	
25-40/41-45/46-50/51-60/61-70	3/3/1/7/ 1
Country of birth	
Iraq/other	8/7

Length of residence in Sweden	
1-5 years/> 5 years	1/14
Marital status	
Married/single or divorced	13/2
Education background	
Less than elementary school/Elementary school/Secondary school/University degree	2/6/6/1
Employment status	
Employed/Unemployed/Unpaid housework/Pension/Studying	7/2/2/2/2
Employed as personal assistant to the youth	
No/Partly/main employment	11/1/3

2.5 Procedure

A team of four researchers with varying healthcare backgrounds of which one was native Arabic speaking and one was a bilingual (Arabic-Swedish) Project Assistant (PA) performed the study.

Structured interviews were performed in the participants' preferred language, Swedish or Arabic, from September 2014 until January 2015. Fourteen interviews with youths, of whom one youth was interviewed through a professional sign language interpreter, and four with caregivers were conducted in Swedish by the first author (EB). Two interviews with youths and eleven with caregivers were conducted in Arabic by the (PA). Pictogram images were used in two interviews with youths as a tool to support his/hers own speech (National Agency for special needs Education and Schools 2010). One of the youths had a teacher and two had a caregiver present for support during the interviews. The interviews were conducted at their homes, in schools or at daily disability activities, based on individual preferences. Each interview lasted approximately 45 minutes.

All questionnaires were presented in the same order to all participants but individually customized depending on the youth's intellectual level. Upon consent, the interviews were audio recorded; otherwise notes were made by the interviewers. Interviews conducted in Swedish were transcribed verbatim by the first author (EB) and those in Arabic were transcribed and translated into Swedish by the PA.

2.6 Data Analysis

Descriptive statistics using SPSS for Windows, version 22.0 were used to present characteristics of the study population, the youths' current support and habilitation contacts, the participants' experiences of information about transition to adult support and habilitation and to present the distribution of the RTP and FNS.

Open-ended questions were analysed using manifest content analysis as described by Downe-Wamboldt (1992) and Graneheim and Lundman (2004). First, answers were read to obtain a sense of the material as a whole. Second, Meaning Units (MU), a constellation of words relating to the central meaning of the text, were identified in the text by the first author (EB) (Downe-Wamboldt,

1992). Third, the MUs were condensed, remaining close to the texts. Fourth, all MUs were grouped and labelled with codes describing their content. Finally, the three authors sorted all MUs into categories based on similarities and differences at a manifest level. The concepts “credibility”, “dependability” and “transferability” were used to ensure the trustworthiness of the qualitative analysis (Lincoln & Guba, 1985) and this was also ensured by the variation in participants and a clear description of the process. To ensure trustworthiness (Graneheim & Lundman, 2004), quotations are presented in the results.

2.7 Ethical Considerations

The study was carried out in accordance with the Declaration of Helsinki (WMA, 2013) and was approved by the Regional Ethical Board (2014/238). All participants received customized information about the study, including the information that participation was voluntary and rules for handling confidentiality. The information was provided in written form, both in Swedish and Arabic, and orally before each interview. It was also individually customized and included the possibility of asking questions, as recommended by Lewis and Porter (2004). Information about the participants was handled confidentially.

3. Results

The results are presented in four themes for youths and three for caregivers.

3.1 Results from Interviews with Youths

The youths' perceived challenges and desires for support during transition to adulthood were described in four themes: *Managing independently*, *Education and employment*, *Leaving parents* and *Future marriage*.

3.1.1 Managing Independently

The majority of the youths had contact with habilitation or health care services. Six out of 16 did not know which kind of professional they had met in the habilitation services (Table 1). Seven of the youths were in Phase 0 (Early Childhood) and totally dependent on parents or personnel for participation in leisure and social activities (Table 3).

