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RESEARCH

After Upper Secondary School: Young Adults with Intellectual Disability not Involved in Employment, Education or Daily Activity in Sweden

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There is limited knowledge about young persons with intellectual disability who are Not in Employment, Education or Daily activity (NEED) in Sweden. The aim of the study was to explore the post-upper secondary school situation for persons with intellectual disability not involved in traditional occupations. A national database containing 2955 persons, representing 24.1% of the total (N = 12,269) was used. The results revealed a heterogeneous group where financial support was common and few made use of disability services. Gender, municipality, programme type, financial support and disability services were significantly associated with not having an occupation as opposed to being in employment, education or daily activity. Time was a central factor, as the early years after upper secondary school appear to be an important period for changing NEED status. This is the first large scale study to describe these persons not involved in traditional occupations in Sweden and further research is required.

Keywords: Intellectual disability; post-school occupation; Not in Employment, Education or Daily activity (NEED); Not in Employment, Education or Training (NEET)

Introduction

The transition of young adults from education to the labour market is of great importance in society. Gaining employment encompasses several benefits such as daily structure, monetary income and social networks, yet also relates to increased well-being and quality of life (Andrews and Rose 2010; Beyer et al. 2010). The role of the education system is to instil knowledge, skills and provide preparation for adult life as a contributing citizen (Swedish Education Act 2010:800). After secondary school it is generally understood that young people move to further studies or employment. However, if this is not possible, support and services should be available. Education and employment are also highly relevant for persons with disabilities, including intellectual disability, and their rights are highlighted in the UN Convention on the Rights of Persons with Disabilities. The Swedish school system for persons with intellectual disability comprises special school options, namely a compulsory elementary school, followed by Upper Secondary School for pupils with Intellectual Disability (USSID).

In order to study post-USSID occupations for persons with intellectual disability in Sweden, a unique national database was created at Halmstad University. This database contains information on 12,269 former USSID students who graduated between 2001 and 2011. Arvidsson, Widén, and Tideman (2015) found that post-school options could be categorized into four groups. The majority (46.9%) participated in daily activity, which are disability day programmes provided under the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387). The second group (22.4%) was employed, mainly in subsidized jobs. The third group (6.6%) was enrolled in different education programmes. The fourth and final group did not take part in the above mentioned traditional occupations. This group, which we defined as Not in Employment, Education or Daily activity (NEED), accounted for a substantial proportion of the study population (24.1%). This is the first time such a group has been identified in a quantitative, large-scale manner. As no previous research exists in Sweden, there is limited knowledge about the situation of this group. The overall aim of the present study is to increase the understanding of the post-USSID situation of persons not involved in traditional occupations. This can lead to knowledge that helps to improve participation, occupational status and living conditions for persons with intellectual disability.

Upper Secondary School for pupils with Intellectual Disability and traditional post-school occupations

USSID is intended for individuals who are assessed to not reach secondary school proficiency due to an intellectual disability (Swedish Education Act 1985:1100; Swedish National Agency for Education 2013). Psychological, pedagogical, medical and social assessments should be conducted to determine whether an individual needs to attend a special school (Swedish Education Act 2010:800). USSID offers students three different programmes covering a four-year period: national programmes, special designed programmes and individual programmes (Swedish National Agency for Education 2016). The individual programmes comprise vocational training or training activities for persons with severe intellectual disability. The options after USSID may be limited. One post-USSID occupation is further education. However, USSID only qualifies pupils to enrol in further studies in, for example, folk high schools, which are adult education establishments that provide courses and study circles. It does not make such persons eligible for other higher post-secondary education in Sweden. Another option is to find employment in the labour market. In 2015, 68% of persons with disability in Sweden were in the labour force, compared with 84% of the general population. Of those with disability and reduced ability to work, the figure was 62% (Statistics Sweden 2016:1). Similar patterns are confirmed by various statistics (National Board of Health and Welfare 2010; Statistics Sweden 2015:1). Apart from Arvidsson, Widén, and Tideman (2015) who found that 22.4% of young adults with intellectual disability were employed, few national statistics exist that clearly show the representation of persons with intellectual disability in the labour market. There are multifaceted barriers to gaining employment, such as negative employer attitudes (Andersson et al. 2015) and lack of adaptation in the work place (Statistics Sweden 2016:1). A literature review highlights both individual and environmental barriers including the organization of welfare systems and supports (Lövgren, Markström, and Sauer 2016). It is also acknowledged that employment may not suit everyone, thus the idealization of employment can be questioned. The third post-USSID option is participation in daily activity, which consists of unpaid disability day programmes and is one of ten services provided under The Swedish LSS Act (LSS 1993:387). Persons with intellectual disability have a right to daily activity, which according to the National Board of Health and Welfare (2008) is intended to provide opportunities for meaningful activities and enhance possibilities for future employment. A proportion of persons in daily activity have both the ability and the desire to engage in another occupation, yet daily activity seldom leads to employment (National Board of Health and Welfare 2008).

LSS services and financial support

Persons with intellectual disability in need of support have a right to various services. Apart from daily activity, LSS offers other services for persons with disability aimed at providing support in everyday life and promoting participation (National Board of Health and Welfare 2015). These include contact persons, companion services and various forms of short and long-term accommodation. The eligibility criteria for LSS are divided into three disability categories, the first of which includes intellectual disability (National Board of Health and Welfare 2015).

