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To cite this article: Renee Luthra | (2019) Young adults with intellectual disability who are not in employment, education, or daily activities: Family situation and its relation to occupational status, Cogent Social Sciences, 5:1, 1622484, DOI: [10.1080/23311886.2019.1622484](https://doi.org/10.1080/23311886.2019.1622484)

To link to this article: <https://doi.org/10.1080/23311886.2019.1622484>



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Published online: 08 Jun 2019.



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Received: 09 November 2018  
Accepted: 20 May 2019  
First Published: 02 June 2019

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## SOCIOLOGY | RESEARCH ARTICLE

# Young adults with intellectual disability who are not in employment, education, or daily activities: Family situation and its relation to occupational status

Renee Luthra<sup>1\*</sup>

**Abstract: Purpose:** In the modern labour market entering and maintaining employment is challenging for youth in general. Young adults with intellectual disability face major difficulties in establishing an occupation. A substantial group of young adults with intellectual disability who are Not in Employment, Education or Daily activity (NEED) have been identified. The aim of this study is to describe and analyse the family situation for those who are NEED.

**Materials and methods:** A national database with 12,269 persons was used, where 24.1% (N = 2,955) of the total were NEED. Family situation in terms of civil status, having children, and living with one's parents, along with background factors were examined.

**Results:** Family situation and background factors have significant associations with not having, as opposed to having, an occupation (employment, education, or daily activity), but differ for men and women. For example, partnerships and having children were only significant for women.

**Conclusions:** This study contributes to the multidimensionality in understanding young people with intellectual disability who are not participating in traditional occupations, where the family situation is an important aspect. This knowledge can contribute to future research and be useful in practice to develop holistic supports that increase participation in occupations.

## ABOUT THE AUTHOR

Renee Luthra is a PhD student in Health and Lifestyle with a specialization in disability studies at Halmstad University. Her research, including the present study, is part of a larger project at Halmstad University that studies what happens to students with intellectual disability after secondary school.

## PUBLIC INTEREST STATEMENT

There is a lack of knowledge about young adults with intellectual disability and the major difficulties they face in establishing an occupation. A large group of young adults with intellectual disability who are Not in Employment, Education or Daily activity (NEED) have been identified. This study seeks to describe and analyse the family situation for those who are NEED through the use of a national database. This study highlights the multidimensionality in understanding young people with intellectual disability who are not participating in traditional occupations, where family situation is an important aspect. This knowledge can also help in developing supports for the target group.

**Subjects: Poverty & Unemployment; Sociology of the Family; Inclusion and Special Educational Needs; Social Work and Disability**

**Keywords: Intellectual disability; Not in Employment Education or Training (NEET); Not in Employment Education or Daily activity (NEED); POST-school occupations; Family; Sweden**

## 1. Introduction

“To have a job means adult status, self-respect, money, independence and the opportunity to broaden one’s social contacts. Young people who are cut off from work are losing a vital chance to get new perspectives and to integrate into wider society” (European Commission, 2002, p.49). Having a job is a key aspect of adulthood and is meaningful for participation, financial stability, self-worth, and quality of life (Jahoda et al., 2009; Lövgren, Markström, & Sauer, 2014). There is increased international and national focus on young adults without an occupation or who are considered “outside” of the system (Eurofound, 2012; Ringsby-Jansson & Olsson, 2006). This includes the heterogeneous group of young people in general in the European term Not in Employment, Education, or Training (NEET) (Eurofound, 2012). The NEET concept has several subgroups that range in vulnerability, experiences, and characteristics (Eurofound, 2012). In Sweden, there has been an increase in unemployment rates for young adults, and changes in the labour market have seen increased temporary employment and a demand for higher education to gain employment (Germundsson & Runesson, 2014). These trends can have a particular effect on vulnerable groups such as young people with disability (Germundsson & Runesson, 2014) making it difficult to establish secure employment, despite that the right to work and gain a living is outlined in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2007, Article 27). Patterns of higher unemployment rates are seen in young people with disabilities compared to young people in general (Statistics Sweden, 2017; Swedish Government Official Reports, 2013). In 2016, the employment rate for the general population was 79% while it was 62% for people with a disability (Statistics Sweden, 2017). In these contexts, however, there is little prior knowledge or national analyses that specifically identify young adults with intellectual disability who are not involved in an occupation. Studies show that contributing factors that facilitate or hinder gaining employment include norms, employer attitudes, family influence, as well as individual differences (Tideman, Lövgren, & Szönyi, 2017). People with intellectual disability can have challenges with processing information or communication and need diverse support, yet there is still limited knowledge about their attachment to the labour market (Tideman et al., 2017). One reason is the previous lack of databases that allow for following people with intellectual disability after they finish secondary school (Swedish Government Official Reports, 2013).