Table 3. Distribution of the Modified Rotterdam Transition Profile

Transition	Phase 0 (n)	Phase 1 (n)	Phase 2 (n)	Phase 3 (n)
Participation				
Education and employment		8	2	6
Finance		12	3	1
Housing		7	6	3
Leisure (social activities)	7	1	2	6
Intimate relationships	9	1	5	1

Sexuality	10	4	1	1
Transportation		6	3	7
Health care				
Care demands		10	2	4
Service and aids		10	3	3
Rehabilitation services		6	7	3

Note. (range 16-24 years) (N = 16).

In terms of formulating care demands and applying for service and aid, most of the youths were in Phase 1 and dependent on parents or personnel for formulating care demands (Table 3). Eight of the youths had received information about the transition to adult support and habilitation services. None of the youths knew if they had received an individual plan in accordance with the Swedish disability legislation (Proposition, 1992/1993:159). Most of them wished to receive information about transition to adulthood, preferably on an individual basis (Table 4).

Table 4. Youths' and Caregivers' Experiences and Desire for Information about Transition to Adult Support and Habilitation. Multiple Response Choice

	Youths (N = 16)	Caregivers (N = 15)
Experiences of information		
Any information	8	6
Information meeting	5	2
Group activity	0	2
Written information	1	1
Individual	8	2
Internet	0	0
Other	2	0
Individual Plan ¹	0	0
Desire for information		
Information meeting	9	1
Group activity	1	3
Written information	1	2
Individual	13	8
Internet	0	1
Do not need	2	

¹ In accordance with the Swedish disability legislation (LSS §10), people receiving LSS service has the right to have an "Individual plan" (Proposition, 1992/1993:159).

Having friends and participation in leisure activities was described as important for all the youths during transition. They explained they had few friends and lacked opportunities to meet other youths on their own, without having parents or siblings around:

I have a friend that that I often hug. He is living next door and I would like to see him without having my mother around (Male, aged 17).

Female youths expressed that they wanted to participate in leisure activities attended by boys and girls. They believed, that their caregivers needed to accept Swedish norms by which males and females attend sports clubs together:

I wish that my parents could understand that their daughter is not growing up in the same society as they did. We have learnt a lot about respect and it says in the Qur'an that you should show respect to each other (Female, aged 17).

The youths wanted to learn how to carry out adult activities, such as buying clothes and makeup, doing household tasks and searching for a job. How to do this was often experienced as challenging. In different ways, the youths expressed that they wanted individual support from any professional with whom they could discuss such issues:

I wish the adult habilitation services would contact me. I have previously seen someone there, not the counsellor and not the doctor, maybe a nurse or occupational therapist, I really don't know, but she was nice (Male, aged 23).

3.1.2 Education and Employment

Depending on the age of the youths, they attended special school or disability day programs (Table 1). Youths who were enrolled in education programmes showed concern about what would happen after finishing school. They desired to continue studying or get a job, believing that participating in any activity was important but earning their own money was preferred. Among the youths who had left school some were in disability day programs, but others had no job or organized activity during the daytime which was experienced as frustrating:

I want something to do during the days, it is more important than earning money, and otherwise I get bored. And, I want to meet friends (Female, aged 24).

Some of the youths were aware of the lack of post-school opportunities due to general difficulties that immigrants might have in getting a job and the fact that they had attended a special needs school. Lacking a secondary school diploma, they had little hope of being accepted at university. Searching and applying for schools or jobs was deemed complicated and something for which they required support:

I can imagine being supported by one person who can tell me about various options and who can demonstrate how to search for information online (Female, aged 19).

3.1.3 Leaving Parents

Thirteen of the youths lived with their caregivers while two lived alone and one lived in housing with special services in accordance with Swedish disability legislation (Table 1). Living at home was seen as convenient by the youths still living in their parental home. Living with caregivers provided sheltering

support and the feeling of security. In addition, requesting support for activities was considered a job opportunity for their caregivers:

My father should be the contact person. He does it anyway and it would be nice if he got paid for it, then he would have a job (Female, aged 23).

On the other hand, a desire to gradually move out of the family home was expressed even though youths believed that their caregivers would be sad if they left home. Some described wanting to move into housing shared with peers in the future. Others described wanting to move into their own apartment, to be able to live independently and find a quiet environment for studying. They all stated that they needed support to find adequate living arrangements and to get support in activities from people other than their parents:

I want a companion person, someone but not my father ... if my father accepts him. He (the companion) must be on time for football practice and always be by my side (Male, aged 23).

3.1.4 Future Marriage

The majority of the youths were still in Phase 0 or 1 (Childhood) regarding intimate relationships and sexuality (Table 3). Adulthood was associated with future marriage, parenthood and with expectations from their families to get married in due time:

According to Islam I'm not allowed to be with a girlfriend without getting married (Male, aged 19).

These expectations aroused thoughts and concerns about both meeting someone to marry and marriage, which was associated with responsibilities. Female youth expressed concerns regarding becoming mothers and bringing up children. Knowledge about marriage and parenthood was desired and they wished that someone, other than the family members, could explain and support them regarding these issues:

How will I handle becoming a mother? I prefer getting support from my family, those I trust, but maybe I can get support from a person who can explain marriage and parenthood to me and help me find information online (Female, aged 21).

The youths expressed a desire to discuss important issues with people other than family members. Such issues concerned love and how to talk to youths of another sex. Some wished to be invited to join a group at the habilitation services:

I would like to join a group where we could talk about things [love and girls] - that would really be supportive for me (Male, aged 23).

3.2 Results from Interviews with Caregivers

The caregivers' challenges and needs were described in three themes: *Challenges with the growing child; Unfamiliarity with the education and support systems* and *Support for the youths*.

3.2.1 Challenges with the Growing Child

About half of the caregivers expressed the need for more information about their youth's condition or disability (Table 5). The need with the highest score was that their spouse needed help in understanding

and accepting the youth's condition. Lowest scores were the need for more friends to talk to and help explain the youths' condition to siblings. However, nine out of 15 caregivers needed more information about the services that their youths might receive in the future.

Table 5. How 15 Independent Caregivers Indicate a Definite Need for Help in Accordance with the Family Needs Survey

Item	n
Needs for Information	
I need more information about my child's condition or disability	8
I need more information about how to handle my child's behaviour	7
I need more information about how to teach my child	7
I need more information about how to play with or talk to my child	7
I need more information about the services that my child might receive in the future	9
I need more information on the services that are presently available for my child	7
I need more information about how children grow and develop	8
I need more information about planning for my child's future well-being (guardianship, trust funds, transition to adulthood)	7
Needs for support	
I need to have someone in my family that I can talk to more about problems	3
I need to have more friends that I can talk to	1
I need to have more opportunities to meet and talk with parents of children who have disabilities	7
I need to have more time just to talk with my child's teacher or therapist	7
I would like to meet more regularly with my counsellor (psychologist, social worker, psychiatrist) to talk about problems	8
I need to talk to a minister/spiritual leader who could help me deal with my problems	3
I need reading material about other parents who have a child similar to mine	8
I need to have more time for myself	7
Explaining to Others	
I need more help in explaining my child's condition to either my parents or my spouse's parents	1
My spouse needs help in understanding and accepting our child's condition	13*
I need more help in how to explain my child's condition to his/her siblings	1
I need help in knowing how to respond when friends, neighbours, or strangers ask questions about my child's condition	2
I need help in explaining my child's condition to other children	2
I need help in explaining my child's condition to teachers and other professionals	8
Community Services	