Various forms of financial support are available in Sweden, some of which are specific to having a disability whereas others are more general. Long-term subsidies known as activity compensation can be paid to persons with reduced ability to work due to disability once they reach the age of 19 years (Social Insurance Agency 2016). After the age of 30 years, such long-term subsidies are referred to as sickness compensation. Individuals participating in labour market policy programmes aimed at making them active in the labour force may be eligible for subsidies during the programme. Individuals who previously had a job but are currently unemployed can apply for unemployment benefit. Other general subsidies include parental benefits when caring for children and social assistance that provides temporary financial aid. Both LSS services and financial support can be considered part of the social safety net available to persons with disability.

International and national relevance

In an international context, there has been focus on young adults in the general population who have no occupation. These individuals are classified as NEET-Not in Employment, Education or Training. In 2011, it was estimated that 7.5 million young people (12.9%) between the ages of 15 and 24 years in Europe belonged to NEET (Eurofound 2012). Eurofound (2012) highlighted that the NEET population is heterogeneous, consisting of subgroups such as those who are unemployed, have health issues or a disability. The corresponding Swedish classification is UVAS (unga som varken arbetar eller studerar [young people who neither work nor study]). In 2012 approximately 8% of young adults aged 15–24 years were classified as UVAS, with the older age group (20–24 years) constituting the highest proportion (Swedish Government Official Reports 2013:74). However, as these statistics relate to NEET or UVAS, they do not necessarily provide a specific picture of young persons with intellectual disability. Previously there were data limitations in following young adults with disability in relation to the labour market. In particular, there is a lack of knowledge about persons with disability who are not in employment or studying (Swedish Government Official Reports 2013:74), which the present study aims to address.

Aim and research questions

The aim of the study is to explore the post-upper secondary school situation of persons with intellectual disability who are not in employment, education or daily activity (NEED). The research questions are:

- How can the group be described in terms of background factors, financial support and LSS services?
- Which factors are associated with not having an occupation as opposed to having an occupation in the form of employment, education or daily activity?
- How does occupational status change in relation to time since graduation from upper secondary school?

Method

Database

The study was based on the Halmstad University Register on Pupils with Intellectual Disability (HURPID) national database, which consists of information about all persons ($N = 12,269$) who followed the USSID curriculum and graduated from USSID in Sweden between 2001 and 2011. The data are based on information collected from final grades, which are public documents in Sweden (see Arvidsson [2016] for database description). The HURPID database was linked with the following Statistics Sweden databases: the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA) and the LSS database. The LISA database provides national employment, education and social information, while the LSS describes services and support for persons with disability based on the Swedish LSS Act. The LISA comprises data collected once a year between 2001 and 2011 and the LSS contains information from 2004–2011.

Sample

The present study is a cross-sectional investigation of those who did not participate in traditional occupations in 2011. A total of 12,269 (men $n = 7138$, 58.2%; women $n = 5131$, 41.8%) former USSID students were included. Adulthood can have different conceptualizations, especially between persons with and without disability (Redgrove, Jewell, and Ellison 2016). Based on the database the sample of young adults in this study had an average age of $M = 24.54$ ($SD = 3.139$). Previously, Arvidsson, Widén, and Tideman (2015) identified four post-school options for these former students: daily activity, employment, education and NEED. The last mentioned group made up 24.1% ($n = 2955$) of the total population of former USSID students.

In the present study, intellectual disability was defined as having attended USSID. There may be irregularities in the diagnoses and assessment of individuals placed in USSID, which the authors of this study acknowledge. The study was approved by the Ethical Review Board in Lund, Sweden (Nos. 2011/326; 2011/782; 2014/691).

Analyses and variables

Descriptive analyses, chi-squared tests, as well as bivariate and multivariate logistic regression analyses were conducted. The regression analyses examined background, financial support and LSS services (independent variables) and their significance with not having an occupation as opposed to having an occupation (i.e., employment, education and daily activity)(dependent variable). The reference categories in the regression analyses were chosen to provide a large and stable comparison (Almquist, Ashir, and Brännström, n.d). The data were analysed in IBM SPSS Version 20.

The following background variables were used in the study: gender (men, women), parents' highest education level (elementary, secondary or post-secondary), parents' country of birth (both born in Sweden, one born abroad or both born abroad), graduation year (2001–2005, 2006–2010 or 2011) where the division is based on the high proportion who graduated in 2011, municipality (metropolitan, larger cities, suburban, rural or others [municipalities characterized by commuting, tourism, manufacturing and densely populated regions]) in accordance with the definitions of the Swedish Association of Local Authorities and Regions, programme type (national, special designed, vocational training, training activities or incomplete grades), and programme specialization (23 programmes). The financial support variables included long-term subsidies (indicating reduced ability to work), labour market involvement subsidies (related to participation in labour market policy programmes and unemployment benefits), parental benefits, social assistance, and subsidies combined (dichotomous). The LSS variables based on the ten LSS services included LSS (dichotomous), LSS-3 groups (none, 1–2 services or 3–5 services) and subsidies +LSS (dichotomous).

Preliminary analyses

Preliminary analyses were carried out on all variables. In the frequencies reported for those not in employment, education or daily activity, graduation year had 21 missing cases. In the regression analyses based on the total population ($N = 12,269$), there were missing values on eight out of the ten independent variables. The totals for missing values were 2.28% for financial support variables and the municipality variable, 15.88% for parents' highest education level and country of birth variables and 0.02% for the programme type variable. Satisfactory assessments were found when controlling for outliers, as well as in the preliminary analyses for the regression analyses.

Results

Demographics

The background variables for persons not in employment, education or daily activity are presented in **Table 1**. The results show slightly more men (53.1%) than women (46.9%) and the largest proportion had both parents born in Sweden (67.3%) with secondary school (57.6%) as their highest combined education level. Many lived in the category designated "other types of municipality". The majority graduated between 2006 and 2010, while a large proportion also

Table 1: Frequencies (n and %) of background variables in the NEED group.