For young adults with intellectual disability who have graduated from Upper Secondary School for pupils with Intellectual Disability (USSID) in Sweden, the transition from secondary school can entail greater challenges with finding an occupation (Arvidsson, 2016). In a full national study, Arvidsson, Widén, and Tideman (2015) found that nearly half (46.9%) of all former USSID students participated in daily activities. Daily activities are unpaid disability day programmes and one of the 10 services provided under the disability act, referred to as LSS (The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), 1993:387). Apart from those participating in daily activities, Arvidsson et al. (2015) found that 22.4% were employed, of which a majority had income support or wage subsidies, and 6.6% were in adult education such as folk high schools (adult education establishments). The remaining 24.1% were not involved in the above-mentioned occupations, and their activities and everyday situations were unknown. This is a significant and large proportion that presents a specific group of young adults with intellectual disability who are not involved in traditional occupations. In the first study by Luthra, Högdin, Westberg, and Tideman (2018) this group was defined as Not in Employment, Education or Daily activity (NEED). It is a heterogeneous group consisting of individuals with diverse abilities, characteristics, and circumstances, yet financial support is common, few receive disability services, and women had a higher likelihood of being NEED compared to the men (Luthra

et al., 2018; Luthra, Westberg, Högdin, & Tideman, 2018). The gender difference raised questions about their family situation. As a result, the present article is a step in providing a further understanding of the NEED group, with a focus on the family situation and its relation to not being involved in traditional occupations. The aim of this study is to describe and analyse the family situation for young adults with intellectual disability who are Not in Employment, Education or Daily activity (NEED). The research questions are:

- (1) What are the key characteristics of the family situation in the group, and how does this compare with those who have an occupation of employment, education or daily activity?
- (2) What patterns can be identified, and what associations can be found, between family and background factors with not having an occupation as opposed to having an occupation of employment, education or daily activity?

### **1.1. Heterogeneity of the NEED group**

Disability occurs in the relationship between the individual and the environment. Therefore, gaining employment or having an occupation is created by the individual's abilities in relation to the environment's demands and adaptations. Intellectual disability is defined as impairments in mental abilities and adaptive functioning, with a prevalence rate of 1% in the general population (American Psychiatric Association, 2013). The same prevalence rate applies to Sweden; however, in Sweden, an administrative definition is used, meaning that people with an intelligence level under 70 who therefore are in need of and utilize supports and services are classified as having an intellectual disability (Swedish Government Official Reports, 2003).

People with disability, including intellectual disability, can face additional challenges in establishing an occupation due to, for example, their disability, background in USSID, and negative attitudes (Andersson, Luthra, Hurtig, & Tideman, 2015). For example, USSID only qualifies for further education at adult education establishments that provide courses and study circles, but not at other higher post-secondary institutions in Sweden. In addition, as the labour market changes with increased demands, qualifications, and a rise in temporary and unstable employment, young people, and people with disability are affected (Germundsson & Runesson, 2014). These structural aspects, as well as possible individual factors, lead to an increased vulnerability for young people with intellectual disability establishing an occupation. This, in addition to varying experiences, abilities, and characteristics, contribute to the heterogeneity of the NEED group. Previous findings suggest that individual factors including diverse abilities and health problems, and structural factors such as challenges with occupations and formal support, are central to the experience of being NEED (Luthra et al., 2018).

In line with the NEET label (Yates & Payne, 2006), the label "NEED" classifies through a negative, defining them by what they are not (not in employment, education or daily activities). However, people have different life situations and diverse characteristics and abilities, all of which are not seen when the only emphasis is on the negative aspect of not being involved in an occupation. In society, having an occupation such as employment is highly valued. However, it is important to acknowledge that employment is not ideal for everyone, rather the appropriate and desired type of occupation can vary between individuals who are NEED. Considering the heterogeneity of the group, it can also be questioned if all young people who are NEED are at risk of social exclusion.

### **1.2. Family and background factors**

In the transition from school, and in everyday life, the family may play an important role. But it is also possible to experience limitations and dissatisfaction with family relationships as well as isolation (Minéur, Bergh, & Tideman, 2009; Swedish Agency for Youth and Civil Society, 2012). Family situation can entail establishing one's own family, such as finding a partner, having children, or moving out of one's parents' home. Creating a family is tied to social norms and expectations of adulthood, as is the desire of wanting children (Frisén, Carlsson, & Wängqvist,

2014). For young people with an intellectual disability, it is more common to live with their parents than it is in the general population (Umb-Carlsson & Sonnander, 2005). Moreover, having a partner or children is less common among persons with disability, including intellectual disability, compared to the general population (Savage & McConnell, 2016; Umb-Carlsson & Sonnander, 2005), although women with disability express expectations of marrying and having children (Powers, Hogansen, Geenen, Powers, & Gil-Kashiwabara, 2008). There are challenges and different ideals and attitudes associated with becoming parents (Höglund & Larsson, 2013; National Board of Health and Welfare, 2005) because women with disability, and those with intellectual disability have been viewed as not suitable for having children (Barron, 2004).

In both the general population and for people with various disabilities, the constellation or dynamic of the family situation is related to one's occupation, for example, in terms of division of family responsibility, having children, when a young person moves out on their own, and having help with facilitating employment (Båtevik & Myklebust, 2006; Petner-Arrey, Howell-Moneta, & Lysaght, 2016; Statistics Sweden, 2015; Swedish Government Official Reports, 2014). The family situation and gender differences are important for understanding young women and men's relation to the labour market (Båtevik & Myklebust, 2006). For people with disability, including intellectual disability, family can be an even more central support since they ensure that proper services and assistance are received, provide love and security, are a social network, and give support related to employment (Pérez, Alcover, & Chambel, 2015; Petner-Arrey et al., 2016; Ringsby-Jansson & Olsson, 2006; van Asselt-Goverts, Embregts, & Hendriks, 2015). The relevance of family situation for persons with disability and the connections between family and occupation highlights the importance in studying its significance for people who are not involved in traditional occupations.

Background factors of gender, age, and immigrant background are relevant for examining the family situation for people with intellectual disability who are NEED. Gender differences in family situations exist, for example, in Norway Myklebust (2012) found gender differences in former students with special support in upper secondary education, where more women lived outside of their parents' home, had romantic relationships and had children. Moreover, men with intellectual disability are more often employed than women (Arvidsson, Widén, Staland-Nyman, & Tideman, 2016; Båtevik & Myklebust, 2006). One relevant factor is that early parenthood for women can relate to lower establishment in the labour market (Båtevik & Myklebust, 2006; Lövgren & Hamreby, 2011), highlighting the relation between family and occupational status.

Age is another central factor for understanding the NEED population. Comparisons can be made to the general population, where young people can have a period of instability or moving between occupations after they finish secondary school. The transition period from school has become more individualised, where greater responsibility is placed on the individual's decision-making and engagement (Yates, Harris, Sabates, & Staff, 2011). At the same time, young people are particularly vulnerable in terms of unemployment and are often inexperienced and lack the competencies required by the labour market (Eurofound, 2012).

According to Engdahl and Forslund (2015), young people with an immigrant background have a harder time establishing themselves in the labour market compared to people with non-immigrant backgrounds. Although this is a diverse group, explanatory factors include language barriers, limited networks, and discrimination. Intellectual disability and an immigrant background can entail added challenges due to, for example, different cultural views and unfamiliarity or language difficulties with services and diagnoses (Björquist, 2016; Sandhu, Ibrahim, & Chinn, 2017). Therefore, immigrant background and its significance for people who are NEED is also examined in the present study.

## 2. Materials and methods

### 2.1. Database

To address the aim of the study, the national Halmstad University Register on Pupils with Intellectual Disability (HURPID) database was used. HURPID is composed of 12,269 former students from USSID, which is all who graduated in Sweden between 2001 and 2011 (for more details on the database, see Arvidsson, 2016). The HURPID database was linked with two other national databases from Statistics Sweden, through the use of social security numbers. The first was the longitudinal integration database for health insurance and labour market studies (LISA), which consists of employment, education, and social information. The second was The Swedish Act concerning Support and Service for persons with certain functional impairments database (LSS), which provides information on services received under the LSS Act.

### 2.2. Sample

This was a cross-sectional study in the year 2011. The year 2011 was selected since this was the most recent year of data in the HURPID database. The total sample of 12,269 former USSID students was used, where the subsample of the NEED group was specifically analysed and compared with the occupations group. In the total HURPID database, 58.2% are men and 41.8% are women with an average age of  $M = 24.54$  ( $SD = 3.139$ ). Of the total, 2,955 (24.1%) were categorised as NEED. This means that they were not participating in employment, education, or daily activity in the year 2011. The other 9,314 (75.9%) were categorised as having a known occupation in employment, education, or daily activity. A criterion for attending USSID is having an intellectual disability. Therefore, the present study defines intellectual disability as solely having attended USSID without opportunity for deeper analyses of variations and assessments of the disability. The study was approved by the Ethical Review Board in Lund, Sweden (Nos. 2011/326; 2011/782; 2014/691).

### 2.3. Measures and data analysis

The variables in the study included background and family variables. The background variables included *gender*, *age in 2011*, and *immigrant background*. Gender was a dichotomous variable indicating man or woman. The variable *age in 2011* indicated if a person was 18–25 years old or 26 years or older. The variable *immigrant background* indicated if the individual had immigrated to Sweden or not and was based on immigration information from the years 1979–2011. In the present study, family situation refers to family status as described in the LISA database. This is one's position in a family, and consists of the variables *married*, *common law* (those who have common children), *single* (includes common law without common children), *single parent with a child or children under the age of 18 years old* (includes common law where one or both partners have children but not together), and *living at home with one's parents* (18 years and older, unmarried, and having no children). In addition, the descriptive analyses used variables that indicated having children of various ages (*children ages 0–3*, *children ages 4–6*, *children ages 7–10*, *children ages 11–15*). In the logistic regression analyses, the independent variables were background and family variables, while the dependent variable was NEED or having an occupation (employment, education, or daily activity). The independent variables were dichotomous and the largest categories were chosen as the reference categories to allow for stable comparison (Almqvist, Ashir, & Brännström, n.d.).