I need help locating a doctor who understands me and my child's needs	8
I need help locating a dentist who will see my child	5
I need help locating babysitters or respite care providers who are willing and able to care for my child	4
I need help locating a childcare centre, pre-school, school, vocational training, or job for my child	5
I need help in getting appropriate care for my child in our church or synagogue** during services	0
I need help in locating camps, sports, recreational, social, and leisure activities for my child	5
I need help in getting transportation services for my child	3
I need help in coordination medical, developmental, educational, and other community services for my child	7
Financial Needs	
I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation	8
I need more help in paying for therapy, childcare, or other services that my child needs	5
I or my spouse need more counselling or help in getting a job	4
I need more help paying for babysitting or respite care	2
I need more help paying for home modifications, equipment or toys that my child needs	6
Family Functioning	
Our family needs help in discussing problems and reaching solutions	5
Our family needs help in learning how to support each other during difficult times	6
Our family needs help in deciding who will do household chores, childcare, and other family tasks	3
Our family needs help in deciding on and participating in recreational activities	3

N = 15, * N = 13 ** or Mosque.

The caregivers expressed concerns about their physically maturing children and that they had become men and women. Their daughters had menstrual periods and their sons had grown beards, but caregivers did not think that their youths fully understood how to manage by themselves when they no longer could help:

I am worried...my child has become a man—the opposite sex to me—and has to shower and shave all alone. I'm not supposed to help him anymore (Mother of a boy, aged 16).

Caregivers were worried when youths “hung out” with friends and travelled alone, and they were worried about the youth’s future life and how they would be able to cope. They expressed concern that they no longer would be the one to care for their child in the future and were unsure if housing personnel really had the right knowledge to ensure their youth’s individual needs:

I am worried about whether he can manage life without me but with support from that so-called personnel... when my child has a cold... he must drink water and take medicine. A mother needs to give reminders all the time (Mother of a boy, aged 21).

3.2.2 Unfamiliarity with the Education and Support Systems

None of the caregivers used the diagnostic term for ID, but used other terms instead such as “think like

a child” or “slow understanding”. The caregivers said that they were unfamiliar with the Swedish education and support systems. Some thought that native born Swedish youths and immigrants were treated differently in school and they were dissatisfied with the way children were grouped according to their disabilities. Others believed that the education systems were unsuitable for youths with disabilities and expressed that they thought it was better in their old country:

The school system in Sweden should be something midway between the Swedish and other cultural programs, the Swedish school system can be even better if they learn about other cultures. In our country they spend more time in school and have more activities with children with disabilities along with other non-disabled children (Father of a girl, aged 17).

Some caregivers believed themselves to have more knowledge of their youth’s needs than the professionals. Some did not want any support at all from the community or the habilitation services as they believed that a child with disability had been determined by God’s will:

I need no help. She’s my daughter and I am obligated to take care of her... (Mother of a girl, aged 17).

3.2.3 Support for the Youths

Caregivers expressed a need for different forms of community service (Table 5). The greatest needs expressed were for locating a doctor or help in coordinating community services. No one expressed the need for appropriate care for their youth during religious services.

Caregivers said they wanted leisure activities and also support for their youths in these leisure activities. Some desired places where their youth could find a boyfriend or girlfriend in order to get married in the future. It was described as challenging for them and it made them unhappy. They expressed that a companion or a contact person might be able to support their youth in his/her social life and that professionals could teach the youth to handle life skills and talk to their youth about problems in transition:

Perhaps a psychologist or a counsellor could talk to my son about life, how he will cope with his life now and as an adult (Mother of a boy, aged 21).

The caregivers expressed the need for information about service their youth might receive in the future (Table 5). Six of the caregivers had received information about transition to adult support and habilitation services (Table 4). They expressed a lack of information about current and future support and habilitation available for their youth, believing that such information might enable them to support their youth during transition. Some requested that a qualified person should make house calls, preferably someone who spoke both Swedish and Arabic, as this would enable them to ask questions so they in turn would be able to support their maturing teen.

4. Discussion

A purposeful consecutively sampling to achieve the desired coverage of target groups were tried. However, only 31 participants agreed to participate, which may indicate that there are similar challenges in reaching out to immigrant youths and their families with information about services. A number of professionals employed by support and habilitation services, who were requested to provide support with recruitment, refused to disseminate information about the study. They did not want to disturb the families out of respect for their vulnerable situation as both immigrants and the parents of children with disabilities. This indicates that professionals who consider themselves advocates for immigrants actually act as gatekeepers and thereby prevent these groups from having their voices heard (Ingvarsdotter, 2014). This might result in immigrants' general needs being neglected when planning support, health care- and habilitation services.

Participants were interviewed without interpreters as using interpreters is difficult and may not always yield accurate translations of the answers given (Morville & Erlandsson, 2016; Ingvarsdotter, Johnsdotter, & Ostman, 2012). Berg (2015) noted that immigrants do not always trust that their confidentiality is respected by interpreters and may be reluctant to speak freely. During the data collection, several issues were raised between the caregivers and the interviewers relating to the appointment schedule and the aim of the study. Furthermore, none of the caregivers in the present study used the term "intellectual disability" to describe their young person's diagnosis, even though they attended special schools or had support in accordance with the Swedish legislation, for which a diagnosis implying ID is required (Proposition, 1992/1993:159). The caregivers were also dissatisfied with the way children were grouped according to cognitive levels in Sweden, and according to the FNS all of the married caregivers expressed that their spouses needed help to understand and accept the youth's condition. Leavitt (2002; 2003) points out that in many cultures, the term "disability" does not exist; instead people might be described as "lame" or "slow", but not disabled. IDs are also stigmatized in many Middle Eastern countries (Crabtree, 2006; Azar & Badr, 2006; Raman et al., 2010). This might also be due to cultural and language barriers, which was also experienced in a Norwegian study concerning needs in immigrant families with disabled children (Berg, 2015). Immigrants from the Middle East might therefore be uncomfortable with categorizing people with disabilities by the terminology commonly used in the community- and habilitation services in the western world. This is noteworthy because it might lead to avoidance of applying for community services or rehabilitation for adults, for which a diagnosis is required (e.g. Proposition, 1992/1993:159). However, after interviews, participants of the present study expressed their gratitude when asked about their situation. These reflections on the process of recruitment and data collection support the importance of building trust and confidence when offering information and providing support, health care, and habilitation for immigrant youths with disabilities and their families (Berg, 2015; Leavitt, 2002, 2003). Campinha-Bacote (2002) argues that providers must strive to obtain knowledge of each client's health-related beliefs and values by understanding their individual worldview. This is in line with

cultural competence and essential for professionals working with immigrants in support and health care services (Daudji et al., 2011; Hasnain, Cohon, & Shanawani, 2008; King et al., 2015; Lindsay et al., 2012).

Most of the participating youths in our study still lived with, and were financially dependent upon, their parents, which is common among youths of the same age in general (Arnett, 2000). Most of them were, however, also dependent upon their parents or personnel for help with leisure and social activities, which differs from non-immigrant youths aged 18-22 who are diagnosed with CP and who were found to be more independent in pursuing these activities (Donkervoort et al., 2009). On the other hand, caring for a youth with disability was stated as a work opportunity and an opportunity for caregivers to earn income. This might also be explained by the fact that families from Middle Eastern countries commonly are family oriented with a strong sense of cultural responsibility to care for family members (Crabtree, 2006; Hasnain, Cohon, & Shanawani, 2008) rather than encouraging individual independence (Armstrong & Ager, 2005). Furthermore, Berg (2015) noted that immigrants commonly spent more time in their family networks due to lack of extended social networks in their host country. Few of the youths in the present study had experienced romantic or intimate relationships, which is consistent with both the results of a Norwegian study showing that youth with similar disabilities did not have any romantic relationships when they were in their early twenties (Myklebust, 2012), and the results of a Dutch study of young adults with CP (Wiegerink et al., 2010). It is however of interest that their caregivers desired opportunities for their youths to find someone to marry. It is noteworthy that the youths in the present study were expected to get married, which aroused concerns for both youths and caregivers as well as a need for information about both marriage and parenthood. This requires special attention in transition planning for immigrant youths, especially girls from Middle Eastern countries. Both boys and girls, and their caregivers, need to be informed about the fact that marriage in Sweden and in many other Western countries must be voluntary.