	<i>n</i>	%
BACKGROUND		
<i>Gender (n = 2955)</i>		
Men	1568	53.1
Women	1387	46.9
<i>Parents' highest education level (n = 2955)</i>		
Elementary	282	9.5
Secondary	1703	57.6
Post-secondary	968	32.8
Unknown	2	0.1
<i>Parents' country of birth (n = 2955)</i>		
Both born in Sweden	1988	67.3
One born abroad	454	15.4
Both born abroad	513	17.4
<i>Municipality (n = 2955)</i>		
Metropolitan	342	11.6
Larger cities	915	31.0
Suburban	428	14.5
Rural	218	7.4
Others	1052	35.6
<i>Graduation year (n = 2934)</i>		
2001–2005	696	23.6
2006–2010	1566	53.0
2011	672	22.7
<i>Programme (n = 2955)</i>		
National	1431	48.4
Special designed	576	19.5
Vocational training	352	11.9
Training activities	100	3.4
Incomplete grades	496	16.8
<i>Programme Specialization (n = 2955)*</i>		
Hotel & restaurant (N)	287	9.7
Agriculture (N)	162	5.5
No specialization (SD)	146	4.9
Industrial (N)	143	4.8
Business & administration (N)	142	4.8
Other specialization (SD)	96	3.2
Vehicle and transportation (N)	68	2.3
Other specialization (N)	65	2.2
Arts (N)	65	2.2
Health care & nursing (SD)	63	2.1
Media (N)	51	1.7
Hotel & restaurant (SD)	46	1.6
Business & administration (SD)	40	1.4
Health care & nursing (N)	40	1.4
Handicrafts (N)	36	1.2
Property & environment (N)	33	1.1
Industrial (SD)	29	1.0
Media (SD)	25	0.8
Arts (SD)	24	0.8
Vehicle & transportation (SD)	16	0.5
No specialization (N)	15	0.5
Agriculture (SD)	12	0.4
Handicrafts (SD)	9	0.3

Note.* (N) = National programmes. (SD) = Special designed programmes.

graduated in 2011 (22.7%). Almost half attended national USSID programmes followed by special designed programmes and incomplete grades. Programme specialization in USSID was diverse but the most common was the national hotel & restaurant programme (9.7%).

These persons are not engaged in traditional occupations and may therefore receive various forms of financial supports. As displayed in **Table 2**, they had all four types of financial support. A large proportion received long-term subsidies (65.5%). The labour market involvement subsidy, which was also common (34.2%), indicates participation in labour market policy programmes or receiving unemployment benefits. Finally, parental benefits (7.0%) and social assistance (29.3%) were also utilized. Chi-square analyses indicate that there is a significant association between gender and labour market involvement subsidies ($\chi^2 (1, n = 2955) = 4.590, p = .032, phi = -.040$), parental benefits ($\chi^2 (1, n = 2955) = 218,449, p = .000, phi = .273$), all subsidies ($\chi^2 (1, n = 2955) = 9.388, p = .002, phi = .058$), and all subsidies +LSS ($\chi^2 (1, n = 2955) = 9.141, p = .002, phi = .057$). The most notable gender difference was with parental benefits, which in this group were more common among women (14.4%) than men (0.4%). There were also cases where individuals had more than one type of subsidy. However, due to the different combinations, these are not presented. The results suggest that the majority of these persons have reduced ability to work, participate in labour market activities or are unemployed, on parental leave or receiving social assistance. A total of 114 persons (3.9%) did not receive any of the subsidies.

Of the total 2955 persons not involved in traditional occupations, only 16.5% ($n = 487$) had some form of LSS service in 2011. Of these, the majority (16.3%) had 1–2 services and 0.2% had 3–5 services. The most common types of LSS service were contact person, residence with special services for adults or other specially adapted housing, and companion service. This means that a large proportion of this group is without any LSS service. When combining the four subsidies and LSS services, 3.6% ($n = 106$) of this group had neither, which was also significantly associated with gender, with 4.6% being men and 2.5% being women.

Table 2: Frequencies (%) of financial support and LSS services in the NEED group. Presented for men, women and total NEED group. Chi-square values (χ^2) presented as Yates' correction for continuity, except for LSS 3 groups, which is presented as Pearson chi-square. Total $n = 2955$ for each independent variable.

	Men	Women	Total	χ^2
FINANCIAL SUPPORT				
<i>Long-term subsidies</i>				
No	34.9	34.0	34.5	.241(n.s)
Yes	65.1	66.0	65.5	
<i>Labour market involvement</i>				
No	64.0	67.8	65.8	4.590*
Yes	36.0	32.2	34.2	
<i>Parental benefits</i>				
No	99.6	85.6	93.0	218.449***
Yes	0.4	14.4	7.0	
<i>Social assistance</i>				
No	71.0	70.4	70.7	.132(n.s)
Yes	29.0	29.6	29.3	
<i>All subsidies</i>				
No subsidies	4.9	2.7	3.9	9.388**
Has subsidies	95.1	97.3	96.1	
LSS SERVICES				
<i>LSS-3 groups</i>				
No LSS	83.0	84.1	83.5	1.001(n.s)
1–2 LSS	16.8	15.7	16.3	
3–5 LSS	0.1	0.2	0.2	
<i>Subsidies +LSS</i>				
No subsidies or LSS	4.6	2.5	3.6	9.141**
Receives subsidies and/or LSS	95.4	97.5	96.4	

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$.

Table 3: Bivariate and multivariate logistic regression analyses with the dependent variable NEED versus other occupations. Results are presented in odds ratios.

	Bivariate	Multivariate		
		Model 1	Model 2	Model 3
BACKGROUND				
<i>Gender</i>				
Men (ref)	1.00	1.00		1.00
Women	1.32***	2.66***		2.01***
<i>Parents' highest education level</i>				
Elementary	1.13	1.10		1.06
Secondary (ref)	1.00	1.00		1.00
Post-secondary	1.08	1.07		1.01
<i>Parents' country of birth</i>				
Both born in Swe (ref)	1.00	1.00		1.00
One born abroad	1.20**	1.03		1.10
Both born abroad	1.10	0.92		0.97
<i>Municipality</i>				
Metropolitan	0.89	1.05		1.11
Larger cities	0.80***	0.81***		0.87*
Suburban	0.78***	0.84*		0.84*
Rural	1.02	1.09		0.99
Other (ref)	1.00	1.00		1.00
<i>Programme</i>				
National (ref)	1.00	1.00		1.00
Special designed	0.79***	0.80***		0.79**
Vocational training	0.32***	0.44***		1.10
Training activities	0.21***	0.30***		0.88
Incomplete grades	1.66***	1.64***		1.75***
FINANCIAL SUPPORT				
<i>Long-term subsidies</i>				
No (ref)	1.00		1.00	1.00
Yes	0.72***		1.99***	8.65***
<i>Labour market involvement</i>				
No (ref)	1.00		1.00	1.00
Yes	5.93***		6.76***	4.21***
<i>Parental benefits</i>				
No (ref)	1.00		1.00	1.00
Yes	3.42***		3.89***	1.97***
<i>Social assistance</i>				
No (ref)	1.00		1.00	1.00
Yes	5.66***		4.67***	4.54***
LSS SERVICES				
<i>LSS-3 groups</i>				
No LSS (ref)	1.00			1.00
1–2 LSS	0.14***			0.10***
3–5 LSS	0.00***			0.00***
Chi ²		(13,N = 1004) =923.94***	(4,N = 11990) =1859.52***	(19,N = 10041) =3858.72***

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$.

Note: Parents' highest education level-unknown category removed due to small number.

Factors associated with having versus not having an occupation

Bivariate and multivariate regression analyses were conducted where background variables (gender, parents' highest education level, parents' country of birth, municipality and programme type), financial support (long-term subsidies, labour market involvement, parental benefits and social assistance) and LSS services (LSS-3 groups) were examined to understand the relation of these variables to not having, as opposed to having, an occupation (employment, education and daily activity). The results are presented in **Table 3**. The multivariate analyses are divided into three models to demonstrate potential changes in the independent variables. Model 1 includes all background variables adjusted for each other. Model 2 includes all financial support variables adjusted for each other. Finally, Model 3 presents all independent variables adjusted for each other.

The bivariate analyses in **Table 3** show a significant correlation between not being involved in traditional occupations and various aspects of a person's background. Gender, parents' country of birth, municipality and programme type had varying associations, whereas parents' highest education level had none. Moreover, the bivariate analyses also demonstrate a significant correlation between NEED status, financial support and LSS.

In the multivariate analyses, Model 3 takes all ten independent variables into account, eight of which were significant. The strongest variable in the background category was gender, in which women were twice as likely not to be involved in traditional occupations (OR: 2.01) compared with men. With programme type, incomplete grades (OR: 1.75) increased the likelihood of not being involved in traditional occupations, while special designed programmes (OR: 0.79) reduced the likelihood of not being involved in traditional occupations, compared with having attended a national programme (reference). Parents' background, including their country of birth and highest education level, was not significant. Living in larger cities (OR: 0.87) and suburban municipalities (OR: 0.84) compared with the category other municipalities indicated less likelihood of not being involved in traditional occupations. With regard to financial support, all four subsidies had strong impacts (OR > 1.00), where being in receipt of any of them indicated a greater likelihood of not being involved in traditional occupations, all other variables adjusted for. For example, receipt of long-term subsidies increased the likelihood over eight times compared with not receiving such subsidies. Finally, LSS was also a significant contributor, as having 1–2 LSS services (OR: 0.10) and 3–5 LSS services (OR: 0.00) indicated less likelihood of not being involved in traditional occupations compared with not having LSS, all other variables adjusted for.

Not in employment, education or daily activity over time

Figure 1 shows each graduating class from USSID from 2004–2011 and the proportions not engaged in traditional occupations from the year they graduated until 2011. The analysis covers the period 2004–2011 due to the fact that no LSS data are available prior to 2004.

These results indicate that the first 1–3 years after USSID play an important role in changing occupational status. This is demonstrated by the dramatic decrease in the number of individuals not involved in traditional occupations during the first few years after graduation. From the data collected up to 2011, **Figure 1** also shows that even several years after graduating, some persons were still not involved in traditional occupations. Finally, the initial proportions

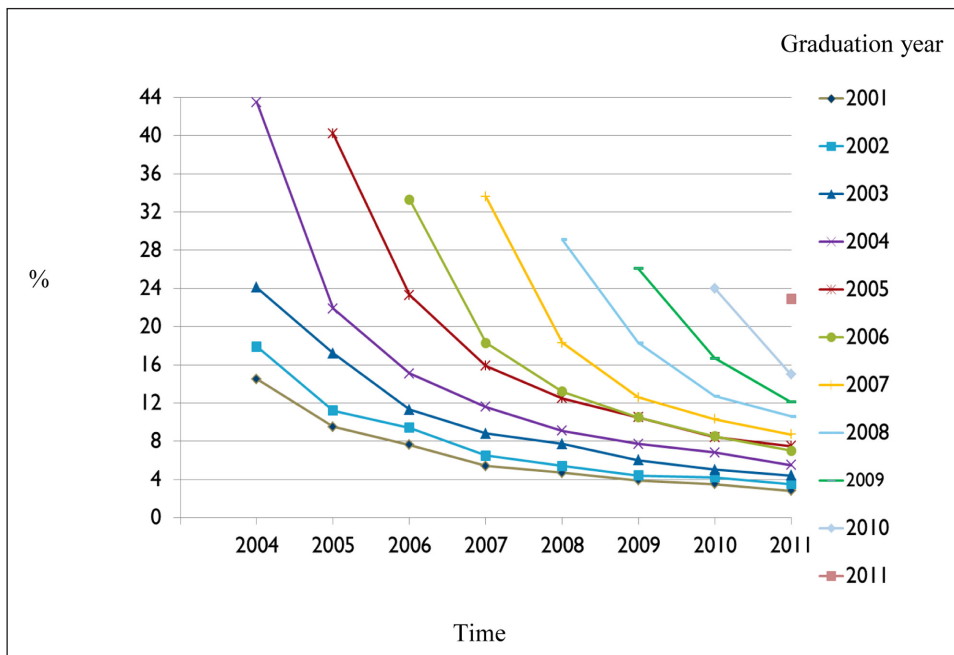


Figure 1: Graduating classes from 2004–2011 and proportions that are NEED over time in the HURPID database.

for each graduating year decreased over time. For example, of those who graduated in 2004, 44% were not involved in traditional occupations shortly after graduation compared to those who graduated in 2011, where the initial proportion was 24.1%. These results suggest that NEED status over time is not static.

Discussion

This study explored the post-USSID situation for young adults with intellectual disability who are not involved in employment, education or daily activity, with focus on the relationship between background factors, financial support and LSS services. The results reveal that the young adults in question constitute a heterogeneous group. They received various subsidies, some with significant gender differences. In 2011 the majority were in receipt of long-term subsidies related to reduced ability to work, involved in labour market policy programmes or unemployed, on parental leave or received social assistance. This gives some idea of the group's livelihood and the type of activities they were involved in. Furthermore, most of them did not make use of LSS services.

There has been a general increase in the number of young adults who are not involved in employment or education (Olofsson 2014). It is difficult to compare rates due to varying definitions and age groups. However, on a general level, NEET in Europe in 2011/2012 was 12.9% and UVAS in Sweden was 8% for persons aged 15–24 years. In the present study the rate of persons with intellectual disability with NEED status in 2011 was 24.1%, but this group also includes a slightly older age range. The general increase in rates relates to individual factors such as background or family, but also to structural conditions associated with the labour market and education (Nilsson and Bäckman 2014). Changes in the labour market include higher demands, increase in temporary employment and flexibility which can lead to unstable jobs, and having higher educational qualifications (Germundsson and Runesson 2014). It is likely that these changes affect those who have a weaker position in the labour market. For example, young persons and persons with disability are strongly represented in temporary employment (Germundsson and Runesson 2014). This can make it difficult for persons with varying abilities to find stable employment, which also applies to the overall lower participation of persons with disability in the labour force (National Board of Health and Welfare 2010; Statistics Sweden 2015:1). It is likely that the combination of individual and structural factors explains some of the reasons for NEED status.

The factors that increased the likelihood of not having an occupation included gender as well as all four types of subsidies. The fact that women are more likely not to be involved in traditional occupations could relate to trends in the general population. It is more common for women to work part-time, not be a part of the work force and have longer periods of parental benefits (Statistics Sweden 2015-06-04). In a longitudinal study following former students with a broad range of special needs, Båtevik and Myklebust (2006) found lower employment rates among the women compared to men; having children was associated with lower employment for women, whereas this association was not found for men. In the present study, the majority in the group with parental benefits were women (14.4% women; 0.4% men), meaning that they may not be involved in an occupation because they are caring for children. These results are similar to the gender differences in the general population, namely that gender and family roles relate to occupational status.

Receiving any subsidy in the present study was linked to NEED status and suggests that there are many situations in which individuals are not engaged in traditional occupations. Long-term subsidies were the most prevalent. This agrees with reports demonstrating an increase in long-term subsidies such as activity compensation (Engdahl and Forslund 2015:3). Activity compensation should provide financial stability and independence as well as supporting other forms of activity that increase functionality (Goine 2014:3); however, this compensation has also been criticized. Long-term subsidies can be beneficial for those who do not have an occupation, but may also pose risks and lead to dependency for some individuals. The Swedish National Audit Office (2015) states that activity compensation has the potential to lock its recipients into the system due to poor coordination among agencies and little financial incentive to obtain employment or education, including the risk of losing one's income. This highlights a greater challenge within the system; instead of promoting activity, it actually prevents people attaining an occupation. Some persons not engaged in traditional occupations who graduated in recent years may not have had enough time to settle into an occupation and may therefore be receiving subsidies.

The labour market involvement subsidies suggest that some persons have a closer proximity to the labour market. While some research indicates an increase in the number of persons with disability who are in receipt of subsidies related to labour market programmes (Swedish Agency for Youth and Civil Society 2012:3), a risk with such programmes is that they may target persons with disability who are already close to employment, thereby excluding those in greater need of support (Engdahl and Forslund 2015:3). Similarly, persons not engaged in traditional occupations who receive these subsidies could constitute a subgroup in a better position to gain employment.

Other factors significantly associated with not having an occupation included the type of USSID programme, in particular having incomplete grades or participating in a special designed programme, which demonstrates the connection between school and post-school occupations. Living in larger cities and suburban municipalities as well as receiving LSS services were associated with less likelihood of not being involved in traditional occupations. Where one lives can influence the availability of services and opportunities. Municipalities are responsible for providing LSS services (LSS 1993:387) and although persons with intellectual disability who meet the criteria have a right to such services, their use and implementation can differ. National statistics (National Board of Health and Welfare 2015) indicate that the number of people receiving LSS services varies between counties and municipalities. The variation relates

to differences in the organization, understanding and implementation of these laws and services (Bengtsson 2005). Persons not involved in traditional occupations already have no daily activity and the present results reveal that few of these persons make use of other LSS services. One explanation could be the availability of services where they live. Another possibility is that they have chosen not to receive or be identified with LSS services including daily activity. Despite its intention, daily activity does not usually lead to employment (National Board of Health and Welfare 2008) and therefore may not be appropriate for some young adults. Agencies and organizations also report that persons with intellectual disability can be hesitant to accept support or LSS services due to not wanting to be different (Olin and Ringsby-Jansson 2009). In Ringsby-Jansson and Olsson's (2006) study, young adults with intellectual disability either used assistance and services irregularly or chose to distance themselves completely. The authors explain this as a result of changes in the welfare system where individual responsibility to seek services has increased, as well as the fact that services are viewed as controlling and stigmatizing. In the present study, a proportion of the group had neither LSS services nor subsidies. They may be involved in other activities, have other forms of financial support or have no association with the subsidy and LSS systems. It also raises the question of whether there are additional challenges present, such as addiction or mental illness.

Parents' background in terms of education and country of birth was not significant when other variables were controlled for, which could be due to combining the backgrounds of both parents. To analyse this in greater detail, mothers and fathers could be examined separately (see Arvidsson et al. Submitted).

The findings of graduation year and NEED status over time suggest that time itself is an important factor. The decrease in the number of persons not involved in traditional occupations in the first years after USSID indicates that this can be a period of adjustment, an important time for finding an occupation or for initiatives to provide support or services. For young adults in general, the transition from education to employment has become more individualized with longer periods of yo-yoing between activities that for some entail increased freedom, while for others lead to increased risks (Olofsson 2014). For young persons with intellectual disability, additional circumstances such as having a USSID background that limits their subsequent occupational options can influence the transition. Moreover, a literature review indicates that persons with intellectual disability can have a prolonged transition due to inefficient programmes, educations or services that do not result in employment (Lövgren, Markström, and Sauer 2016). This could partly explain why many former USSID students are categorized as not being involved in traditional occupations or why some remain so for longer periods. It could also be due to both individual and environmental factors that influence and challenge the transition from school to employment (Lövgren, Markström, and Sauer 2016; Nilsson and Bäckman 2014). The present findings also show a decrease in the number of persons not involved in traditional occupations in the initial period after graduating for each class between 2004 and 2011, possibly indicating some improvement during this 6-year period which warrants further investigation. The present analysis examined NEED status over time on group level. It seems reasonable that some have not been outside of traditional occupations for the entire period since they graduated and therefore future research should examine individual patterns of moving between occupations versus retaining a NEED status for longer periods.

NEED or NEET?

On an international level, NEET refers to persons who are not in employment, education or training where training includes labour market policy programmes (Swedish Government Official Reports 2013:74). NEET status is complex and various subgroups exist. Yates and Payne (2006) discuss this complexity as well as the negative connotations of NEET. They describe subgroups including those in a temporary transition phase, those caring for children and those with complications such as health issues, disability or behavioural problems. One of the main factors associated with NEET is having an incomplete or no secondary education (Government Offices of Sweden 2015; Swedish Government Official Reports 2013:74). Correspondingly, the present study also demonstrates a significant association between incomplete USSID grades and NEED status. One NEET subgroup comprises persons with disability. This is an extremely varied group, yet NEET research has not specifically highlighted persons with intellectual disability. The present study has identified a specific subgroup of persons with intellectual disability who have graduated from USSID and are not engaged in employment, education or daily activity. It is likely that these individuals have been included more generally in the larger NEET concept, yet never precisely or statistically identified. This could indicate similarities between NEET and NEED, but at the same time the NEED group itself is diverse. Identifying this specific group not involved in traditional occupations provides more precise knowledge and thereby increases our understanding that actions and support should be tailored to the individual. As already stated, the NEED group can be further broken down into more distinct subgroups. Therefore, in accordance with Yates and Payne (2006) who problematize the clustering of diverse individuals under the NEET label, the NEED subgroups should also be further studied. Understanding these subgroups would, for example, allow us to make a distinction between those who are temporarily not in an occupation compared with those who are inactive for a longer period as well as increasing our understanding of individual needs on a more general level.

Limitations and future research

A major strength of this study is that it provides an overarching understanding of the group not involved in traditional occupations through the use of a national database, making this knowledge unique. However, there are also limitations in terms of the database. Firstly, data were only available until 2011, meaning that the following years up to the present day should also be explored. Secondly, the databases do not include other aspects such as level of functioning or the

presence of additional mental or behavioural problems. Finally, following individuals' movement between occupations over time by means of the database is limited.

This study provides a good initial understanding and constitutes a point of departure for future research. The practical implications of the study include highlighting one path from USSID that leads to not being involved in traditional occupations, which raises questions about the consequences of special school forms, categorization and the systems and services meant to facilitate post-school occupations. Future studies will conduct interviews with individuals characterized as not in employment, education or daily activity in order to deepen understanding of the processes and experiences associated with NEED status.

Conclusion

The present study is the first to describe persons with intellectual disability who are not engaged in employment, education or daily activity in terms of background, financial support and LSS services. These individuals constitute a significant and heterogeneous group, whose members are likely to have varying situations. Some of these situations may be due to individual circumstances, while others could be linked to structural problems including lack of opportunities after USSID, barriers in the labour market and challenges associated with systems and the social safety net that are intended to provide support. In accordance with the study's findings, the support or targeted actions designated to improve occupational status and promote participation in society for young adults with intellectual disability must take account of the diversity of the group. Further research is needed to increase knowledge of the processes that lead to not being involved in traditional occupations and to facilitate a deeper understanding of persons in these situations.

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Competing Interests

The authors have no competing interests to declare.

References

- Almquist, Ylva, Sahar Ashir, and Lars Brännström. N.d. *A Guide to Quantitative Methods* Version 1.0.3. Stockholm University. Centre for Health Equity Studies.
- Andersson, Jennie, Renee Luthra, Peter Hurtig, and Magnus Tideman. 2015. "Employer Attitudes Toward Hiring Persons with Disabilities: A Vignette Study in Sweden". *Journal of Vocational Rehabilitation* 43(1): 41–50. DOI: <https://doi.org/10.3233/JVR-150753>
- Andrews, Abbye, and John L. Rose. 2010. "A Preliminary Investigation of Factors Affecting Employment Motivation in People with Intellectual Disabilities". *Journal of Policy and Practice in Intellectual Disabilities* 7(4): 239–244. DOI: <https://doi.org/10.1111/j.1741-1130.2010.00272.x>
- Arvidsson, Jessica. 2016. "Sysselsättning och Social Rättvisa: En Nationell Registerstudie om 12,269 Unga Vuxna med Intellectuell Funktionsnedsättning [Post-School Occupation and Social Justice: A National Registry Study about 12,269 Young Adults with Intellectual Disability]". PhD diss., Halmstad University.
- Arvidsson, Jessica, Carin Staland Nyman, Stephen Widén, and Magnus Tideman. Submitted. "Efter(sär)gymnasial Sysselsättning för Unga Vuxna med Intellectuell Funktionsnedsättning – Betydelsen av Föräldrars Utbildningsnivå och Födelseland [Post-Special School Occupation for Young Adults with Intellectual Disability-The Importance of Parents' Education Level and Country of Birth]". *Socialvetenskaplig tidskrift*.
- Arvidsson, Jessica, Stephen Widén, and Magnus Tideman. 2015. "Post-School Options for Young Adults with Intellectual Disabilities in Sweden". *Research and Practice in Intellectual and Developmental Disabilities* 2(2): 180–193. DOI: <https://doi.org/10.1080/23297018.2015.1028090>
- Båtevik, Finn Ove, and Jon Olav Myklebust. 2006. "The Road to Work for Former Students with Special Educational Needs: Different Paths for Young Men and Young Women?". *Scandinavian Journal of Disability Research* 8(1): 38–52. DOI: <https://doi.org/10.1080/15017410500301171>
- Bengtsson, Hans. 2005. *Politik, Lag och Praktik: Implementeringen av LSS-Reformen* [Politics, Law and Practice: Implementation of LSS Reform] (2nd ed.). Lund: Studentlitteratur.
- Beyer, Stephen, Tony Brown, Rachel Akandi, and Mark Rapley. 2010. "A Comparison of Quality of Life Outcomes for People with Intellectual Disabilities in Supported Employment, Day Services and Employment Enterprises". *Journal of Applied Research in Intellectual Disabilities* 23: 290–295. DOI: <https://doi.org/10.1111/j.1468-3148.2009.00534.x>
- Engdahl, Mattias, and Anders Forslund. 2015:3. *En Förlorad Generation? En ESO-Rapport om Ungas Etablering på Arbetsmarknaden* [A Lost Generation? An ESO Report on Young Persons' Establishment in the Labour Market]. Report to the expert group for studies in public finance. Stockholm: Government Offices of Sweden, Ministry of Finance.
- Eurofound. 2012. *NEETs – Young People not in Employment, Education or Training: Characteristics, Costs and Policy Responses in Europe*. Luxembourg: Publications Office of the European Union.

