JYU DISSERTATIONS 711

Nina Heräjärvi

Developing Quality of Life Implementation Feedback Model to Improve Quality of Life for Finnish Young Adults with Severe Physical Disabilities

UNIVERSITY OF JYVÄSKYLÄ
FACULTY OF EDUCATION AND
PSYCHOLOGY

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Esitetään Jyväskylän yliopiston kasvatustieteiden ja psykologian tiedekunnan suostumuksella
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ABSTRACT

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The overall aim of this first Finnish PhD dissertation on the subject was to use the quality of life and systems thinking frameworks to develop a quality of life implementation feedback model for health care and upper secondary education organizations to improve quality of life among young adults with severe physical disabilities after their transition to adulthood. These frameworks guide processes at the individual, organizational, and system levels. To this end, the first aim was to examine the individual-level personal outcomes of quality of life of young adults with severe physical disabilities (Study I). The second objective was to identify individual or organizational level predictors of completion of upper secondary education among young adults with multiple disabilities (Study II). The third aim was to identify individual-level factors associated with negative public health care experiences after the young adults' transition from child to adult health care in (Study III).

Statistical analyses were conducted for the development of the quality of life implementation feedback model. The individual-level results showed that young adults with severe physical disabilities had a lower physical, social, and environmental quality of life. Males with severe physical disabilities had a lower physical, psychological, and environmental quality of life than males without disabilities. Pain lowered the quality of life (Study I). The individual and organizational level results indicated the following facts. Young adults with multiple disabilities struggled to complete upper secondary education. Those who live in rural areas and have no literacy skills were less likely to have completed upper secondary education than those who live in urban areas and have moderate or good literacy skills (Study II). The individual level results showed that a negative experience with the need for new assistive devices, the ease of obtaining a physician's appointment, and the physician's proficiency in disability skills and knowledge were associated with a negative experience with health care after the young adults' transition from child to adult health care (Study III). Based on systems thinking and quality of life frameworks, this evidence-based individual and organizational-level quality of life feedback model promotes quality improvement in upper secondary education and primary health care to improve these young people's quality of life.

Keywords: quality of life, systems thinking framework, severe physical disability, intellectual disability, upper secondary education, health care, transition

TIIVISTELMÄ (ABSTRACT IN FINNISH)

Heräjärvi, Nina
Elämänlaadun toimeenpanon palautemallin kehittäminen suomalaisten vaikeasti liikuntavammaisten nuorten aikuisten elämänlaadun parantamiseksi
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Tämän aiheesta tehdyn ensimmäisen suomalaisen väitöskirjan päätavoitteena oli käyttää elämänlaadun ja systeemiajattelun viitekehyksiä ja kehittää elämänlaadun toimeenpanon palautemalli terveydenhuollon ja toisen asteen koulutuksen organisaatioille vaikeasti liikuntavammaisten nuorten (*N*=74) elämänlaadun parantamiseksi heidän siirryttyään aikuisuuteen. Elämänlaadun ja systeemiajattelun viitekehykset ohjaavat prosesseja yksilö-, järjestelmä- ja organisaatiotasoilla. Ensimmäinen tavoite oli tutkia vaikeasti liikuntavammaisten nuorten aikuisten yksilötason henkilökohtaisia elämänlaadun tuloksia (tutkimus I). Toinen tavoite oli tunnistaa yksilö- ja organisaatiotason tekijät, jotka ennustavat vaikeasti liikuntavammaisten nuorten aikuisten toisen asteen koulutuksen suorittamista (tutkimus II). Kolmas tavoite oli tunnistaa yksilötason tekijät, jotka liittyivät kielteiseen kokemukseen julkisesta terveydenhuollosta nuorten siirryttyä lasten terveydenhuollosta aikuisten terveydenhuoltoon Suomessa (tutkimus III).

Tilastolliset analyysit tehtiin elämänlaadun toimeenpanomallin kehittämistä varten. Yksilötason tulosten perusteella vaikeasti liikuntavammaisten nuorten aikuisten fyysinen, sosiaalinen ja ympäristöön liittyvä elämänlaatu oli heikompi verrattuna vammattomiin nuoriin aikuisiin. Vaikeasti liikuntavammaisilla miehillä oli matalampi fyysinen, psyykkinen ja ympäristöön liittyvä elämänlaatu kuin vammattomilla miehillä. Vaikeasti liikuntavammaisilla nuorilla aikuisilla naisilla oli heikompi elämänlaatu vain fyysisen elämänlaadun verrattuna vammattomiin naisiin (tutkimus I). Kahdellakymmenelläviidellä nuorella (34%) ei ollut suoritettuna mitään toisen asteen koulutusta. Lukutaidon puuttuminen ja maaseudulla asuminen ennustivat toisen asteen koulutuksen puuttumista (tutkimus II). Vaikeasti liikuntavammaisten nuorten kielteiset kokemukset uusien apuvälineiden saamisesta, lääkärin vastaanottoajan saamisesta ja lääkärin osaamisesta vammaistaidoissa ja -tiedoissa olivat yhteydessä kielteisiin kokemuksiin terveydenhuollosta nuorten siirryttyä lasten terveydenhuollosta aikuisten terveydenhuoltoon (tutkimus III). Systeemiajatteluun ja elämänlaadun viitekehyksiin pohjautuva näyttöön perustuva yksilö- ja organisaatiotason elämänlaadun toimeenpanon palautemalli edistää toisen asteen koulutuksen ja perusterveydenhuollon laadun kehittämistä vaikeasti liikuntavammaisten nuorten elämänlaadun parantamiseksi.

Avainsanat: elämänlaatu, systeemiajattelu, vaikea liikuntavamma, kehitysvamma, toisen asteen koulutus, terveydenhuolto, transitio

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This PhD dissertation is dedicated to my family. I will always love you.

Jämsänkoski 1.12.2023
Nina Heräjärvi

FIGURES

TABLES

CONTENTS

LIST OF ORIGINAL PUBLICATIONS

This PhD dissertation consists of the following publications, which are referred to in the text as Study I, Study II, and Study III.

I Heräjärvi, N., Leskinen, M., Pirttimaa, R., & Jokinen, K. (2020). Subjective quality of life among youth with severe physical disabilities during the transition to adulthood in Finland. *Disability and Rehabilitation, 42*(7), 918–926. https://doi.org/10.1080/09638288.2018.1511756

II Heräjärvi, N. U., Leskinen, M. O., Pirttimaa, R. A., Jokinen, K. J., & Arvio, M. A. (2020). Predictors of completion of upper secondary education of young adults with severe physical and multiple disabilities in Finland. *European Journal of Special Needs Education, 35*(3), 318–332. https://doi.org/10.1080/08856257.2019.1665230

III Heräjärvi, N., Leskinen, M., Pirttimaa, R., Virtanen, T., & Jokinen, K. (2023). Identifying the factors associated with negative public health care experiences of young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland. *Alter – European Journal of Disability Research* (accepted for publication).

Considering the comments and instructions given by the co-authors, the author of the present PhD dissertation wrote the original research plan, collected the data, conducted the analyses in collaboration with the second co-author, and wrote the reports of the three publications.

1 INTRODUCTION

The concept of quality of life (QoL) with its physical, psychological, social, and environmental domains has been accepted as an important and universal outcome of the educational, health, social, and leisure time services provided for young people with severe physical disabilities (Claes, Van Hove, Van Loon, Vandevelde, & Schalock, 2010; Ilic, Milic & Arandelovic, 2010; Kober & Eggleton, 2009; McDougall, Baldwin, Evans, Nichols, Etherington, & Wright, 2016; Shandra, 2021) because the practices embedded in these services can be seen as having a significant impact on the quality of life of young people with disabilities (Friedman, 2017; McDougall et al., 2016). Furthermore, these services and supports can be perceived as environmental variables that have impact on these young peoples' autonomy, participation in activities, and quality of life related personal outcomes in their lives. These personal outcomes of quality of life are affected by environmental constraints which can be increased with adaptations and accessible environments (Badia et al., 2016; Jenaro, Vega, Flores, & Cruz, 2013). Thus, quality services and supports may enable the young people to participate in society and life situations. Young people with disabilities encounter the transition to adulthood in all quality-of-life domains. Therefore, quality of life can be seen as an outcome measure for this group. The World Health Organization defines quality of life as “the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features in their environment” (The WHOQOL Group, 1995, p. 1405). Personal outcomes in terms of quality of life represent the individual's perception about her/his physical, psychological, social, and environmental domains of his/her quality of life. These domains are represented in the Quality of Life framework from the subjective and objective perspectives. Campbell, Converse, and Rogers (1976) define the subjective quality of life as the individual's own assessment of her/his own life. This assessment can encompass physical, psychological, social, and environmental domains of the QoL (WHO, 2020). However, the subjective perception of person's own quality of life interacts with the objective perspective of quality of life. For example, quality of services (environmental QoL) provided for persons with disabilities can have an impact on these individuals' personal outcomes in their subjective quality of life (Jenaro, Vega, Flores, & Cruz, 2013). In this dissertation, level IV or level V of the Gross Motor Function Classification System Expanded and Revised (GMFCS – E & R) is used to classify severe physical disability. In the majority of environments, level IV young adults utilize mobility devices with wheels. At level V, a manual wheelchair is required in all settings to transport young adults. Individuals who belong into these categories are considered as having a severe physical disability (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). Furthermore, this PhD dissertation uses the definition of intellectual impairment provided by the WHO (n.d.), which defines intellectual disability 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".

This dissertation's Study I focuses on the subjective assessment of quality of life among young adults with severe physical and intellectual disabilities after their transition to adulthood. Schalock et al. (2008, 276) suggest that the QoL framework integrates personal outcomes and evidence-based quality of life framework practices in the delivery of services and supports. Quality of life personal outcomes in the quality of life domains are subjective perspectives of the individual's life. All domains of QoL (physical, psychological, social, environmental) are covered in this dissertation's quality of life data collection instrument: WHO Quality of Life – BREF (WHOQOL-BREF) (WHO, 2022). The WHOQOL-BREF does not explicitly request the person to describe her or his personal goals. However, personal and environmental factors have an impact on the personal outcomes (Schalock et al., 2008). Quality of life and its personal outcomes can be studied by asking all the respondents the same questions about their subjective quality of life.

Furthermore, environmental factors represent objective elements of quality of life. They can be perceived to be policies, programs, and services targeted to enhance the quality of life of individuals (Sirgy, 2011). Therefore, individuals can be asked to express their subjective perceptions about their environmental factors (objective quality of life), such as services provided to them. In this regard, Study III aims to identify factors associated with participants' health care dissatisfaction after their transition from child to adult health care in Finland. Thus, the systems-thinking framework provides a frame of reference to see the interconnectedness of the individual, organizations, and the service delivery system (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008).

The objective quality of life is represented by enviromental domains of quality of life, such as educational and health care services. These environmental domains (WHOQOL-BREF covers the following environmental domains: safety, home environment, financial resources, access to services, access to information, leisure activities, physical environment, and access to transport, see WHO, 2022) can be viewed as a collection of environments and external factors that influence and interact with peoples' personal factors and personal outcomes (Campbell, Converse & Rogers, 1976 ; Claes, Van Hove, van Loon, Vandevelde, & Schalock, 2010, 62; Van Loon, Claes, Vandevelde, Van Hove, & Schalock, 2010). Thus, the quality of life consists of both subjective and objective dimensions (Schalock, 2004). Study II examines objective environmental quality of life outcomes by aiming to identify predictors associated with completion of upper secondary education among young adults with severe physical and multiple disabilities. Study III focus subjective quality of life by identifying the factors associated with heatlh care dissatisfaction of young adults with severe physical disabilities with and without intellectual disabilities after their transition to adult health care. In Study III, participants were asked to rate their subjective quality of life outcome of their objective environment in terms of satisfaction (see Felce & Perry, 2006; Walsh et al., 2006) with the primary health care they received. As a result, it is assumed that personal outcomes and subjective quality of life among young adults with severe physical and intellectual disabilities are influenced by the young adults' broader environment as well as the services (such as upper secondary education and primary health care services) that they receive (Friedman & VanPuymbrouck, 2019; WHO, 2007, xvii).

Many disciplines, including anthropology, business, psychology, and sociology, have studied the concept of transition (Hart & Swenty, 2015; Maunder & Crafter, 2012). All people go through life transitions that alternate with periods of stability in their lives (Levinson & Levinson, 1996; Levinson, Darrow, Klein, Levinson, & McKee, 1978). According to Levinson and Levinson (1996), transitions comprise individual's life structure that is “the underlying pattern or design of a person's life at any given time.” Importantly, this underlying pattern of life structure includes periods of transitions and periods of stable life (Merriam, 2005). Individuals usually consider transitions as significant life events that change their lives. The transition process usually has a beginning and an end (Smith & Dowse, 2019). “The transition can be defined as a life event or period characterized by changes in external circumstances from the preceding event or period or event” (Enz & Talarico, 2016). When demonstrating that a transition has occurred, one can compare the preceding period (or event) and identify evident differences between the two periods. These clear differences indicate that a change has happened (Enz & Talarico, 2016). Transition thus implies a change from one period to another, with changes in the external environments of individuals being immediately noticeably, or shortly thereafter (Enz & Talarico, 2016).

Transitioning from youth to adulthood is one of the significant life events in the lives of all young people, including young people with disabilities (Alwin, 2012; Brollier, Shepard, & Markley, 1994). Moreover, young people experience transitions in education, health care and housing. These can be described as normative changes, which are expected and socially normal events that typically occur within a specific period (Enz & Talarico, 2016). Transitions in education and health care occur in their respective systems. For young people with disabilities, the transition from basic/comprehensive education to secondary education and from child to adult health care (Doyle, Mc Guckin, & Shevlin, 2017; King, Baldwin, Currie, & Evans, 2005; Stewart, Law, Young, Forhan, Healy, Burke-Gaffney, & Freeman, 2014: Wang, Burns McGrath, & Watts, 2010) can be challenging. Furthermore, when young people with disabilities transition to adulthood, their services and support decrease (King, Baldwin, Currie & Evans, 2005), and their transitional outcomes are poor (Pearson, Watson, Gangneux, & Norberg, 2021). It has been demonstrated that after the transition from childhood to adulthood, the quality of life of young adults with physical and intellectual disabilities decreases permanently (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009; Lin, Ju, Lee, Yang, & Lo, 2011) and a part of that decrease in of quality of life may be explained by difficulties in receiving needed secondary educational services and difficulties with completion of secondary education (Cheatham & Randolph, 2022; Hermanoff, Määttä, & Uusiautti, 2017; McKissik, Diegelmann, & Parker, 2017; Pearson, Watson, Gangneux, & Norberg, 2021; Trainor et al., 2020) and problems with access and quality of health care services (Bratt, Johansson, Moons, & Goossens, 2021; Toulany, Gorter, & Harrison, 2022; Zheng et al., 2014; WHO, 2021).

It has been shown that the severity of young person's disability can have a negative impact on her/his educational achievements. Those young adults who have severe disabilities, have more difficulties in completing secondary education (Lindsay et al., 2018). Moreover, these young people lack educational services to support their secondary education (Nganji & Brayshaw, 2017; Osgood, Foster, & Courtney, 2010). In Finland, the support (e.g., classroom assistants, assistive technology devices and enabling technologies, interpreters), interventions, and educational materials provided for students with multiple disabilities (e.g., severe physical disability with a co-occurring intellectual disability) are not adequate or accessible to meet their individualized needs (Ministry of Social Affairs and Health, 2018). For example, these young people may have difficulties in acquiring adequate literacy skills (reading and writing). Attending and completing upper secondary education, on the other hand, would require adequate literacy skills. Furthermore, good literacy skills would improve participation in Finnish society and activities. It has been demonstrated, however, that young people with intellectual disabilities do not have access to local educational opportunities in their communities, nor do they have educational services that are tailored to their needs and hopes (Hermanoff, Määttä, & Uusiautti, 2017; Äikäs, 2012). Educational institutions for young people with disabilities are nowadays located in bigger cities (Beach et al., 2018; Hermanoff, Määttä, & Uusiautti, 2017). For those young people who do not live in Finland's big cities, this means that they must leave their homes to attend school. However, all young people with severe physical disabilities with or without a co-occurring intellectual disability, may not be willing to move from their hometowns to larger cities at the age of 16, when the educational transition from primary to upper secondary education in Finland typically occurs. Nonetheless, completion of upper secondary education would provide these young adults with the skills and knowledge necessary to function more effectively in society and to improve their general well-being, welfare, and quality of life (WHO, 2011).

Young adults with severe physical disabilities with or without a co-occurring intellectual disability experience problems related to their health and quality of life during and after their educational transition from primary to secondary education and transition from child to adult health care. Earlier research has documented that after the transition from adolescence to young adulthood, young adults with severe physical disabilities with or without a co-occurring intellectual disability seem to experience a permanent deterioration in their subjective quality of life (Lin, Ju, Lee, Yang, & Lo, 2011; Riquelme, Cifre, & Montoya, 2011; Usuba, Oddson, Gauthier, & Young, 2014) since they encounter several health concerns and challenges receiving services and supports. Furthermore, these young people may experience a health deterioration in the early adulthood or adulthood (Benner et al., 2017; Usuba et al., 2014; Young et al., 2006). This deterioration in health is manifested for example by functional worsening, cognitive decline, severe fatigue, pain, obesity, passive lifestyle, epilepsy, and problems with mental health (Benner, et al., 2017; Coppus, 2013; Smith, Peterson, Victor, & Ryan, 2021; Roebroeck et al., 2009; van der Slot et al., 2021). It has been demonstrated that health care services for young adults with disabilities face challenges as they transition to adulthood: discontinuity of health care services, and a lack of follow-up care are issues (Kalleson, Jahnsen, & Østensjø, 2021; Skogby, Bratt, Johansson, Moons, & Goossens, 2021). In Finland, the multi-professional follow-up appointments in the child neurology units end usually when the child reaches the age of 16. Consequently, these young people use the same primary health care services that all Finnish residents. However, after the health care transition from child to adult primary health care, young people with severe physical disabilities with or without a co-occurring intellectual disability may experience health care access problems, difficulties with receiving the necessary assistive devices, and problems with receiving health care from physicians with knowledge and skills related to the complex health care needs of young adults with severe physical disabilities with or without a co-occurring intellectual disability. Furthermore, these young adults may have ongoing and untreated pain that decreases their quality of life (Miró et al., 2017; Riquelme, Cifre, & Montoya, 2011; Smith et al., 2022). Therefore, these young adults may be dissatisfied with their health care (Gal, Weisberg-Yosub, Shavit, & Doron, 2010). They can be dissatisfied with their assistive devices (Benedict & Baumgardner, 2009; Henry, Long-Bellil, Zhang, & Himmelstein, 2011; Samuelsson & Wressle, 2008), access to a physician's appointment (Academic Network of European Disability Experts (ANED), 2014; Bindels-de Heus et al, 2013; European Association of Service Providers for Persons with Disabilities (EASD), 2017; Gibson & O´Connor, 2010; Gorter et al., 2021; Oulton et al., 2016; Solanke, Colver, & McConachie, 2018; Yee & Breslin, 2010), and physicians' knowledge and skills in caring for them (Kirschner & Curry, 2009; Minihan et al., 2011; Nishikawa, Daaleman, & Nageswaran, 2011; Shakespeare, Iezzoni, & Groce, 2009; WHO, 2011).

In sum, after the life transitions in education and health care, young adults with severe physical and intellectual disabilities are at risk of not receiving the educational and health services that they need (Crowley, Wolfe, Lock, & McKee, 2011; Hermanoff, Määttä, & Uusiautti, 2017; Horner-Johnson & Newton, 2012; Oswald, Gilles, Cannady, Wenzel, Willis, & Bodurtha 2013; Wang, Burns Mc Grath, & Watts, 2010; Äikäs, 2012). As a result, it appears that these young people experience discontinuity in educational services and health care after their transitioning from comprehensive to upper secondary education and from child to adult health care (Hermanoff, Määttä, & Uusiautti, 2017; Hästbacka, Nygård, & Nyqvist, 2016; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). Thus, the transitional outcomes and subjective quality of life among young adults with severe physical disabilities with or without a co-occurring intellectual disability are not as good as those of young adults without those disabilities following their transition from basic education to upper secondary education and from child to adult health care (Pandey & Agarwal, 2013; Pearson, Watson, Gangneux, & Norberg, 2012; Toulany, Gorter, & Harrison, 2022; Verlenden, Zablotsky, Yeargin-Allsopp, & Peacock, 2022; WHO 2011). These young adults may lack secondary education or face significant difficulties in completing secondary education, despite the fact that secondary education provides them skills and knowledge to advocate for themselves and to obtain employment. Furthermore, young adults with severe physical and intellectual disabilities may have problems with access to health care and face problems with continuity of care after their transition from child to adult primary health care.

It is important to ensure that young adults would be satisfied with their health care after the health care transition. However, it has been showed that young adults with disabilities may be dissatisfied with their adult health care (Gal, Weisberg-Yosub, Shavit, & Doron, 2010). Among the factors causing dissatisfaction are: assistive devices (Benedict & Baumgardner, 2009; Henry, Long-Bellil, Zhang, & Himmelstein, 2011; Samuelsson & Wressle, 2008), access to a physician's appointment (Academic Network of European Disability Experts (ANED), 2014; Bindels-de Heus et al., 2013; European Association of Service Providers for Persons with Disabilities (EASD), 2017; Gibson & O´Connor, 2010; Gorter et al., 2021; Oulton et al., 2016; Solanke, Colver, & McConachie, 2018; Yee & Breslin, 2010), and physician's expertise (knowledge and skills) with their health care (Kirschner & Curry, 2009; Minihan et al., 2011; Nishikawa, Daaleman, & Nageswaran, 2011; Shakespeare, Iezzoni, & Groce, 2009; WHO, 2011). Previous research has indicated that young people with disabilities lack continuity of care although they would need it after their transition to adult health care (Kalleson, Jahnsen, & Østensjø, 2021). Consequently, young adults with severe physical and intellectual disabilities may be at risk of negative life outcomes in their adulthood (Carter, Austin, & Trainor, 2012).

Schwartz, Stark, and Rapkin (2020) propose a new approach to measuring health care outcomes. They suggest that individual, positive health care experience may lead to better appraisal of person's health and quality of life. Dissatisfaction with health care, on the other hand, provides information for health care organizations to improve, develop, and implement health care for young adults with severe physical and intellectual disabilities. For these reasons, the objective of Study III is to identify factors associated with dissatisfaction with health care among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition to adult health care in Finland.

This PhD dissertation approached the quality of life of young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition to adulthood from two perspectives. The first perspective is mainly subjective since the aims were to examine the personal outcomes or quality of life domains, and to identify factors associated with dissatisfaction with health care after the participants` transition from child to adult health care. The second perspective is objective with the aim to identify the factors associated with completion of upper secondary education among young adults with severe physical disabilities with or without a co-occurring intellectual disability. To this end, the main goal of this PhD dissertation was to examine the transition outcomes in quality of life, upper secondary education, and transition outcomes after the transition from child to adult health care among young adults with severe physical disabilities with or without a co-occurring intellectual disability using the quality of life and systems thinking frameworks. At the individual level of the systems thinking framework, the goal was to investigate personal outcomes in subjective quality of life and the factors associated with dissatisfaction with health care after participants transitioned from child to adult health care in Finland. At the organizational level of the systems thinking framework, the objective was to determineobjective quality of life indicators that predicted completion of upper secondary education. This PhD dissertation`s evidence-based feedback information can be used to guide upper secondary and primary health care organizational and system change and service delivery within the quality of life and systems thinking frameworks.

Thus, the first aim of this PhD dissertation was to investigate personal outcomes in subjective quality of life among young adults with severe physical and intellectual disabilities. The second goal was to examine the objective quality of life by identifying the factors that predicted completion of upper secondary education among study participants. The third aim of this PhD dissertation was to investigate subjective quality of life by identifying factors associated with dissatisfaction with health care among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult primary health care. This PhD dissertation is the first in Finland to explore the quality of life among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition to adulthood.

All quality-of-life domains are interconnected and related to each other (Skevington, Lofty & O'Connell, 2004). According to the WHO's quality of life model (1997), quality of life includes the domains of physical quality of life, psychological quality of life, social quality of life, and environmental quality of life. All these domains may impact the possibilities of young persons with disabilities to attend to education (Jenaro, Vega, Flores & Cruz, 2013). Quality of life can be measured at three levels in the quality of life framework: microsystem, mesosystem, and macrosystem. The subjective quality of life is included in the microsystem, whereas the objective quality of life is included in the mesosystem (Schalock, 2004). This PhD dissertation aims to measure quality of life at microsystem and mesosystem levels. At the microsystem level (subjective QoL, personal appraisal, see Schalock, 2004), the focus was on measuring participants' subjective quality of life and its physical, psychological, social, and environmental domains, as well as participants' dissatisfaction with health care services. At the mesosystem level (objective QoL, functional assessment, see Schalock, 2004), the focus was to measure how participants' functional status (type of disability, literacy skills, and participants' location as an external circumstance) is associated with completion of upper secondary education.

2 CONCEPTUAL FRAMEWORKS

2.1 Quality of life framework

The concept of quality of life is used in research, policy, and practice (Skevington & Böhnke, 2018). It has been adopted as an important approach to provide services for individuals with disabilities. The idea prevailed for a long time that the concept of QoL had a dichotomous character of subjective and objective dimensions. But in 1996, Schalock suggested that the artificial dichotomy of subjective and objective dimensions in the concept of quality of life may be replaced with a core set of quality-of-life dimensions which have both objective and subjective aspects. Close to this approach, the WHO's definition emphasizes the individual's own perception of their life in their living environment. This definition also considers the individual's perception of their quality of life "in relation to their goals, expectations, standards, and concerns." According to this definition, quality of life refers to subjective assessment embedded in social, environmental, and cultural context (WHO, 2012). Thus, "the quality-of-life construct is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relations, and their relationship to salient features in their environment" (WHOQOL Group 1995, 1405). Olés (2016, 1403) confirms that this definition includes the subjective perception of quality of life with personal goals and values, as well as the individual's cultural and environmental contexts.

Quality of life concept has been compared to the concept of well-being. These concepts have been used interchangeably (Selwyn & Wood, 2016; Statham & Chase, 2010). It has been suggested that the concept of quality of life is different concept from well-being and they should be treated as different concepts (Upton & