

Original Paper

Transitioning to Adulthood in Sweden: Comparing the Priorities of Immigrant Youths with Disabilities and Caregivers, from Middle-Eastern Countries

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Abstract

Background: *There is limited knowledge about perceived challenges during the transition to adulthood among immigrant youths who are originally from Arabic-speaking countries but now residing in Sweden. Aim:* *The aim of this study was to describe self-identified problems encountered by immigrant youths with disabilities from Middle Eastern countries who were living in Sweden during their transition to adulthood and to compare these descriptions to the problems identified by their caregivers.*

Methods: *Seventeen semi-structured interviews using the Canadian Occupational Performance Measure were conducted with 17 immigrant youths with intellectual disabilities aged 13-24 years and 16 caregivers, originally from Middle Eastern countries. The participants' prioritized problems were categorized using the International Classification of Functioning, Disability and Health-Children & Youth Version, focusing on Activity and Participation.*

Results: *A difference in priorities during transition was found when comparing the youths' and the caregivers' views. Most of the youths' priorities were identified in the chapter "Major Life Area" about basic economic transactions and seeking employment, whilst the caregivers thought their youths' prioritized "self-care".*

Conclusion and implications for practice: *Planning the best transition for immigrant youths with disabilities involves enabling them to identify their own preferences and needs while collaborating with*

caregivers and taking into consideration the cultural norms and traditions of collective caregiving.

Keywords

caregivers, disability, ICF-CY, immigrants, transition, youth

1. Introduction

When children with disabilities grow older, leaving childhood for adulthood involves a life-course transition that usually means leaving their parental home for independent or supported living, finishing school, and entering the labour market or participating in work arrangements (Donkervoort et al., 2009; Stewart et al., 2010). The World Health Organization (WHO) defines disability as “an umbrella term for impairments, activity limitations, and participation restrictions”. Transition for youths with disabilities further involves transitioning from child-centred to adult-centred support and health care systems. This has been associated with a feeling of “falling off a cliff” for both youths and parents (Stewart et al., 2001). The recommendation is to begin the preparation for transition in early adolescence (Gorter & Roebroek, 2013). Key factors for a successful transition are: promoting the youths’ participation and the gradual taking of responsibility in their individual transition process with individual support from healthcare professionals (Björquist, Nordmark, & Hallström, 2015; Gorter et al., 2015; Reiss, Gibson, & Walker, 2005).

Participation, defined by WHO (2001) as “involvement in life situations”, is an important component of the International Classification of Functioning, Disability and Health (ICF) framework for youths during this critical process (Gorter & Roebroek, 2013). In parallel, the version for children and youths, ICF-CY (WHO, 2007) is a useful measurement in rehabilitation planning for youths (Vargus-Adams & Majnemer, 2014). Important components are activities and participation and environmental factors, which for maturing children and youths include the family—their caregivers in particular (Rosenbaum & Gorter, 2011). Caregivers are concerned about these youths, which is why their opinions regarding what is important for their growing child matter; however, young people are capable of setting goals (Maggs et al., 2011) and identifying problems for which a youth-friendly measurement is the Canadian Occupational Performance Measure (COPM) (Gorter et al., 2015; Nieuwenhuijsen et al., 2009).

Nowadays, most countries in the Western World have multicultural populations. In Sweden, approximately one in five children was born abroad or one or both of their parents were born abroad; the most common non-European country of origin is Iraq (Statistics Sweden, 2016). The number of these children with a disability is unknown because Swedish healthcare registers do not record the country of origin. However, a literature review done from a multicultural perspective showed that evidence-based knowledge is limited regarding how immigrant children and youths with disabilities in Sweden access services (Björngren Cuadra, 2012). A regional Swedish report examining parental education and organized by Child and Youth Habilitation Services was aimed at Arabic-speaking families. It showed that cultural differences existed in terms of the way disability and support expectations were viewed (Nilgert, 2009).

Culturally sensitive services for families with diverse cultural backgrounds are essential for the support and services geared to youths with disabilities, and this is in line with Family Centred Service (FCS) (Lindsay et al., 2012, King et al., 2015). When a youth transitions to adulthood, a person-centred approach is used, meaning emerging adults with disabilities are viewed as individual clients (King et al., 2005). Overlooking cultural aspects may cause difficulties in the transition planning (Kim & Morningstar, 2005). However, there is a knowledge gap regarding how immigrant youths and their caregivers—originally from Middle-Eastern countries—perceive problems facing the transition to adulthood. The aim of this study was therefore to describe self-identified problems encountered by immigrant youths with disabilities from Middle Eastern countries who were living in Sweden during their transition to adulthood and to compare these descriptions to the problems identified by their caregivers.

2. Methods

2.1 Study Design, Setting and Inclusion Criteria

This article describes the second part of a larger study designed to enable transitioning immigrant youths with disabilities and their caregivers to make their voices heard concerning needs and prioritised problems (Björquist et al., 2017). It was conducted by a team consisting of the four authors with varying health care competencies, of which one, (NA) was a native Arabic speaker and experienced in rehabilitation for persons with disabilities and families in Jordan. The team also included an Arabic- and Swedish-speaking project assistant, henceforth PA. The study was conducted in three counties in the west and south of Sweden with high immigrant populations. The inclusion criteria for participants were: youths aged 13-25 with any form of disability and their caregivers with a background in Arabic-speaking countries. “Disability” was defined as any disability for which a person needed or received support from the community and/or habilitation services. “Caregiver” was defined as a parent, sibling, or other significant person involved in the youth’s care. Semi-structured interviews were used for data collection.

2.2 Recruitment Process

Recruitment took place between May 2014 and January 2015. First, 33 youths were identified by the habilitation units in two of the counties and two schools with access to habilitation services in the third county. Participants were recruited by post. Simultaneously, information about the study was made public in the form of 200 posters and an invitation to participate was published on websites in all three counties. The posters were distributed through habilitation units for children and youths and for adults, schools and associations for people with disabilities, in facilities for community-based programmes and immigrant organisations. This recruitment stage resulted in the participation of two youths and two caregivers. Secondly, people in contact with the target group assisted with the recruitment. This resulted in the participation of 13 youths and 12 caregivers. Additionally, participants were recruited through a snow-ball sampling while conducting interviews at special schools and facilities for work

arrangements known as “daily activities” (LSS, Act concerning Support and Service for Persons with Certain Functional Impairments (Proposition, 1993:387)). This resulted in the participation of two youths and two caregivers. In total 17 youths and 16 caregivers agreed to participate.

2.3 Questionnaires for Data Collection and the Translation Process

Two questionnaires about background characteristics were used to describe the study group. The questionnaire for youths asked about age, gender, type of disability, education/employment, living arrangements, their country of birth and that of their parents. The questionnaire for caregivers asked about age, gender, country of birth, length of residence in Sweden, marital status, educational background and employment status. The latter also asked caregivers to describe their youths’ characteristics and their relation to their youth. The questionnaires were prepared in Swedish by three of the authors (EB, EN, IH) and translated into Arabic, then back-translated by the PA and the third author (NA).

COPM (Law et al., 2005) is an individualized five-step outcome measure for semi-structured interviews with a client and/or caregiver, aimed at identifying individual perceptions of problems with activities such as: a) self-care, b) productivity, and c) leisure and social activities. COPM focuses on activities a client wants, needs, or is expected to participate in. Importance, performance and satisfaction are ranked on a Visual Analogue Scale (VAS) of 1-10 by using score cards. The original English version (Law et al., 2005) was translated into Arabic by the third author (NA) in concurrence with the original author and back-translated from Arabic to English by an authorized translator, according to the WHO rules for translation of measurements (WHO, 2013). It was thereafter tested in focus group interviews with five Arabic-speaking youths and parents respectively (WHO, 2013). There is a Swedish version of the COPM (Förbundet Sveriges Arbetsterapeuter, 2006), which was pre-tested on five Swedish youths aged 16-21 with various types of disabilities and five parents. In many studies COPM is considered to have good validity and reliability (Carswell et al., 2004) and has been used in research on children and/or youths mainly with physical disabilities (e.g., Chiarello et al., 2010; Cusick, Lannin, & Lowe, 2007; Lauruschkus, 2015; Law et al., 2015). The interviews for data collection in the study were based on COPM, in accordance with the instructions in the Swedish COPM, 4th edition (Förbundet Sveriges Arbetsterapeuter, 2006), based on the original version (Law, 2005).