Several analyses were conducted, and a selection is presented in this article. Descriptive and chi-squared analyses were conducted in order to address the research question of key characteristics of the family situation. Chi-squared analyses and simple and multiple logistic regression analyses were conducted to address the research question of patterns and associations between family and NEED status. Preliminary analyses were performed on all of the variables. In the total HURPID population, there were 279 missing values thereby making the total  $N = 11,990$  for the variables *children ages 0–3*, *4–6*, *7–10*, and *11–15* as well as for the variables *immigrant background* and *age in 2011*. These missing values were excluded from the analyses. There were no missing values for



any variables within the NEED group making the total N = 2,955. The preliminary analyses for logistic regression analyses, including controlling for multicollinearity, found that the family variable *single* had high correlations. As a result, this variable was removed from the regression analyses. The preliminary analyses for the remaining independent variables were satisfactory. The analyses were performed in IBM SPSS version 20.

### 3. Results

#### 3.1. Background and family demographics

The background and family variables for the NEED group, those who have an occupation, and for the total database (N = 12,269) are presented in Table 1. In the NEED group, there were slightly more men (53.1%) than women (46.9%), and the majority were in the younger age range of 18–25 years old (72.4%). The larger proportion of the group had not immigrated to Sweden. For the subgroup that had immigrated (14.9%), this occurred in the time period of 1981–2010 with the largest clusters being in the years 1990–2000 (results not shown in the table). There was a slightly larger proportion of women within the NEED group compared to the occupation group, even though the majority were men in both groups. There was also a larger proportion of younger

**Table 1. Background and family variables presented for people who are NEED (N = 2,955), in an occupation (N = 9,314), and total (N = 12,269)**

	NEED N %	Occupations N %	Total N %
<b>BACKGROUND</b>			
<i>Gender</i>			
Men	1568 53.1	5570 59.8	7138 58.2
Women	1387 46.9	3744 40.2	5131 41.8
<i>Age 2011</i>			
18–25 years old	2139 72.4	5507 61.0	7646 63.8
26 years and older	816 27.6	3528 39.0	4344 36.2
<i>Immigrant background</i>			
Non-immigrant background	2514 85.1	7964 88.1	10478 87.4
Immigrant background	441 14.9	1071 11.9	1512 12.6
<b>FAMILY</b>			
<i>Married</i>			
Not married	2817 95.3	9105 97.8	11922 97.2
Married	138 4.7	209 2.2	347 2.8
<i>Common law</i>			
Not common law	2819 95.4	9102 97.7	11921 97.2
Common law	136 4.6	212 2.3	348 2.8
<i>Single Parent</i>			
Not single parent	2831 95.8	9241 99.2	12072 98.4
Single Parent	124 4.2	73 0.8	197 1.6
<i>Lives with parents</i>			
Does not live with parents	1569 53.1	5540 59.5	7109 57.9
Lives with parents	1386 46.9	3774 40.5	5160 42.1
<i>Single</i>			
Not single	1784 60.4	4547 48.8	6331 51.6
Single	1171 39.6	4767 51.2	5938 48.4

people as well as a slightly larger proportion that had immigrated within the NEED group in comparison to the occupation group.

The frequency results for the family variables (Table 1) show that in the total database ( $N = 12,269$ ) few were married, common law, or single parents, while 48.4% were single. Overall, the majority did not live with their parents (57.9%), yet those who did were still a large proportion (42.1%). Within the NEED group and within the occupation group, similar patterns were found for the family variables. However, several differences appeared when comparing the two groups. There were larger proportions within the NEED group who were married (4.7%), common law (4.6%), or single parents (4.2%) compared to the proportions within the occupation group (2.2%, 2.3%, and 0.8%, respectively), whereas there was a larger proportion in the occupation group that was single (51.2%) compared to the proportion in the NEED group (39.6%). In addition, living with one's parents also had a larger proportion within the NEED group (46.9%) compared to within the occupation group (40.5%).