- Germundsson, Per, and Ingrid Runesson. 2014. "Unga med Funktionsnedsättning-Om Sysselsättningsvillkoren på den Flexibla Arbetsmarknaden" [Young Persons with Disability – Employment Conditions in the Flexible Labor Market]. In *Den Långa Vägen till Arbetsmarknaden-Om Unga Utanfö* [The Long Road to the Labour Market-About Young Outsiders], edited by Jonas Olofsson, 255–268. Lund: Studentlitteratur.
- Goine, Hans. 2014:3. *Tio År med Aktivitetsersättning – En Studie av Situationen för Unga med Aktivitetsersättning på grund av Nedsatt Arbetsförmåga* [Ten Years with Activity Compensation – A Study on the Situation for Young Persons with Activity Compensation due to Decreased Work Ability]. On the way in: Young persons' lives and livelihoods – report from research seminar in Umeå 15–16 January 2014: 17–26. Social Insurance Agency.
- Government Offices of Sweden. 2015. *Vägar Framåt – Strategi för Unga som Varken Arbetar eller Studerar* [Roads Ahead – Strategy for Young Persons who Neither Work nor Study]. Ministry of Education and Research.
- Lövgren, Veronica, Urban Markström, and Lennart Sauer. 2016. "Forskningsöversikt om Arbetsfrämjande Stöd till Personer med Funktionsnedsättning" [Research Review on Employment Promotion Support for People with Disabilities]. In *Arbetsliv för Alla-Funktionsnedsättning och Arbete* [Working Life for All-Disability and Employment], edited by Berth Danermark, and Susanna Larsson Tholén, 129–148. Gleerups.
- National Board of Health and Welfare. 2008. *Daglig Verksamhet Enligt LSS – En Kartläggning* [Daily Activities According to LSS – An Analysis]. National Board of Health and Welfare.
- National Board of Health and Welfare. 2010. *Alltjämt Ojämnt! Levnadsvillkoren för Vissa Personer med Funktionsnedsättning*. [Still Unequal! Living Conditions for Certain Persons with Disability]. National Board of Health and Welfare.
- National Board of Health and Welfare. 2015. *Personer med Funktionsnedsättning-Insatser Enligt LSS år 2014* [Persons with Certain Functional Impairments – Measures Specified by LSS 2014]. Official Statistics of Sweden, Statistics – Social Welfare.
- Nilsson, Anders, and Olof Bäckman. 2014. "Unga Vuxna som Varken Arbetar eller Studerar" [Young Adults who Neither Work nor Study]. In *Den Långa Vägen till Arbetsmarknaden-Om Unga Utanfö* [The Long Road to the Labour Market-About Young Outsiders], edited by Jonas Olofsson, 57–76. Lund: Studentlitteratur.
- Olin, Elisabeth, and Bibbi Ringsby-Jansson. 2009. *Unga med Funktionshinder på Väg Ut i Arbetslivet: En Utmaning för Valfärdssystemet* [The Way into the Work Force for Young Persons with Disability: A Challenge for the Welfare System] (FoU Report 1: 2009). FoU i Väst/GR.
- Olofsson, Jonas. 2014. "Ökade Sociala Risker-En Bakgrund om Ungdomsarbetslöshet och Utanföskap" [Increased Social Risks-A Background on Youth Unemployment and Exclusion]. In *Den Långa Vägen till Arbetsmarknaden-Om Unga Utanfö* [The Long Road to the Labour Market-About Young Outsiders], edited by Jonas Olofsson, 21–37. Lund: Studentlitteratur.
- Redgrove, Fiona Janet, Paul Jewell, and Caroline Ellison. 2016. "Mind the Gap Between School and Adulthood for People with Intellectual Disabilities". *Research and Practice in Intellectual and Developmental Disabilities* 3(2): 182–190. DOI: <https://doi.org/10.1080/23297018.2016.1188671>
- Ringsby-Jansson, Bibbi, and Sören Olsson. 2006. "Outside the System: Life patterns of Young Adults with Intellectual Disabilities". *Scandinavian Journal of Disability Research* 8(1): 22–37. DOI: <https://doi.org/10.1080/15017410500301122>
- Social Insurance Agency. 2016. https://www.forsakringskassan.se/privatpers/funktionsnedsattning/aktivitetsersattning_och_sjukersattning_lank/aktivitetsersattning.
- Statistics Sweden. 2015:1. *Information on Education and the Labour Market 2015: 1-The Labour Market Situation for People with Disabilities 2014*. Stockholm: Statistics Sweden- Population and Welfare Department.
- Statistics Sweden. 2015-06-04. Gender Statistics. http://www.scb.se/en_/Finding-statistics/Statistics-by-subject-area/Living-conditions/Gender-statistics/Gender-statistics/.
- Statistics Sweden. 2016:1. *Information on Education and the Labour Market 2016: 1-The Labour Market Situation for People with Disabilities 2015*. Stockholm: Statistics Sweden- Population and Welfare Department.
- Swedish Agency for Youth and Civil Society. 2012:3. *FOKUS12 – Levnadsvilkor för Unga med Funktionsnedsättning* [Living Conditions for Young Persons with Disability]. Stockholm: Writings from Swedish Agency for Youth and Civil Society.
- Swedish Education Act. 1985:1100. The Swedish Parliament, 1985-12-12. https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-19851100_sfs-1985-1100.
- Swedish Education Act. 2010:800. The Swedish Parliament, 2010-06-23. http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Skollag-2010800_sfs-2010-800/.
- Swedish Government Official Reports. 2013:74. *Unga som Varken Arbetar eller Studerar – Statistik, Stöd och Samverkan* [Young Persons who Neither Work nor Study-Statistics, Support and Cooperation]. Stockholm.
- Swedish National Agency for Education. 2013. *Mottagande i Grundsärskolan och Gymnasiesärskolan* [Admission to Special School and Special Upper Secondary School]. Skolverkets allmänna råd. Stockholm.
- Swedish National Agency for Education. 2016. *Gymnasiesärskola Före ht 2013* [Special Upper Secondary School Before Fall 2013]. <http://www.skolverket.se/skolformer/gymnasieutbildning/gymnasiesarskola/gymnasiesarskola-fore-ht-2013>.

- Swedish National Audit Office. 2015. *Aktivitetsersättning – En Ersättning Utan Aktivitet?* [Activity Compensation – A Compensation Without Activity?]. Riksrevisionen. Stockholm. RiR 2015: 7.
- The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). 1993:387. The Swedish Parliament, 1993-05-27.
- Yates, Scott, and Malcom Payne. 2006. "Not so NEET? A Critique of the Use of "NEET" in Setting Targets for Interventions with Young People". *Journal of Youth Studies* 9(3): 329–344. DOI: <https://doi.org/10.1080/13676260600805671>

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