A majority of the youths in the present study were dependent on parents or personnel for formulating care demands and applying for service and felt that there was a lack of information about the transfer to support and habilitation services for adults. The caregivers' needs that are described in the present study concerned different kinds of information, in particular, future services their youths might receive. This is in line with the results of a Swedish survey showing a lack of knowledge about support on the part of parents of children with disabilities who were born abroad compared to parents born in Sweden (Broberg et al., 2014). It is also in line with a Swedish study in which the FNS was used to identify the needs of the parents of children 7-17 years of age with mild ID (Huus et al., 2016). Both youths and caregivers in the present study desired personalized information and support to handle transition and is consistent with the results of earlier studies involving non-immigrant Swedish youths with CP and their parents (Björquist, Nordmark, & Hallström, 2015, 2016). When a youth becomes an adult, it is up to the individual to organize and demand support, health care, and habilitation services. This might be challenging after having been taken care of in a sheltered paediatric context (Alriksson-Schmidt et al.,

2014). However, youths with disabilities—immigrants or not—need to learn how to use services themselves to become less dependent on their parents (Gorter & Roebroek, 2013). Service providers should therefore focus on youths' development of autonomy and self-esteem to encourage participation in the transition process (Donkervoort et al., 2013; Gorter & Roebroek, 2013). To assist youths in taking control over this process, it must be valuable to listen to each individual's views and identify his/her involvement in their transition. This is in line with Article 12 of the United Nations (UN) Convention on the Rights of the Child (UNCRC, 1990), which refers to respect for the views of the child and the general principles in Article 3 of the UN Convention on the Rights of Persons with Disabilities, including the independence of persons and the freedom to make one's own choices (United Nations Human Rights Convention on the rights of persons with disabilities, 2006). The results of this study are based, and discussed on group level and obvious there are individual differences that require individualized support. We suggest individualized and culturally-sensitive service and use of the RTP as a tool in transition planning, to increase the engagement and the involvement of immigrant youths with disabilities.

5. Conclusions and Implications for Practice

Recruiting immigrants in research studies is challenging and health-care professionals acting as gatekeepers lead to lack of knowledge about the self-identified needs of immigrants with ID and their caregivers. This study shows that one good way of recruiting participants is through collaboration with persons who are in direct contact with immigrant youths, particularly those in special schools. However, youths and caregivers participating in this study clearly showed that they both appreciated being able to talk to someone and that they had a lot to say.

Unfamiliarity with the term ID among immigrant caregivers of Middle Eastern origin and the need for information about their youths' condition and future support underscore the importance of information about the nature of their youths' individual disability and the ability for them to receive support, health care and habilitation services. Unfamiliarity with the term ID might be a possible reason for not contacting authorities. One good way to initiate contact with immigrant youths with ID and their families would therefore be to reach them through the schools. Providing them with personalized information and support from a designated professional in a language of their preference might then meet their individual needs.

Immigrant youths of Middle Eastern origin strive to participate in Swedish society and to be less dependent on their parents in the future. They have expectations as do youths in general, but are concerned about future marriage and parenthood, which must be given attention in transition planning. Service delivery should therefore be made with an awareness of cultural traditions and family oriented living, yet still focus on supporting youths with ID in their emancipation process. To identify individual challenges and needs in transitioning youth, it is therefore important to listen to each individual and to strengthen his/her autonomy. We suggest the RTP as a tool to facilitate transition planning for these

young people, if it is used in a way that is customized for the individual.

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