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Young adults with severe physical disabilities

Negative public health care experiences after their health care transition in Finland

Jeunes adultes souffrant d'incapacités physiques majeures: expériences négatives en matière de soins de santé publique après leur transition vers les soins de santé en Finlande

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Abstracts

English Français

This study aimed to identify factors associated with negative public health care experiences of Finnish young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care. Paediatric neurologists used clinical examination Gross Motor Function Classification System (Expanded & Revised) level IV or V to diagnose severe physical disabilities in all 74 subjects (M age 20.2). Thirty-nine of the participants (53%) had a co-occurring intellectual disability according to ICD-10 (IQ < 70). Paediatric neurologists developed the instrument Severely Disabled Youths' Life Situation and the Functioning of the Service Systems in Finland to collect data. Fisher's exact tests examined the association between experiences with health care factors and public health care. Binary logistic regressions predicted negative public health care experiences from negative experiences with needing new assistive devices, difficulty getting a physician's appointment, and physician's lack of disability knowledge. Multi-professional neurology clinics for young adults with severe physical disabilities and disability education for physicians could improve health care access.

Cette étude vise à identifier les facteurs associés à l'insatisfaction des jeunes adultes finlandais qui présentent une incapacité physique majeure, avec ou sans déficience intellectuelle concomitante, à la suite de leur transition des services santé pour enfants aux services pour adultes. Les pédiatres neurologues ont utilisé la grille d'évaluation clinique du Système de classification de la fonction motrice globale (étendu et révisé) de niveau IV ou V afin de diagnostiquer l'incapacité physique majeure spécifique à chacun des 74 participants (âge moyen : 20,2 ans). Trente-neuf (53%) participants présentaient une déficience intellectuelle concomitante, selon la CIM-10 (QI inférieur à 70). Les pédiatres neurologues ont développé l'instrument Severely Disabled Youths' Life Situation and the Functioning of the Service Systems in Finland afin de recueillir et traiter les données. Enfin, les tests de Fisher examinaient les corrélations entre l'insatisfaction des facteurs de soins et les soins de santé. Des régressions logistiques binaires ont permis d'associer l'insatisfaction à l'égard des services santé à la nécessité d'utiliser de nouveaux appareils d'assistance, à la difficulté accrue d'accéder à des rendez-vous médicaux et à l'ignorance des médecins à l'égard des problématiques du handicap. L'étude recommande la création de cliniques neurologiques multi-professionnelles qui accueilleraient les jeunes adultes qui présentent des incapacités physiques majeures, avec ou sans déficience intellectuelle, et qui initieraient les médecins aux caractéristiques de ces catégories de patients et à leurs enjeux spécifiques.

Index terms

Mots-clés : jeunes adultes, handicap physique majeur, déficience intellectuelle, transition au sein des services santé, expérience des services de santé

Keywords: Young Adults, Severe Physical Disability, Intellectual Disability, Health Care Transition, Health Care Experiences

Author's notes

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Full text

Introduction

- ¹ Young adults who have severe physical disabilities with or without a co-occurring intellectual disability regularly use healthcare services (Houtrow, Valliere & Byers, 2018) due to the intricate nature of their healthcare requirements (Hosking et al., 2017). In Finland healthcare for children with disabilities includes public primary and specialised medical services which are provided for all citizens (Ministry of Social Affairs and Health, n.d.). Moreover, children with disabilities receive regular follow-up appointments in multi-professional paediatric neurology clinics, usually until they reach the age of 16 (Arvio et al., 2012; Craiu et al., 2020; Rosqvist et al., 2009; Sillanpää, Saarinen & Lähdesmäki, 2020). After transitioning from child to adult healthcare, young adults with disabilities in Finland receive the same primary adult healthcare services as other Finnish citizens without disabilities. If necessary, they may also receive specialised healthcare services organised by municipalities (Arvio et al., 2012; Ministry of Social Affairs and Health, n.d.). However, general practitioners (physicians) may lack the necessary skills and knowledge to effectively treat young adults who have severe physical disabilities after they have transitioned to primary adult healthcare services (Kauppinen, 2022).
- ² Healthcare transition is defined as a deliberate and systematic process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they transition from child-centred to adult-oriented healthcare systems (Blum et al., 1993). It is important to understand the healthcare experiences of



young adults who have severe physical disabilities with or without a co-occurring intellectual disability after their healthcare transition. They may be at risk for major functional impairment, experience deterioration in their health and have unmet healthcare needs (Arvio et al., 2012; Campbell et al., 2016; Menezes et al., 2021; Solanke, Colver & McConachie, 2018). Additionally, they may experience a decreased quality of life (Arvio et al., 2012; Campbell et al., 2016; Gorter et al., 2021; Perrin, 2012). Young adults may struggle to advocate for themselves in adult healthcare settings because they are expected to assume greater responsibility and autonomy (Campbell et al., 2016; Colver et al., 2020) in managing their diverse health and disability services (Nurmi-Koikkalainen et al., 2020), which they may perceive as lacking coordination (Särkikangas, 2020). Furthermore, young adults may also be dissatisfied with their healthcare (Gal et al., 2010).