### 3.2. Background and family situation within the NEED group

Chi-square tests were conducted for a closer examination of the associations between background factors and family situation within the NEED group and are shown in Table 2. The results indicated significant associations between gender and family situation for being married ( $\chi^2(1, n = 2955) = 48.166, p = .000, \phi = .129$ ), common law ( $\chi^2(1, n = 2955) = 79.439, p = .000, \phi = .166$ ), single parent ( $\chi^2(1, n = 2955) = 126.992, p = .000, \phi = .209$ ), and living with parents ( $\chi^2(1, n = 2955) = 90.865, p = .000, \phi = -.176$ ). In terms of civil status, more women in the group were married (7.6%), common law (8.3%), or single parents (8.7%) compared to men (2.1%, 1.3%, and 0.3%, respectively). More than half of the men lived with their parents, while the majority of women did not. Chi-square analyses examining age in 2011 and family situation indicated a significant relationship between age and being married ( $\chi^2(1, n = 2955) = 39.902, p = .000, \phi = .118$ ), common law ( $\chi^2(1, n = 2955) = 36.924, p = .000, \phi = .114$ ), single parent ( $\chi^2(1, n = 2955) = 7.403, p = .007, \phi = .052$ ), living with parents ( $\chi^2(1, n = 2955) = 206.370, p = .000, \phi = -.265$ ), and single ( $\chi^2(1, n = 2955) = 65.404, p = .000, \phi = .150$ ). The older age group of 26 and older were more often married (8.7%), common law (8.5%), single parents (5.9%), or single (51.5%) compared to the younger age group of 18–25-year-olds. The majority who lived at home with their parents belonged to the younger age group (55.1%). Finally, within the group, immigrant background only had significant associations with being married ( $\chi^2(1, n = 2955) = 53.542, p = .000, \phi = .137$ ) and living with one's parents ( $\chi^2(1, n = 2955) = 7.428, p = .006, \phi = -.051$ ). There were larger proportions that had immigrated and were married (11.6%), while living at home with one's parents was more prevalent among those with a non-immigrant background (48.0%) in comparison to those with immigrant background (40.8%). Additional descriptive analyses (not presented in the table) of gender differences and immigrant background show that there were more men with an immigrant background who were married (6.3%) compared to men without immigrant background who were married (1.4%). A similar pattern was found for women, although with higher proportions, where more women with an immigrant background were married (17.8%) compared to women without immigrant background who were married (5.8%). In summary, the background variables of gender, age, and immigrant background had various significant associations with the family situation within the NEED group.

For those in the NEED group that were married (4.7%), common law (4.6%), or single parents (4.2%), many had children of various ages. Analyses (not presented in the tables) showed that in the group it was more common to have younger children ages 0–3, followed by having children ages 4–6. When examining gender differences, women were more often married and had children (women 4.3%, men 1.1%), common law and had children (women 8.1%, men 1.2%), or single parents with children (women 8.7%, men 0.3%).



**Table 2. Family variables in relation to gender, age in 2011, and immigrant background within the NEED group. Results are presented in column percentages from crosstab analyses. Chi-square values ( $\chi^2$ ) are presented in Yates' correction for continuity. Total for NEED group N = 2,955**

	GENDER		AGE 2011		IMMIGRANT BACKGROUND		$\chi^2$
	Men (n = 1,568) %	Women (n = 1,387) %	18-25 (n = 2,139) %	26+ (n = 816) %	No (n = 2,514) %	Yes (n = 441) %	
Married	2.1	7.6	3.1	8.7	3.5	11.6	<b>53.542***</b>
Common law	1.3	8.3	3.1	8.5	4.7	3.9	.475 n.s
Single parent	0.3	8.7	3.6	5.9	4.1	4.8	.264 n.s
Lives with parents	55.2	37.6	55.1	25.5	48.0	40.8	<b>7.428**</b>
Single	41.1	37.9	35.1	51.5	39.7	39.0	.057 n.s

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

### 3.3. NEED as opposed to having an occupation

Logistic regression analyses were conducted in order to assess significant associations between family and background factors (independent variables) to not having, as opposed to having, an occupation (employment, education, and daily activity) (dependent variable). The results of these analyses are presented in Table 3. First, simple logistic regression analyses are shown for each independent variable. This is followed by multiple logistic regression analyses that take into account all the independent variables for the total population ( $N = 11,990$ ). Multiple logistic regression analyses, without the variable gender, are then conducted for men ( $N = 6,979$ ), and women ( $N = 5,011$ ).

The simple analyses indicated that all independent variables had a significant association,  $p < 0.001$ , with being NEED versus having an occupation. For all of the independent variables, there was an increased likelihood of being NEED (odds ratios over 1.00) as opposed to having an occupation, except for age in 2011. This data suggests that being 26 years and older meant a lower likelihood of being NEED. The strongest variable in the simple analyses was being a single parent to a child or children under 18 years old, which suggested almost six times (OR: 5.55,  $p < 0.001$ , CI = 4.14,7.43) the likelihood of being NEED compared to not being a single parent. The multiple analysis for the total population ( $N = 11,990$ ), that accounts for all of the independent variables adjusted for each other showed the same pattern as the simple analyses, with a single parent to a child or children under 18 years old still being the strongest variable (OR 6.44,  $p < 0.001$ , CI = 4.76,8.71).

The models for men and women shown in Table 3 suggest various patterns. For men, the factors that indicated a higher likelihood of being NEED versus having an occupation were having an immigrant background (OR: 1.46,  $p < 0.001$ , CI = 1.24,1.72) and living with one's parents (OR: 1.34,  $p < 0.001$ , CI = 1.19,1.52), all other factors in the model adjusted for. However, for women, several other factors had a significant association to being NEED. These included being married (OR: 3.92,  $p < 0.001$ , CI = 2.93,5.24) and common law (OR: 5.33,  $p < 0.001$ , CI = 3.96,7.18), which, respectively, suggest almost four and five times the likelihood of being NEED. In addition, for women being a single parent with a child or children under 18 years old (OR: 7.44,  $p < 0.001$ , CI = 5.39,10.3) was a significant predictor indicating almost eight times the likelihood of being NEED, all other factors adjusted for. Similar to men, women living with their parents (OR: 1.31,  $p < 0.001$ , CI = 1.14,1.52) also increased the likelihood of being NEED. The other predictor that showed a similar pattern regardless of gender was age in 2011, which indicated that being 26 years or older meant a lower chance of being NEED for men (OR: 0.60,  $p < 0.001$ , CI = 0.53,0.69) and women (OR: 0.56,  $p < 0.001$ , CI = 0.48,0.65).

### 4. Discussion

This cross-sectional study provides a further understanding of people with intellectual disability who are NEED, by analysing key characteristics of their family situation. These results provide new knowledge about family as being significant for understanding young adults with intellectual disability who are not involved in traditional occupations and highlights the associations between family situation and occupational status.

Having an occupation has positive benefits (Jahoda et al., 2009; Lövgren et al., 2014), yet people with intellectual disability face difficulties with establishing and maintaining an occupation such as employment (Arvidsson, 2016; Ellenkamp, Brouwers, Embregts, Joosen, & van Weeghel, 2016). An intellectual disability can entail challenges with processing information, communication, or with everyday activities, and diverse supports may be needed in order to gain and maintain employment (Tideman et al., 2017). These difficulties are amplified by, for example, changes in the labour market and negative perceptions (Andersson et al., 2015; Germundsson & Runesson, 2014). Simultaneously, one's family situation has a central role in everyday life and can relate to occupational status (Båtevik & Myklebust, 2006; Lövgren & Hamreby, 2011; Petner-Arrey et al., 2016; Statistics Sweden, 2015; Swedish Government Official Reports, 2014), yet this has been

**Table 3. Simple and multiple logistic regression analyses. The simple regression analyses is for each independent variable and based on the total population of 12,269; however, due to missing cases the variables Age2011 and Immigrant background had N = 11,990. The multiple regression analyses accounts for all independent variables and is presented for the total population. Multiple regression analyses, that excludes the variable gender, is then presented for men and women. The dependent variable is being NEED versus having an occupation (employment, education, or daily activity). Results are presented in odds ratios and confidence intervals**

	Simple OR (95% CI)	Total N = 11990 OR (95% CI)	Multiple Men N = 6979 OR (95% CI)	Women N = 5011 OR (95% CI)
<b>Gender</b>				
Men	1.00	1.00		
Women	<b>1.32***</b> (1.21,1.43)	<b>1.21***</b> (1.11,1.32)		
<b>Age2011</b>				
18–25	1.00	1.00	1.00	1.00
26+	<b>0.60***</b> (0.54,0.65)	<b>0.58***</b> (0.53,0.64)	<b>0.60***</b> (0.53,0.69)	<b>0.56***</b> (0.48,0.65)
<b>Immigrant background</b>				
Non-immigrant background	1.00	1.00	1.00	1.00
Immigrant background	<b>1.30***</b> (1.16,1.47)	<b>1.23**</b> (1.09,1.39)	<b>1.46***</b> (1.24,1.72)	1.00 ns(0.83,1.21)
<b>Married</b>				
Not married	1.00	1.00	1.00	1.00
Married	<b>2.13***</b> (1.71,2.66)	<b>2.70***</b> (2.14,3.40)	1.47 ns(0.97,2.21)	<b>3.92***</b> (2.93,5.24)
<b>Common law</b>				
Not common law	1.00	1.00	1.00	1.00
Common law	<b>2.07***</b> (1.66,2.58)	<b>2.74***</b> (2.18,3.44)	0.80 ns(0.50,1.28)	<b>5.33***</b> (3.96,7.18)

(Continued)

**Table 3. (Continued)**

	Simple OR (95% CI)	Total N = 11990 OR (95% CI)	Multiple Men N = 6979 OR (95% CI)	Women N = 5011 OR (95% CI)
<b>Single parent</b>				
Not single parent	1.00	1.00	1.00	1.00
Single parent	<b>5.55***</b> (4.14,7.43)	<b>6.44***</b> (4.76,8.71)	1.94 n.s(0.59,6.37)	<b>7.44***</b> (5.39,10.3)
<b>Lives with parents</b>				
Does not live with parents	1.00	1.00	1.00	1.00
Lives with parents	<b>1.30***</b> (1.19,1.41)	<b>1.34***</b> (1.22,1.46)	<b>1.34***</b> (1.19,1.52)	<b>1.31***</b> (1.14,1.52)
$\chi^2$		(7, N = 11990) = 456.626***	(6, N = 6979) = 135.150***	(6, N = 5011) = 358.808***

\*\*\*  $p < 0.001$ , \*\*  $p < 0.01$ , \*  $p < 0.05$ . Note. The category single was removed due to preliminary analyses not being satisfactory.

unexplored in relation to people with intellectual disability who are not involved in traditional occupations.

The descriptions of the family situation for people who are NEED show that even though it was more common to have a partner or be a single parent in this group than in the occupation group the proportions were generally low, which is in line with the findings by Umb-Carlsson and Sonnander (2005). Many young adults, in general, live longer in their parents' home, and moving out occurs slightly earlier for women than for men possibly due to women studying or moving in with a partner (Statistics Sweden, 2015). In comparison to the general population, smaller proportions of young adults with different types of disability have moved out on their own (Swedish Agency for Youth and Civil Society, 2011) and many remain in their parents' home (Umb-Carlsson & Sonnander, 2005). The present study confirms a similar picture that while many former USSID students with intellectual disability lived outside of their parents' home, there was still a large proportion that remained at home including people who are not involved in traditional occupations.

The analyses that examined the family situation more closely within the NEED group in addition to the results from the regression analyses illustrate key points. Firstly, the family situation for people who are NEED varied by gender, age, and if the person had immigrated to Sweden. Secondly, family and background factors had significant associations with being NEED as opposed to having an occupation, however, this differed for men and women. Together this paints a complex picture of understanding young adults not involved in traditional occupations since both background and family are contributing factors.

Gender differences revealed that more women in the NEED group were married, common law, and single parents as well as not living at home with their parents. Similar patterns in gender differences have been found by Myklebust (2012), even though their study examined to some extent a broader group of people with disability and Norway has slightly different systems, including school systems, than Sweden. Women in the NEED group were more often in partnerships and had children or were single parents with children. This raises questions about the dynamic of not having an occupation and being a mother. Motherhood can be regarded as a natural expectation of adulthood, even though having an intellectual disability can challenge these ideals (National Board of Health and Welfare, 2005; Powers et al., 2008). The results are cross-sectional, therefore, it is unknown if this is a temporary or long-term situation. Additional longitudinal analyses are required to better understand this subgroup of women. In the general population, there are differences for men and women in how the family situation relates to employment and participation in the labour force. Gender differences can be found in parental leave, income, employment, caring for children, and domestic work, where, for example, women who bear more responsibility for taking care of their family and children entails absence from, and unstable relations to, the labour force (Swedish Government Official Reports, 2014). The association between early parenthood for women and occupational status has been demonstrated in young adults both internationally and in Sweden (Eurofound, 2012; Swedish Government Official Reports, 2013; Yates et al., 2011) as well as for young people with special educational needs due to somatic, psychological, and social challenges (Båtevik & Myklebust, 2006). For women with intellectual disability in the present study, there was a higher likelihood of not being involved in traditional occupations if they were married, common law, or single parents, all three of which were categories related to having children. It seems reasonable that the family situation of partnership and caring for children in part relates to why these women are not involved in an occupation, whereas this association was not found for men. These gender differences, although new findings for the NEED group, are congruent with trends demonstrated in other research (Båtevik & Myklebust, 2006; Eurofound, 2012; Swedish Government Official Reports, 2013; Yates et al., 2011), and highlight that family situations have different associations for men and women with intellectual disability and their occupational status. The causality between parenthood and NEED status should be further studied to determine if being NEED leads to parenthood or vice versa.

The analyses of age suggest a transition period after secondary school for people who are not involved in a traditional occupation, where finding a partner or living independently takes time. The transition could be further challenged by difficulties that people with intellectual disability face, for example, with finding employment and having limited social networks (Andersson et al., 2015; Foley, Dyke, Girdler, Bourke, & Leonard, 2012). To live independently requires financial stability, which mainly can be attained through employment. People with disability have increased financial vulnerability due, for example, to low-income rates and the use of financial support from the government (Swedish Agency for Youth and Civil Society, 2012). Being NEED might result in further limited income to cover the costs of independent living and thereby contribute to living in the parents' home. Another aspect of living at home is that parents can have a central role in providing everyday support, for example, in navigating service systems. This may be even more relevant for people with an intellectual disability who also are not involved in an occupation, where their family perhaps provide practical or even financial support. Families can be encouraging and helpful, yet their involvement can also hinder the individual from developing their own sense of independence (Foley et al., 2012). Young age was related to NEED status for both men and women. This suggests that the transition period after secondary school, such as USSID, is an important time for implementing support and resources, especially since young people are vulnerable to unemployment and can be regarded as lacking the competencies needed in a competitive labour market (Eurofound, 2012).

For those in the NEED group who had immigrated to Sweden, more were married compared to non-immigrants, and slightly more non-immigrants lived with their parents. Descriptive results also showed that of the people who were NEED with immigrant background more women were married compared to men. This presents an important subgroup, and how the interaction between gender, immigrant background, and marriage relates to not being involved in an occupation should be studied further. It was not generally common in the total database population to have immigrated to Sweden; however, for men, the immigrant background had a significant association to being NEED, while this was not found for women. Individuals with immigrant backgrounds are a diverse group with a wide range of situations and are highlighted in other research on young people and unemployment (Engdahl & Forslund, 2015; Eurofound, 2012). Having immigrated to Sweden might lead to additional barriers when combined with having an intellectual disability. Björquist (2016) found that youths with intellectual disability and Middle Eastern backgrounds expressed challenges in their transition after school such as finding employment or daily activity. The caregivers of these youth expressed little knowledge about the diagnosis and the support system in Sweden and conveyed feelings of their child being treated differently in schools compared to native-born children. Challenges associated with settling into a new country and culture, or structural barriers such as discrimination, are important for understanding the complexity in what contributes to not having an occupation. It is important to keep in mind that in the NEED group, as a whole, the majority of people are not immigrants. It seems that the association between having immigrated, being male, and not having an occupation is only valid for a smaller subset of the group.

The importance of, and the right to work for people with disability (see UN Convention on the Rights of Persons with Disabilities (United Nations, 2007, Article 27)), is closely connected to full participation in society. A more successful transition from school to the labour market for people with intellectual disability contributes, for example, to active citizenship and improves the financial status of the individual. This encourages more systematic knowledge and structural interventions to prevent people from not having an occupation and support those who already find themselves in this situation to gain employment. However, interpreting NEED as only a negative situation for all young people that is conceptually connected to a locus of disadvantage must be questioned (Yates & Payne, 2006). Further research is needed to continue to explore how individuals experience the NEED situation.



#### 4.1. Limitations and future directions

This is the first time that the family situation in the NEED group has been studied. However, there are also limitations with the study. Database studies can provide rich data and study a large and national population. At the same time, the variables can be restricting. In the present study, the family variables are broad categories that do not allow for detailed nuances. For example, we are not able to distinguish if those classified as single parents live independently with their child or if they live at home with their own parents. This is an important subgroup to identify because not being involved in an occupation and having children could increase the chances of having to rely on one's parents financially. Additionally, the family variables encompass both parents and legal guardians of children. Parents who no longer have custody of their children are not visible in the variables. The immigrant background is based on when an individual is officially registered in Sweden, and there could be a range in time from arriving in Sweden to registration and this information is beyond the database. The study has focused on people who themselves have immigrated to Sweden, and not second generation immigrants. The study is cross-sectional, which provides a picture of the NEED group in 2011. But it is also important to study how family situations and occupational status change over time, such as conducting longitudinal analyse to explore the direction of whether family situation causes not having an occupation or not having an occupation causes the family situation.

The practical implications of the study include providing new knowledge on the family situation for people with intellectual disability who are NEED. This knowledge highlights the complexity in not being involved in traditional occupations, where the family situation is an important dimension. In future studies, we complement these results with qualitative interviews. This allows for exploring the quality and dynamics of family situations and relations, as well as a more in-depth understanding of the processes and individuals' experiences of being NEED.

#### 5. Conclusion

A national analysis of NEED, young adults with intellectual disability not involved in employment, education or daily activity, presents findings of the group's family situation and how this relates to their occupational status. For example, family situation and background factors have significant associations with not having, as opposed to having, an occupation, but with different associations for men and women. This is unique knowledge since it focuses on a previously unexplored group and is supported by national quantitative data. On a broader level, these results relate to the complexity and multidimensionality in understanding young people with intellectual disability who are outside of traditional occupations. This suggests that along with challenges that people with intellectual disability face in establishing an occupation, the family situation also has a central role. A recommended holistic approach in understanding and working with the target group is needed, which considers multiple factors, in order to increase employment opportunities and thereby full participation in society for people with intellectual disability.

#### Acknowledgements

This work was supported by Halmstad University and Misa AB.

#### Funding

This work was supported by the Misa AB [Misa AB]; Halmstad University [Halmstad University].

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#### Declaration of interest

The author reports no conflicts of interest.

#### Citation information

Cite this article as: Young adults with intellectual disability who are not in employment, education, or daily activities: Family situation and its relation to occupational status, Renee Luthra, *Cogent Social Sciences* (2019), 5: 1622484.

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