2.4 Procedure

The interviews were conducted from September 2014 until January 2015. Fifteen interviews with youths and four with caregivers were conducted by the first author (EB) in Swedish. Two interviews with youths and 12 with caregivers were conducted by the PA in Arabic. Both interviewers were trained in conducting the COPM. Youths and caregivers were interviewed separately. The interviews were performed in a semi-structured manner in the participants’ preferred language and followed the major categories of COPM. Interviews were individually customized; e.g., by using Alternative and Augmentative Communication (AAC); three of the youths used pictogram images (National Agency for special needs Education and Schools, 2010) and keyword signing for speech support (Cambridge

and Forrester-Jones, 2003; Meuris et al., 2014). Two of them had an older sibling present for support. One interview (in Swedish) was conducted with the help of a professional sign language interpreter. Initially, the participants were asked to identify what they/their youth perceived as important but problematic during transition, then to rate the importance of each problem they identified on a scale of 1 (not important at all) to 10 (extremely important). Secondly, they were instructed to select up to 5 major problems. Finally, the participants were asked to rate each problem on performance and satisfaction using a scale of 1 to 10. The score card was illustrated with a sad, neutral and smiley face (scoring 1, 5 and 10 respectively). The scoring was done in dialogue with the participant and interviewer who completed the COPM form. Each interview lasted 30-60 minutes with no difference between youths and caregivers. With the participant's permission, 15 of the interviews with youths and 10 with the caregivers were audio recorded. The first author (EB) transcribed the recordings verbatim, whilst those in Arabic were transcribed and translated into Swedish by PA.

2.5 Data Treatment

Based on the completed COPM forms, the youths' top 5 self-identified, prioritised problems were noted in a table and those identified by caregivers in another. All notes were then coded and categorized into the three categories and nine subcategories following the COPM form (Law et al., 2005) by two of the authors (EB, EN) (Table 1).

Table 1. Youths' and Caregivers' Prioritised Problems Organized into COPM Categories and Sub Categories (Law et al., 2005)

	No. Youths (60)	No. Caregivers (69)
Daily activities		
Personal care	2	20
Functional mobility	2	6
Community management	6	3
Productivity		
Household	11	4
Play/School	6	8
Paid/unpaid work	14	8
Leisure		
Quiet recreation	5	2
Active recreation	2	2
Socialization	12	8
Not definable in COPM	-	8

The data were thereafter re-coded using the ICF-CY framework (WHO, 2007). ICF-CY has two parts:

Functioning and Disability and Contextual Factors. Each part contains two components denoted by a letter, such as a *d* for “Activity and Participation” component and *e* for “Environmental Factors”. Within each component, the classification is organized into chapters. Each chapter has two four-level categories, each with a short definition for assisting the selection of an appropriate code (WHO, 2007). Two of the authors (EB, EN) then coded the data following the ICF general linking rules (Cieza et al., 2005) and discussed this with the last author (IH) until consensus was reached.

The coding process was as follows:

1. Each annotation in the tables was linked to one of the most specific ICF-CY codes possible, with a focus on the component “Activity and Participation”. During this process, imprecise annotations were checked with the completed COPM forms or the transcribed interviews. For example, if “cooking” was noted as a prioritised problem and was described in detail earlier in the form/transcribed interview as “cannot heat food in the microwave”, the most suitable code was determined to be “Preparing simple meals...” (*d6300*).
2. Annotations not sufficient for deciding the most precise code were coded in less detail. Additional codes were assigned for annotations that had more than one obvious component depending on their content. For example, “calling for transport services” was coded “Using telephones...as a means of communication” (*d3600*) and “Services, systems (...) that meet the needs of individuals...” (*e510*). Annotations not identified in ICF-CY were marked as “not covered (“nc”) and noted verbatim.
3. All codes were compared so as to use the same codes for comparable content in the notes. An example of the ICF-CY coding is shown in Table 2.
4. All main codes were organised on a group level by categorization into the ICF-CY components and chapters (WHO, 2007).
5. To test for differences in proportions between what the youth and caregivers deemed to be priorities, an on-line Z-score test for proportions was used (Social Science Statistics, 16-02-12). P-values below the standard value of 0.05 were considered statistically significant (Björk, 2013).

Table 2. Example of ICF-CY Coding Process

Identified problem	ICF-CY code	Additional information	ICF-CY chapter
Youth			
Shopping (Female aged 17)	<i>d 860</i>	How to pay for cosmetics	Major life areas
Handling own money (male aged 23)	<i>d 860</i>	Getting own pocket money to buy things	Major life areas
Seeking employment (Female aged 21)	<i>d 8450</i>	How to search for a nice job	Major life areas

Caregivers

Dressing her/himself (Father)	d 5400	...has to dress her/him; she/he cannot do it by her/himself	Selfcare
Brushing teeth (Mother)	d 5201	Cannot brush teeth properly; mother has to do it at least once a day	Selfcare
Showering (Sibling)	d 5101	Cannot wash hair with shampoo him/herself	Selfcare

3. Ethical Considerations

This study was carried out in accordance with the Declaration of Helsinki (WMA, 2013) and approved by the Regional Ethical Board, Lund, Sweden (Ref. 2014/238). The participants received customized information about freedom of participation and guaranteed confidentiality. They all gave their written informed consent; parents also gave written consent for participants younger than 18 years of age. Ethical considerations had to be taken into account, as we asked the participants to identify their perceived problems but did not offer any support. We therefore carefully explained that the study did not involve any treatments or further support. Questions were, however, answered after the interviews by providing general information about support or habilitation in Sweden.

4. Results

Nine males and eight females, aged 13-24 years participated in the COMP-interviews with youths. Ten mothers, five fathers and one sibling participated in COPM-interviews with caregivers. Seven of the youths, aged 17-24 participated, but not their caregivers. Two of the caregivers had youths with severe intellectual disabilities who did not participate themselves. Fourteen of the youths and all the participating caregivers had Middle Eastern backgrounds. Almost all the participants had lived in Sweden for more than five years. All except one of the youths had an intellectual disability (ID), of which 11 had a mild ID. Furthermore, a large range of disabilities was represented, including hearing and visual impairments. The characteristics of the participants are presented in Table 3.

Altogether 33 participants completed the COPM interviews. Six of the youths and nine of the caregivers were able to identify the maximum of five priorities and the rest identified less than five. The youths (n=17) prioritised a total of 60 problems that they faced during transition to adulthood and the caregivers (n=16) identified a total of 69 problems that they perceive their youth prioritised.

The youths' prioritised problems and the youths' problems as identified by caregivers and coded by the ICF-CY are presented in Table 4. Three of the problems identified by the caregivers were classified within the component "Body Functions and Structures" and were described as "problems falling asleep" (b1341)/"sleeps all night" (b1340) and "understanding his/her own disability" (b180). For both the youths and the caregivers, two prioritised problems respectively described as "finding/obtaining a

“daily activity” (in accordance to LSS)” were not identified in ICF-CY (“nc”).

Approximately one third (19) of the youths’ prioritised problems were from the chapter “Major Life Areas” (d8). Eight of them were coded “Basic economic transactions” (d860) described as, e.g., buying coffee or managing their own pocket money. Seven were coded “Seeking employment” (d8450) and were all described as “searching for a job”. The largest group of the youths’ prioritised problems as identified by their caregivers (21) were from the chapter “Self-Care” (d5), with “washing the whole body...” (d5101) being most represented (12) within this chapter and described as, e.g., “showers by him/herself”. Statistically significant differences were shown between the youths’ prioritized problems and those identified by the caregivers in the ICF-CY chapters “Major Life Areas” (P-value =0.010) and “Self-Care” (P - value = 0.000).

In the chapter “Domestic Life” (d6), the same total (8) of priorities was found for both the youths’ self-identified problems and youths’ problems as identified by the caregivers, and these mostly concerned preparing simple meals (d6300), described as for example “heating food in the microwave” or “preparing snack after school”.

Table 3. Characteristics of Participating Youths (N=17) and Caregivers (N=16)

	n
Male / Female	
Youth	9 / 8
Caregivers	5 / 11
Age	
Youth	
13/ 16-17 / 18-19 / 21-24	1 / 5 / 4 / 7
Caregivers	
<30/35-40 / 41-45 / 46-50 / 51-60 / 61-70	1/2 / 3 / 2 / 7 / 1
Country of birth*	
Youth	
Sweden / Iraq / other	3 / 8 / 6
Caregivers	
Iraq / other	9 / 7
Youth’s caregiver’s country of birth*	
Iraq / Palestine / other Middle Eastern country / other country outside Europe	9 / 3 / 4 / 1
Caregiver’s length of residence in Sweden	
1-5 years / > 5 years	1 / 15
Caregiver’s educational background	
Lower than elementary school / Elementary school / Secondary school /	2 / 7 / 6 / 1

University degree	
Caregiver's marital status	
Married / single or divorced	14 / 2
Youth living with / in Both parents / mother / own household / special service housing	13 / 1 / 2 / 1
Education / employment	
Youth	
Elementary special school / secondary special school / Daily activity ¹ / nothing	2 / 9 / 5 / 1
Caregivers	
Employed** / Unemployed / Unpaid housework / Pension / Studying	7 / 2 / 3 / 2 / 2
Youth's type of disability***	
CP ² / moderate or severe ID ³ / mild ID / Autism / visual impairment / hearing impairment / Epilepsy / do not know or use other explanation	3 / 5 / 11 / 1 / 5 / 2 / 1 / 16

* Seven of the youths, aged 17-24 years, participated but not their caregivers.

** Partly / mainly employed as personal assistant¹ to the youth: 1 / 3.

*** Multiple response options.

¹ LSS, Act concerning Support and Service for Persons with Certain Functional Impairments is an entitlement law involving measurements for support in daily living (Proposition, 1993:387).

² Cerebral palsy is a common motor disorder often involving associated impairments, e.g., Intellectual Disability (ID) (Rosenbaum et al., 2007; Novak et al., 2012).

³ Intellectual disability is a developmental disability characterized by limitations in intellectual functioning and adaptive behaviour (AAIDD, 2015).

Table 4. ICF-CY Chapters Classified within the Activity and Participation (d) Component for the Youths' Prioritised Problems (58) and Youths' Priorities as Identified by Their Caregivers (61) with Examples of Statements and ICF-CY Codes

ICF-CY Chapter	Number of codes	Example of youth's statement	ICF-CY code	Number of codes	Example of caregiver's statement	ICF-CY code
Learning and applying knowledge	1	Learning how to speak Swedish (female, age 21)	d134	3	Understands the football coach's instructions (Father of boy, age 23)	d1551
General tasks demands and demands	4	Use the television, change channels (female, age 17)	d2100+e140	4	Knows when it is time to catch the school bus (mother of girl, age 17)	d2306

Communication	4	Use my cell phone, not only answers but can call (male, age 19)	d3600	4	Communicates by phone (sibling to boy, age 16)	d3600
Mobility	8	Travel by bus all by myself (male, age 23)	d470	7	Walks outside by herself (Father of girl, age 13)	d460
Self-care	2	Shave myself (male, age 19)	d5202	21	Dresses herself (Father of girl, age 17)	d5400
Domestic life	8	Heat food in the microwave (female, age 23)	d6300	8	Makes his bed himself (Mother of boy, age 16)	d6406
Interpersonal interactions and relationships	6	Make friends of my own (female, age 23)	d7500	3	Finding himself a wife (Mother of boy, age 23)	d7701
Major life areas	19	Searching for a job (male, age 17)	d8450	8	Manages own pocket money (Father of boy, age 17)	d860
Community, and social civic life	6	Visit a gym for both boys and girls (female, age 18)	d920+e410	3	Engages in any kind of organised sports activity, for example basketball (Mother of boy-age 23)	d9201

5. Discussion

The youths' priorities mostly concerned major life areas such as searching for jobs and having their own money, whilst the caregivers thought their youths prioritised their self-care. Nieuwenhuisen and colleagues (2009) who interviewed youths with cerebral palsy (CP) using COPM and ICF for coding showed that more than half of the youths perceived problems with self-care. However, they described that work, socialization, and functional mobility were problems that mattered more to them. Also, another Swedish study involving youths with CP who were 17-18 years of age (Björquist, Nordmark, & Hallström, 2015) showed that socializing was experienced as important but problematic during the transition.

Our results showed a difference between the youths' and the caregivers' views in terms of what was most important for the youths during transition. Similar differences were found in a Canadian study comparing the priorities of youths with CP and their mostly non-immigrant parents. Here the parents were more concerned about their youth's ability to manage personal care such as going to the toilet and

dressings, than the youths themselves (Maggs et al., 2011). Following the Perceived Efficacy and Goal Setting System (PEGS) for the children and COPM for the parents, a Swedish goal-setting intervention for children with disabilities showed that the children mainly identified goals concerning leisure and school work, whereas the parents identified Activities for Daily Living (ADL) goals (Vroland-Nordstrand, 2015). This different view of what is problematic in the transition to adulthood and consequently the support the youths themselves prefer and may need, highlights the importance of involving the youths in their individual planning for transition. According to Armstrong and Ager (2005) and Hasnain and colleagues (2008) it is less common to encourage individual independence in countries such as those in the Middle East that have a collectivistic orientation for caretaking within the family network. Today, making the child's needs central is a highly relevant issue within both support and healthcare services. According to the Convention on the Rights of the Child, Article 12 (United Nations Human Rights, 1990) children should be involved in decision making appropriate to their individual level of maturity, meaning the views of youths in their late adolescence should be given greater consideration. Furthermore, when youths with disabilities become legal adults (in Sweden, at the age of 18), these rights should naturally be provided in accordance with the principle stated in the Convention on the Rights of Persons with Disabilities, Article 3 confirming the individual's freedom to make his or her own choices (United Nations Human Rights, 2006). These conventions make a strong argument for the implementation of FCS in services, which involves viewing both children and parents as knowledgeable partners to professionals (King et al., 2004; Rosenbaum et al., 1998). Unfortunately, in services for youths with Intellectual Disabilities (ID), it is often the case that parents are viewed as being the most knowledgeable about the youth's needs, and it is they who decide what is in the youth's best interest. Because people with ID need some support in decision-making throughout life (Rosenbaum & Ronen, 2013), this tends to continue years after the youths have become adults.

Although collaboration with parents has been found to be effective and in line with culturally sensitive care provided by services for immigrant children with disabilities (Fellin, Desmarais, & Lindsay, 2015; King et al., 2014), in individual transition planning for youths with disabilities, focus on the youth's development of appropriate autonomy, in cooperation with systems of care, has been shown to be a successful way to facilitate and empower the youths during their transition process (Gorter & Roebroek, 2013, Gorter et al., 2015, Kraus de Camargo, 2011). Wiegerink and Roebroek (2013) have also discussed how transitioning youths with disabilities need to have the possibility to approach professionals with personal issues that they find important—such as love and sexuality—without having their parents present. We suggest, however, that the best way to plan for immigrant youths' transition is to take into account the diversity of cultural norms among immigrant families, and this involves cooperation with caregivers (Kim & Morningstar, 2005). That said, it is also important to listen and pay attention to the individual youth's own preferences; hence, when enabling youths with intellectual limitations to participate in their own transition planning, professionals need to prepare to implement supportive tools where necessary. The British researchers Cameron and Murphy (2004)

identified the effectiveness of using “Talking Mats” as a communication resource for young persons with ID in person-centred transition planning. “Talking Mats” is a pictorial system for AAC, similar to the pictogram images used in our study. It involves images showing both topics and symbols for options and emotions (Murphey & Cameron, 2008). These authors suggest that in individual transition planning, professionals can offer the use of images that are relevant during the transition to adulthood. We believe this system is one tool that enables transitioning youth with intellectual and speech limitations to put their own preferences into words. It is an excellent way of helping immigrant youths not fully familiar with the language in their host country to express themselves.

As our study only involved one group of immigrants with Middle-Eastern backgrounds residing in Sweden, we cannot make generalisations for all immigrants based on our results. Recruiting participants by invitation and information campaigns turned out to be almost impossible. We were most successful in contacting participants when we received help from teachers in special schools. The result was therefore that almost all participating youths had an ID in addition to other limitations. We thereby had the opportunity to enable immigrant youths with mild and moderate ID to express their priorities during transition. Previous COPM research with youths had either involved those with mainly physical disabilities (e.g., Chiarello et al., 2010; Law et al., 2015) or children/youths who were interviewed with their caregiver as a proxy (e.g., Chiarello et al., 2010; Cusick, Lannin, & Lowe, 2007; Pollock et al., 2014). To the best of our knowledge, there is limited research based on COPM that focuses specifically on the self-identified problems of transitioning immigrant youths with disabilities. Information about ethnic background is not always reported in research; however, some COPM studies (e.g., Chiarello et al., 2010; Maggs et al., 2011) have reported including a minor proportion immigrant youths.

The ICF-CY was used as an international framework for organizing the data to identify nuances not shown in the COPM categories. Furthermore, the National Board of Health and Welfare (2011) in Sweden recommend ICF/ICF-CY be used in services to increase collaboration between systems of care. However, Klang Ibragimova et al. (2011) discussed how ICF-CY has multidimensional structures, and several codes share common topics in the components. In the coding process of the present study, two of the authors (EB, EN) therefore had to decide which codes best described the content and use the same codes for similar problem content. As our COPM interviews ended up with extracted notes on problems as worded by the participants (Law et al., 2005), we returned to the completed forms and/or transcribed interviews in the cases where the meaning in the notes was unclear. Klang Ibragimova and colleagues (2011), in contrast, suggest that when coding interviews according to ICF, it is suitable to start analysing the text using content analysis as suggested by Graneheim and Lundman (2004) and then code meaning units which are defined as sentences or small parts of text consisting of the main meaning of its content (Downe-Wamboldt, 1992).

The reason for not summarizing the total scores for performance and satisfaction in accordance with the COPM instructions (Law et al., 2005) was that neither the youths nor all the caregivers managed to rank on VAS; they ranked either 1 or 10 on importance, performance and satisfaction. Nevertheless, we

found COPM to be a useful measurement for planning conversations. We therefore recommend the use of COPM to identify priorities and goals in person-centred transition planning for youths, regardless of the country of origin, because it is youth-friendly and enables the client to express thoughts following a semi-structured measure.

6. Conclusion and Implications for Practice

Differences were found between the youths' self-identified problems and the youths' problems as identified by caregivers. The youths faced problems with managing tasks like simple financial transactions and job seeking, whereas the caregivers thought their youths prioritised personal self-care which was found to be similar to non-immigrant families. The discrepancy between the youths' and the caregivers' views of what is most important in this transition highlights the importance of enabling immigrant youths with disabilities to participate in their individual transition planning. It is important that youths have the opportunity to speak for themselves about their preferences. To enable immigrant youths' participation in their individual transition process, we suggest using the COPM as a tool to identify individual problems and transition goals. By using their preferred communication tool, they are able to contribute their own thoughts. However, collaboration with the caregivers is necessary, to best plan the transition for immigrant youths with respect to cultural norms and traditions of collectivistic caretaking.

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