- 3 Compared to the literature on adults and older individuals with physical or other disabilities (Meseguer-Santamaría et al., 2013; Törnblom, Jonsson & Sunnerhagen, 2013), there are fewer studies that have specifically examined healthcare experiences and factors contributing to dissatisfaction among young adults who have severe physical disabilities. Even less is known about young adults with severe physical disabilities who also have an intellectual disability (Campbell et al., 2016; Hepburn et al., 2015; Schmidt et al., 2007).
- 4 User satisfaction with healthcare services is a quality-of-care indicator used to evaluate healthcare and identify service features from the user's perspective (Jackson, Chamberlin & Kroenke, 2001; Sitzia & Wood, 1997). Torsha et al. (2022) found that studying satisfaction can uncover challenges in healthcare delivery and the factors that lead to dissatisfaction among individuals with disabilities. In their study, individuals with disabilities were asked to rate their satisfaction with access to information and communication, accessible infrastructure and capacity development when evaluating the disability-friendliness of healthcare. According to these authors, identifying dissatisfaction among individuals with disabilities in these domains may help in directing interventions towards the specific factors that contribute to dissatisfaction. Consequently, incorporating means to resolve the dissatisfaction of individuals with disabilities with healthcare into healthcare delivery can improve the quality of care and the overall healthcare experience (Bankauskaite & Saarelma, 2003; Bourne et al., 2010). Dissatisfaction may be a more accurate indicator of healthcare delivery issues than satisfaction because it seems to be a distinct concept from satisfaction (Lee et al., 2010). One indicator is that despite many healthcare users being dissatisfied with their care and having unmet needs, they still report being satisfied with their healthcare (Williams, Coyle & Healy, 1998). In a study by Williams, Coyle & Healy (1998), respondents only reported being dissatisfied under the following four conditions: their needs were unmet, they viewed the request as the service's "duty" (the healthcare provider's obligation is to do something), the healthcare service was considered "culpable" for meeting the respondent's need and no mitigating factors for this "culpability" were identified. The term *culpability* refers to respondents believing that the healthcare service has not fulfilled its duty and has caused a negative experience. Furthermore, respondents would express dissatisfaction with their healthcare if there were no mitigating factors, such as the perception that healthcare practitioners are doing their best (Williams, Coyle & Healy, 1998: 1354). The concept of satisfaction with healthcare is a complex phenomenon, and healthcare users usually do not report dissatisfaction until they perceive the quality of service to be very poor (see Williams, 1994). In light of this information, studies (see Bankauskaite & Saarelma, 2003; Bourne et al., 2010; Lotstein et al., 2008; Palese et al., 2017; Williams, Coyle & Healy, 1998) suggest that research should focus on identifying important factors that lead individuals with disabilities to be dissatisfied with their healthcare in an effort to improve healthcare quality (Hillier, Galizzi & Ferrante, 2017; Lee et al., 2010). Overall, enhancing the experience and satisfaction of persons with disabilities with their healthcare may have implications for improving healthcare quality (Gal et al., 2010; Perrin, 2012), as well as developing healthcare services to meet their specific needs (Bloom et al., 2012; Meseguer-Santamaría et al., 2013; Xesfingi & Vozikis, 2016).
- 5 International studies have reported that individuals with physical or intellectual disabilities may experience dissatisfaction with healthcare (Alkawai & Alowayyed, 2017; Bindels-de Heus et al., 2013; Gal et al., 2010: 12-4) for several reasons, including the availability of assistive devices (Benedict & Baumgardner, 2009; Borade, Ingle & Nagarkar, 2021; Henry et al., 2011; Samuelsson & Wressle, 2009). Assistive devices include mobility devices such as wheelchairs, walking sticks and canes; devices for personal hygiene, such as shower chairs and commode chairs; and treatment and training devices, such as standing aids and beds. Individuals with disabilities may also express dissatisfaction with assistive device services (Carlsson & Lundälv, 2019; Chen et al., 2011; Desideri et al., 2016; Gowran et al., 2020; Wressle & Samuelsson, 2008), and with physicians' appointment availability (Academic Network of European Disability Experts (ANED), 2014; Bindels-de Heus et al., 2013; European Association of Service Providers for Persons with Disabilities (EASPD), 2018; Gibson & O'Connor, 2010; Gorter et al., 2021; Oulton et al., 2016; Solanke, Colver & McConachie, 2018; Yee & Breslin, 2010). Furthermore, they may be dissatisfied with their physicians' knowledge and skills in caring for them (Kirschner & Curry, 2009; Minihan et al., 2011; Nishikawa, Daaleman & Nageswaran, 2011; Shakespeare, Iezzoni & Groce, 2009; World Health Organization (WHO), 2011), as well as with the rehabilitative services they receive (Lotstein et al., 2008; Majnemer et al., 2012; Mlenzana et al., 2013; Sixsmith et al., 2014; WHO, 2011).
- 6 There is a lack of research on healthcare dissatisfaction, healthcare experiences and healthcare transition among young adults with disabilities in Finland (Hepburn et al., 2015). However, young people with severe physical disabilities have reported dissatisfaction with assistive devices, assistive device services, and healthcare services (Arvio et al., 2012; Zeng & Parmanto, 2004). They also face difficulties accessing healthcare (ANED, 2014; EASPD, 2018), have unmet needs and experience a lack of healthcare coordination (Särkikangas, 2020). Moreover, the lack of healthcare information for young individuals with physical disabilities is understandable because healthcare system data was collected from Nordic countries other than Finland. All Nordic countries (Finland, Sweden, Norway, Iceland and Denmark) have quite similar public healthcare systems that are primarily funded by taxes and provide universal healthcare coverage with easy and equal access (Christiansen et al., 2018). This type of easy and equitable access benefits young adults with physical disabilities during their transition to adult healthcare. In Nordic countries other than Finland, individuals with cerebral palsy have a health follow-up program (Alriksson-Schmidt et al., 2020). Yet, there are no cognitive functioning follow-up programs for young adults with cerebral palsy in any of the Nordic countries (Stadskleiv et al., 2021). It appears that the health, healthcare problems and healthcare experiences of young adults with physical disabilities after their transition from child to adult healthcare cannot be identified or addressed within the Finnish healthcare system.
- 7 Beginning in 2023, healthcare services were reorganised into 21 well-being service counties as part of the Finnish social and healthcare reform. Since the reform aims to improve the availability and quality of public health services as well as reduce health inequalities in Finland (Finnish Government, n.d.), the experiences of young adults with disabilities may provide valuable information for the organisation of healthcare services.
- 8 Researching the perspectives of individuals with intellectual disabilities may lead to improved healthcare practices (Elberse, 2012; Walmsley & Johnson, 2003). However, individuals with intellectual disabilities have typically not been included in studies that collect data on their healthcare experiences (Gal et al., 2010). Several reasons can be identified for their exclusion from research. Firstly, they have been considered incapable of participating in scientific research (Copeland, Luckasson & Shauger, 2014), and their experiences have been viewed as unimportant, irrelevant, impractical and subjective. Secondly, research circumstances, such as the location of the study, the timing and duration of the interview and the questions or language used, may not be accessible to individuals with intellectual disabilities (Elberse, 2012).
- 9 Inclusive health research emphasises the importance of including vulnerable and marginalised individuals, such as those with intellectual and/or physical disabilities, in health research. This is because they experience health inequalities (Krahn, Walker & Correa-De-Araujo, 2015; Mahmoudi & Meade, 2015; Mithen et al., 2015; Reichard, Stolzle & Fox, 2011), have a higher prevalence of health problems and have a shorter life expectancy compared to the general population (Naaldenberg et al., 2015). Understanding these individuals' perspectives and experiences with healthcare (Richards et al., 2013) is important for reducing health disparities and improving the quality of care they receive (Frankena et al., 2016, 2019). Individuals with intellectual disabilities can be included in research about their healthcare experiences by using proxies such as parents, carers and personal assistants as facilitators (Holt et al., 2018). Furthermore, accommodations (Sullivan et al., 2019), such as simplified and accessible questions as well as answer scale options (Fang et al., 2011; Frankena et al., 2019), allow these individuals to provide more valid and reliable information about

their experiences (Vlot-Van Anrooij et al., 2018). Earlier studies have shown that Finnish young adults with severe physical disabilities with or without a co-occurring intellectual disability experience difficulties accessing health care (ANED, 2014; EASPD, 2018). Furthermore, they may be dissatisfied with the health care they receive after their transition from child to adult health care. However, their experiences and factors that may lead to those difficulties and dissatisfaction with health care are not well known (Nurmi-Koikkalainen et al., 2017).

- 10 Therefore, the two aims of this study are as follows:
- 1) To determine whether a negative experience with the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician's proficiency in disability skills/knowledge, and the need for rehabilitative services, is associated with or can predict negative experiences with public healthcare among young adults with severe physical disabilities (with or without a co-occurring intellectual disability).
 - 2) To determine whether a negative experience with any of the five factors mentioned above (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician's proficiency in disability skills/knowledge, and the need for rehabilitative services) is associated with or can predict negative experiences with public healthcare in two distinct groups: young adults with severe physical disabilities with a co-occurring intellectual disability and young adults with severe physical disabilities without a co-occurring intellectual disability.

Methods

Procedure

- 11 The Social Insurance Institution of Finland and five central hospitals in Finland conducted a project from 2010 to 2012 titled "Severely Disabled Youths' Life Situation and the Functioning of the Service Systems in Finland." The project, which assessed the life situation and services for young adults who have severe physical disabilities, received ethical approval from the Ethical Committee of the Joint Authority for Päijät-Häme Social and Health Care in Lahti, Finland. Participants, parents, caregivers and personal assistants provided written informed consent. The present sub-study of the larger project aims to identify factors associated with negative experiences with public healthcare among Finnish young adults who have severe physical disabilities, with or without a co-occurring intellectual disability, after their transition from child to adult healthcare. The inclusion criteria for young adults in this study consisted of having a severe physical disability and falling within the age range of 19 to 22 years. This age range was chosen as it represents the transition from child to adult public healthcare.

Participants and data collection

- 12 Päijät-Häme Central Hospital used purposeful sampling to recruit former patients from five Finnish child neurological clinics who were young adults with severe physical disabilities as participants in the study ($N = 74$). A paediatric neurology physician determined the severity of physical disability by classifying participants as level IV or level V on the Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R) and conducting a clinical examination. In Level IV, individuals use wheeled mobility devices such as wheelchairs, powered mobility devices, or body support walkers in various settings. In Level V, a manual wheelchair is needed to transport the person in all settings (Palisano et al., 2008; Paulson & Vargus-Adams, 2017). Clinical psychologists in Finland's five neurological clinics diagnosed young people with intellectual disability (intelligence quotient less than 70) using the ICD-10 classification system. According to the World Health Organization (2019), intellectual disability is defined as a "condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities." The diagnosis was based on repeated intelligence tests. A physician's clinical examination confirmed the diagnosis of intellectual disability.
- 13 Of the 74 participants, 39 (53%) had a severe physical disability with a co-occurring intellectual disability, while the remaining 35 (47%) had a severe physical disability without a co-occurring intellectual disability. The ages of the participants ranged from 19 to 22 years old ($M = 20.2$, $SD = 1.2$). Out of the total participants, 32 (43%) were female and 42 (57%) were male. Participants used various assistive devices, including mobility and hearing aids, positioning and daily living devices, vision, hearing and cognitive devices, as well as prosthetics, orthotics, orthopaedic shoes and home adaptations.
- 14 Between 2010 and 2012, two researchers from Päijät-Häme Central Hospital collected data from participants during home visits lasting 1.5 to 6 hours. Proxies, who were most familiar with the participants' situations and had daily contact with them, facilitated (Holt et al., 2018) young adults with severe physical disabilities with a co-occurring intellectual disability in the completion of the one-paper form questionnaire titled "Severely Disabled Youths' Life Situation and the Functioning of the Service Systems in Finland" (Arvio et al., 2012). This questionnaire was completed by participants with intellectual disabilities ($n = 39$). To ensure accessibility, proxies used picture communication symbols (PCS) from Boardmaker (2022) (Frankena et al., 2019). Proxies provided additional information, such as how the physician's appointment was obtained and the physician's knowledge of the disability. However, all responses were obtained directly from the participants. If the participant's and the proxy's responses were different, then the participant's response would be considered the final decision. In the study, this discrepancy between the responses occurred twice.

Table 1. Description of participants ($N = 74$)

Variable	<i>n</i>	%
Physical disability	74	100.00
With a co-occurring intellectual disability	39	52.70
Education		
Basic education	25	33.78
Secondary education	49	66.22
Occupational status		
Disability pension	35	47.30
Daytime activity centre	29	39.19
Other	10	13.51
Housing situation		
Home with parents	36	48.65
Nursing home, residential/respite car, home with parents and respite care	32	43.24
Other	6	8.11

Note. $N = 74$. Education: completed or currently undergoing.

Instrument

- 15 This study used data collected by the Severely Disabled Youths' Life Situation and the Functioning of the Service Systems in Finland' project instrument (Arvio et al., 2012). This non-standardised and adapted instrument (Emerson, Felce & Standcliffe, 2013) was developed by Finnish healthcare professionals who had prior experience caring for participants in child neurology clinics. To cater to the requirements of young adults who have severe physical disabilities, as well as those who have severe physical disabilities along with a co-occurring intellectual disability (Neugebauer, Tóthová & Dolezalová, 2021), researchers developed simplified questions and answered options using a yes-no format (Fang et al., 2011). Two participants who have severe physical disabilities and co-occurring intellectual disabilities piloted the questionnaire, which contains 104 items divided into ten subscales. Background information, well-being, health, physical functioning, social relations, housing, healthcare, educational services, occupation, and service system experiences of individuals with disabilities were included as subscales. Participants rated their experience with this study's dependent variable, their experience with public healthcare, dichotomously: a positive experience was coded as "yes" (0), and a negative experience was coded as "no" (1). In addition, participants rated their experiences with the five independent variables using dichotomous ratings: a positive experience (yes = 1) and a negative experience (no = 0). Participants considered all physicians they had visited in the previous two years when rating their experiences with physician-related questions.

Statistical analysis

- 16 IBM's Statistical Package for the Social Sciences (SPSS) 27.0 for Windows was used for all analyses. The data contained missing values (1.35%) in three variables (six questions) because six participants were unable to answer them. The SPSS programme automatically excludes system-missing data from analyses. The potential bias caused by missing data was not taken into account in the statistical analysis (Dong & Peng, 2013; Zhuchkova & Rotmistrov, 2022). Consequently, the reported results for young adults who have severe physical disabilities, with or without a co-occurring intellectual disability, have *N* values of 68 and 70, depending on the variable. Due to missing values in six questions, the sample size (*n*) for all reported results for young adults with severe physical disabilities was 32. However, for young adults with severe physical disabilities and a co-occurring intellectual disability, the sample size (*n*) was either 37 or 38. A *p*-value of < 0.05 was considered statistically significant.

Variables

- 17 In all analyses, the dependent variable was participants' experience with public healthcare. Based on the literature review, five possible factors associated with negative experiences with healthcare were chosen as independent variables for the statistical analyses. These included the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment and referrals, the physicians' possession of disability skills/knowledge, and the need for rehabilitative services (therapies, rehabilitation and adaptive training courses).

Analysis

- 18 Five 2 x 2 Fisher's exact tests of independence were used to identify associations between the dependent variable – experience with public healthcare – and experience with the five independent variables among young adults who have severe physical disabilities, with or without a co-occurring intellectual disability (*N* = 74). Furthermore, five 2 x 2 Fisher's exact tests of independence were used to identify associations between the dependent variable, experience with public healthcare, and experience with the independent variables among two groups: young adults who have severe physical disabilities without a co-occurring intellectual disability and young adults who have severe physical disabilities with a co-occurring intellectual disability. The Phi coefficient of effect size was used to measure the strength of the association between the dependent and independent variables. The Phi coefficient ranges from 0 to 1, with values indicating different levels of correlation: no or very weak correlation (0–0.19), weak correlation (0.20–0.29), moderate correlation (0.30–0.59), strong correlation (0.60–0.69) and very strong correlation (0.70–1.00).
- 19 Three binary logistic regression analyses were conducted to predict individuals' experience with public healthcare. In all binary logistic regressions, the dependent (outcome) variable was the level of experience with public healthcare. In all binary logistic regressions, the independent variables (predictors that were single items) were selected based on a significant level of $p < 0.05$ in the five 2 x 2 Fisher's exact tests of independence (see Tables 2 and 3). Intellectual disability was considered an important factor because 39 respondents had a physical disability along with a co-occurring intellectual disability. Therefore, intellectual disability was included as an independent variable in the equation to assess its ability to predict a negative experience with public healthcare. All independent factors were entered as a block into the equation.
- 20 The first binary logistic regression was used to investigate whether the independent factors, such as the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician's possession of disability skills and knowledge, the need for rehabilitative services and the presence of an intellectual disability, could predict a negative public healthcare experience among all participants. The second binary logistic regression was used to examine whether the independent factors could predict a negative public healthcare experience among young adults who have severe physical disabilities without a co-occurring intellectual disability (*n* = 35). The third binary logistic regression was employed to investigate whether the independent factors could predict a negative healthcare experience among young adults with severe physical disabilities and a co-occurring intellectual disability (*n* = 37). The results are presented as odds ratios (OR) and their corresponding 95% confidence intervals.

Results

- 21 Table 1 presents the participants' disabilities, education level, occupational status and housing situation.
- 22 Overall, 41 out of 74 participants reported having negative experiences with public healthcare. Among young adults with severe physical disabilities, Fisher's exact tests of independence (Table 2) indicated statistically significant associations between a negative public healthcare experience and a negative experience with the following three factors: the need for new assistive devices ($p = .003$), the ease of obtaining a physician's appointment ($p = .009$) and the physician's possession of disability skills and knowledge ($p = .006$). There were no statistically significant associations between a negative experience with public healthcare and a negative experience with the remaining two factors: the need for assistive device repair/maintenance ($p = .139$) and the need for rehabilitative services ($p = .335$).

Table 2. Results of Fisher's exact tests of independence for young adults with severe physical disabilities according with healthcare (*N* = 69–70)

Healthcare experiences	Experiences with factors related to healthcare		n	Fisher's exact p
	Positive n (%)	Negative n (%)		
	No need for new assistive devices	Need for new assistive devices		
Positive	20 (68.9)	9 (31.0)	29	
Negative	13 (31.7)	28 (68.3)	41	9.463 $p = .003^{**}$ $\phi = -.368$ $N = 70$
	No need for assistive device repair	Need for assistive device repair		
Positive	21 (72.4)	8 (27.6)	29	
Negative	22 (53.7)	19 (46.3)	41	2.522 $p = .139$ $\phi = -.190$ $N = 70$
	Easy to obtain a physician's appointment	Not easy to obtain a physician's appointment		
Positive	27 (93.1)	2 (6.9)	29	
Negative	27 (65.9)	14 (34.1)	41	7.153 $p = .009^{**}$ $\phi = -.320$ $N = 70$
	Physician possesses disability skills/knowledge	Physician does not possess disability skills/knowledge		
Positive	18 (64.3)	10 (35.7)	28	
Negative	12 (29.3)	29 (70.7)	41	8.302 $p = .006^{**}$ $\phi = -.347$ $N = 69$
	No need for rehabilitative services	Need for rehabilitative services		
Positive	25 (89.3)	3 (10.7)	28	
Negative	32 (78.0)	9 (22.0)	41	1.462 $p = .335$ $\phi = -.146$ $N = 69$

Note. * $p < 0.05$. ** $p < 0.001$.
No need for rehabilitative services (therapies, rehabilitation, adaptive training courses).

23 Among young adults who have severe physical disabilities without a co-occurring intellectual disability ($n = 32$), separate 2×2 Fisher's exact tests of independence revealed statistically significant associations between a negative public healthcare experience and negative experiences with two factors: the ease of obtaining a physician's appointment ($p = .010$) and the physician's possession of disability skills/knowledge ($p = .003$). Furthermore, among young adults who have severe physical disabilities with a co-occurring intellectual disability ($n = 37-38$), separate 2×2 Fisher's exact tests of independence (Table 3) indicated a statistically significant association between the need for new assistive devices (a negative experience) and negative experiences with public healthcare ($p = .040$).

Table 3. Results of Fisher's exact tests of independence for young adults by disability type according to experience with healthcare

Disability type	Experience with healthcare	Positive n (%)	Negative n (%)	n	Fisher's exact p
Severe physical disability		No need for new assistive devices	Need for new assistive devices		
	Positive	6 (42.9)	8 (57.1)	14	
	Negative	13 (72.2)	5 (27.8)	18	2.815 $p = .149$ $\Phi = -.297$ $n = 32$
Severe physical disability with intellectual disability		No need for new assistive devices	Need for new assistive devices		
	Positive	3 (21.4)	11 (78.6)	14	
	Negative	14 (60.9)	9 (39.1)	23	5.451 $p = .040^*$ $\Phi = .384$ $n = 37$
Severe physical disability		No need for assistive device repair	Need for assistive device repair		
	Positive	8 (57.1)	6 (42.9)	14	
	Negative	7 (38.9)	11 (61.1)	18	1.054 $p = .476$ $\Phi = .181$ $n = 32$
Severe physical disability with intellectual disability		No need for assistive device repair	Need for assistive device repair		
	Positive	13 (86.7)	2 (13.3)	15	
	Negative	15 (65.2)	8 (34.8)	23	2.154 $p = .259$ $\Phi = .238$ $n = 38$
Severe physical disability		Easy to obtain physician's appointment	Not easy to obtain physician's appointment		
	Positive	14 (100.0)	0 (0.0)	14	
	Negative	11 (61.1)	7 (38.9)	18	6.969 $p = .010^*$ $\Phi = .467$ $n = 32$
Severe physical disability with intellectual disability		Easy to obtain physician's appointment	Not easy to obtain physician's appointment		
	Positive	13 (92.9)	1 (7.1)	14	
	Negative	16 (69.6)	7 (30.4)	23	2.786 $p = .123$ $\Phi = .274$ $n = 37$
Severe physical disability		Physician possesses disability skills/knowledge	Physician does not possess disability skills/knowledge		
	Positive	10 (71.4)	4 (28.6)	14	
	Negative	3 (18.7)	15 (83.3)	18	9.791 $p = .003^{**}$ $\Phi = .553$ $n = 32$
Severe physical disability with intellectual disability		Physician possesses disability skills/knowledge	Physician does not possess disability skills/knowledge		
	Positive	8 (57.1)	6 (42.9)	14	
	Negative	9 (39.1)	14 (60.9)	23	1.137 $p = .328$ $\Phi = .175$ $n = 37$
Severe physical disability		No need for rehabilitative services	Need for rehabilitative services		
	Positive	14 (100.0)	0 (0.0)	14	
	Negative	15 (83.3)	3 (16.7)	18	2.575 $p = .238$ $\Phi = .284$ $n = 32$
Severe physical disability with intellectual disability		No need for rehabilitative services	Need for rehabilitative services		
	Positive	11 (78.6)	3 (21.4)	14	
	Negative	17 (73.9)	6 (26.1)	23	0.103 $p = 1.00$ $\Phi = .053$ $n = 37$

Note. * $p < 0.05$. ** $p < 0.01$.

Severe physical disability: $N = 32$; Severe physical disability with intellectual disability: $N = 37-38$.

- 24 According to the results of the first binary logistic regression model (Table 4), negative experiences with the following factors predicted the dependent (outcome) variable, which is negative experiences with public healthcare among young adults who have severe physical disabilities, with or without a co-occurring intellectual disability: the need for new assistive devices, the ease of obtaining a physician's appointment and the physician's possession of disability skills and knowledge. The model was statistically significant, $X^2(4, N = 68) = 24.70, p < .001$, explaining 41.2% (Nagelkerke R^2) of the variance. It correctly predicted negative experiences with public healthcare in 76.5% of the cases. The Hosmer-Lemeshow goodness-of-fit test ($p > 0.05$) indicated that the model fits well.
- 25 The odds of having a negative experience with public healthcare was 4.70 times higher among participants who had a negative experience with their need for new assistive devices (95% CI = 1.32, 16.73). It was 3.90 times higher among those who had a negative experience with their physician's disability skills and knowledge (95% CI = 1.18, 12.87) and 10.86 times higher among those who had a negative experience with the ease of obtaining a physician's appointment (95% CI = 1.22, 96.66). This is in comparison to participants who had a positive experience with public healthcare and had a positive experience with their need for new assistive devices, physician's disability skills and knowledge and ease of obtaining a physician's appointment. Intellectual disability was not a significant predictor in the statistical analysis.
- 26 The results of the second binary logistic regression model (Table 4) indicated that a negative experience with a physician's disability skills and knowledge predicted the dependent (outcome) variable: a negative experience with public healthcare among young adults who have severe physical disabilities without a co-occurring intellectual disability. The model was statistically significant, $X^2(2, n = 32) = 16.99, p < .001$, explaining 55.2% (Nagelkerke R^2) of the variance. It correctly predicted a negative experience with public healthcare in 62.2% of the cases. The Hosmer-Lemeshow goodness-of-fit test ($p > 0.05$) indicated that the model fits well. The odds of having a negative public healthcare experience was 11.24 times higher among individuals who had a

negative experience with a physician’s disability skills and knowledge (95% CI = 1.26, 99.98) compared to those who had a positive experience. A negative experience with the ease of obtaining a physician’s appointment did not predict a negative experience with public healthcare.

27 The results of the third binary logistic regression model (Table 4) indicated that a negative experience with the need for new assistive devices predicted the dependent (outcome) variable: a negative experience with public healthcare among young adults who have severe physical disabilities with a co-occurring intellectual disability. The model was statistically significant, $X^2(1, n = 37) = 5.71, p < 0.05$, explaining 19.5% (Nagelkerke R^2) of the variance. It correctly predicted a negative experience with public healthcare in 67.6% of the cases. The Hosmer-Lemeshow goodness of fit test ($p < 0.05$) indicated that the model did not fit the data optimally.

Table 4. Results of three binary logistic regressions predicting negative experiences with healthcare

Predictor	Model	Participants	OR	95% CI
	1	ALL		
Need for new assistive devices			4.70*	1.32, 16.73
Ease of obtaining a physician's appointment			10.86*	1.22, 96.66
Physician's disability skills and knowledge			3.90*	1.18, 12.87
Intellectual disability			1.11	0.11, 1.45
	2	SPD only		
Ease of obtaining a physician's appointment			0.00	0.00, 0.00
Physician's disability skills and knowledge			11.24*	1.26, 99.98
	3	SPD + ID		
Need for new assistive devices			5.70*	1.23, 26.25

Note. All (N = 68); SPD only (N = 32); SPD + ID (N = 37). OR = odds ratio; CI = confidence interval; SPD = severe physical disability; ID = intellectual disability; need for new assistive devices (0 = negative experience (need for new assistive devices); 1 = positive experience (no need for new assistive devices)); ease of obtaining a physician's appointment (0 = negative experience (not easy to obtain a physician's appointment); 1 = positive experience (easy to obtain a physician's appointment)); physician possesses disability skills and knowledge (0 = negative experience (physician does not possess disability skills and knowledge); 1 = positive experience (physician possesses disability skills and knowledge)).

*p < 0.05.

Discussion

28 The aim of this distinctive study was to identify the factors associated with negative experiences with public healthcare among young adults who have severe physical disabilities, with or without a co-occurring intellectual disability after their transition from child to adult healthcare in Finland. The results indicated that negative experiences with three factors predicted negative experiences with public healthcare among the participants. These factors include the need for new assistive devices, the ease of obtaining a physician’s appointment and the physician’s possession of disability skills and knowledge. Furthermore, a negative experience with a physician’s disability skills and knowledge predicted a negative experience with public healthcare among young adults who have severe physical disabilities without a co-occurring intellectual disability ($n = 32$). Finally, a negative experience with the need for new assistive devices predicted a negative experience with public healthcare among young adults who have severe physical disabilities with a co-occurring intellectual disability ($n = 37$). The results suggest that these young adults have difficulties accessing and using the healthcare they need.

Need for new assistive devices

29 The finding that the need for new assistive devices predicted a negative experience with public healthcare among participants is consistent with earlier studies that have documented both the lack of assistive devices and the unmet needs associated with them (Ajasto, Arvio & Arvio, 2012; Benedict & Baumgardner, 2009; Henry et al., 2011). A negative experience with assistive devices may be explained by a lack of knowledge and awareness of all available devices (see Adya et al., 2012; Nurmi-Koikkalainen et al., 2020) or difficulties in obtaining assistive devices due to bureaucracy and long wait times associated with acquiring them (Ajasto, Arvio & Arvio, 2012; Benedict & Baumgardner, 2009). Moreover, the results of the present study indicated that the need for new assistive devices was associated with a negative experience with public healthcare among a group of young adults who have severe physical disabilities with a co-occurring intellectual disability. This finding may imply that, as a result of their co-occurring intellectual disability, these young people may have complex needs for assistive devices that were not addressed by the healthcare system. Since numerous agencies organise the provision of assistive devices in Finland (Finnish Institute for Health and Welfare, 2020), participants may have encountered a lack of coordination in healthcare delivery (see Särkikangas, 2020). Furthermore, participants may not have known whom or which healthcare agency to contact regarding their need to update various types of assistive devices, which are important for promoting their independence and participation (Carver et al., 2016). However, an interesting finding (see Table 2) was that 13 participants (31.7%) had a negative experience with healthcare, despite not needing new assistive devices. This finding suggests that their negative experience with healthcare is not due to their need for new assistive devices but rather to other issues related to assistive devices.

Ease of obtaining a physician’s appointment

30 The finding that a negative experience with the ease of obtaining a physician’s appointment predicted a negative experience with public healthcare among participants is consistent with previous research on the subject (ANED, 2014; EASPD, 2018; Gibson & O’Connor, 2010; Gorter et al., 2021; Solanke, Colver & McConachie, 2018; Vogan et al., 2016). Persons with disabilities (DeVries McClintock et al., 2016) and young adults with disabilities face challenges in accessing healthcare when transitioning to adult healthcare (Solanke, Colver & McConachie, 2018). Possible explanations for the negative experience with the ease of obtaining a physician’s appointment can be inferred. The regular, multi-professional follow-up appointments of the participants in paediatric neurology clinics ended when they transitioned to adult healthcare. Thus, the participants may have had difficulty advocating for themselves in adult healthcare settings (McClintock et al., 2018) and obtaining referrals to access specialist physician appointments because referral systems can be complex (Mudrick & Yee, 2007; Parish et al., 2009; WHO, 2011). Since the participants needed extensive healthcare, they may have found the various healthcare and disability services for individuals with disabilities (see Nurmi-Koikkalainen et al., 2020) to be complex and fragmented, potentially resulting in a lack of access to necessary healthcare services (Kanste et al., 2017; Lämsä et al., 2018; Ministry of Social Affairs and Health, 2018). Interestingly, 27 participants (65.9%) reported a negative experience with public healthcare, despite the ease of obtaining a physician’s appointment. This finding may suggest that, although participants find it easy to schedule a physician’s appointment, there may be other unknown factors that contribute to a negative experience with public healthcare.

Physician’s possession of disability skills and knowledge

- 31 A lack of physician's skills and knowledge related to disabilities predicted a negative experience with public healthcare. After the regular follow-up appointments at paediatric neurology clinics with physicians aware of their disability-related healthcare needs ended, the participants accessed the same primary healthcare services as other Finnish individuals (Arvio et al., 2012; Ministry of Social Affairs and Health, n.d.). Participants may have felt that their general practitioners (physicians) were unprepared to manage their healthcare needs after transitioning from child to adult primary healthcare (Arvio et al., 2012) because they lacked the skills and knowledge required to treat young adults with physical disabilities (Kauppinen, 2022). Furthermore, young adults with intellectual disabilities may not have received healthcare from a physician specialising in intellectual disability medicine, as there are only 14 physicians with this specialisation in Finland (Suomen Lääkäriliitto, 2019). Nonetheless, an unexpected finding was that 12 participants (29.3%) had a negative experience with public healthcare, even though they reported that the physician possessed disability-related skills and knowledge. This result may suggest that there are other problems related to the physician's possession of disability skills and knowledge that may contribute to the participants' negative experience with public healthcare.
- 32 The two groups, young adults who have severe physical disabilities with or without a co-occurring intellectual disability, were analysed separately. The results showed that a negative experience with the physician's skills and knowledge related to disabilities predicted a negative experience with public healthcare among young adults who have severe physical disabilities without intellectual disabilities. This finding supports Kauppinen's notion (2022) that young adults with severe physical disabilities require physicians who are aware of their disabilities and needs. The participants' negative experience with the physician's disability skills and knowledge appears to reflect their negative experiences with adult primary healthcare (Arvio et al., 2012). This is because their complex healthcare needs would have benefited from continuity of care after their transition from child to adult primary healthcare. This discontinuity of care was also reported in Norway, which healthcare system is comparable to Finland's healthcare system (see Kalleson, Jahnsen & Østensjø, 2021). To ensure continuity of care, participants may have benefited from regular, coordinated, multi-professional follow-up appointments and a physician who is familiar with the needs of young adults with physical disabilities after their transition from child to adult healthcare (Kauppinen, 2022). This problem with continuity of care may lead to health disparities among individuals with disabilities. According to the Ministry for Foreign Affairs of Finland (2019), only 39% of persons with disabilities reported their health as fairly good or good, compared to 78% in the general population.
- 33 This study has important limitations that need to be considered. First, the small sample size with missing values in six questions, resulted in a reduced sample size for all analyses. This limitation prevents any definitive conclusions from being drawn regarding the results. However, the sample size can be considered large for Finland because the country has a small number of young adults (ages 19-22) with severe physical disabilities, especially those who also have a co-occurring intellectual disability (see Kivelä et al., 2019). A physical disability affects about 1.3% (approximately 650 children) (Kivelä et al., 2019) of the yearly birth cohort in Finland, which consists of approximately 50,000 children (Statistics Finland, n.d.). While the number of young adults with a severe physical disability and a co-occurring intellectual disability is even lower, the exact number is not known because there is no statistical data on individuals with disabilities in Finland (Ministry for Foreign Affairs in Finland, 2019). Second, the use of proxies may have influenced participants' responses. To support evidence-based practice in public healthcare delivery, future research should prioritise the collection of longitudinal quantitative and qualitative data on the satisfaction of young people with disabilities regarding healthcare. Third, the data is quite outdated, and the categorisation of the dependent and independent variables results in the omission of subtle distinctions. Fourth, the models had limited control due to the small sample size.

Implications for Policy

- 34 A variety of strategies can be employed to improve the healthcare experience, satisfaction and access (WHO, 2011) among young adults with complex healthcare needs (Orlin et al., 2014). Based on the findings of this first Finnish study, which revealed that young adults with severe physical disabilities, regardless whether they also had an intellectual disability, had negative experiences with their assistive devices (resulting in the need for new ones), the ease of obtaining a physician's appointment and the physician's proficiency in skills and knowledge related to disabilities, there are three potential policy implications.
- 35 First, the findings suggest that young adults with severe disabilities would benefit from accessible healthcare in Finland after transitioning from child to adult healthcare. Therefore, identifying potential barriers to accessing adult healthcare is critical. Related to this, one option could be to establish multi-professional neurology clinics for individuals with physical disabilities in Finland, as suggested by Dr. Mäenpää (see Kauppinen, 2022) and the Finnish Disability Forum (n.d.). This type of clinic could be constructed as part of Finland's health and social service reform initiatives (Finnish Disability Forum, n.d.). These multi-professional clinics could effectively address the complex healthcare needs of young adults and ensure continuity of care by providing regular follow-up appointments and accessible healthcare services as they transition from child to adult healthcare. Moreover, these clinics could regularly update young adults' assistive devices and provide them with accessible information about assistive devices that could enhance their daily lives. In these clinics, young people with physical disabilities, with or without a co-occurring intellectual disability, could receive regular and coordinated guidance, information and assistance about services from various healthcare professionals, such as physiotherapists, occupational therapists and social workers (Finnish Disability Forum, n.d.). In addition, these clinics would identify the needs of young people with physical disabilities, whether or not they have an intellectual disability (Finnish Disability Forum, n.d.), and provide them with practical solutions to receive daily assistance. Finally, these clinics might employ peer health navigators who are trained community members with physical disabilities (Herrman et al., 2022). Peer health navigators have the experiential knowledge to provide individualised assistance and support, empowering young people with physical disabilities, with or without a co-occurring intellectual disability, to access and navigate the complex and fragmented healthcare system (Magasi et al., 2019).
- 36 Second, young adults who have severe physical disabilities, with or without a co-occurring intellectual disability, require physicians who have a comprehensive understanding of their unique healthcare needs and expectations (Gal et al., 2010). Thus, it would be beneficial to include disability-related content and interactions with young adults who have severe physical disabilities, with or without a co-occurring intellectual disability, in the medical school curriculum for physicians (Bosques, Philip & Francisco, 2021; Iezzoni & Long-Bellil, 2012; Lee & So-Youn, 2021; Minihihi et al., 2011). Furthermore, the involvement of medical students in disability studies and training could enhance their knowledge and understanding of disability (Dungs, Pichler & Reiche, 2020). After receiving this type of education, physicians working in adult primary healthcare in Finland could be better equipped to manage the healthcare needs of young adults who have severe physical disabilities, with or without a co-occurring intellectual disability.
- 37 Third, supporting and counseling these young people to share their experiences and opinions regarding their healthcare might empower them to navigate adult healthcare (Chalachanová, Lid & Gjemestad, 2021; Colver et al., 2020; Keyes, Webber & Beveridge, 2015). In addition, collecting data on young people's experiences with public adult healthcare can be useful in identifying potential areas for improvement in these services. Their feedback on their healthcare experiences may lead to an improvement in the quality of healthcare services provided to young adults with severe physical and intellectual disabilities (Gal et al., 2010). According to several studies (see Canha et al., 2016; Friedman, 2022; Friedman & VanPuymbrouck, 2019; Minihihi et al., 2011; Schalock et al., 2008), the provision of quality public healthcare for individuals with disabilities may have a positive impact on their health outcomes and overall quality of life.

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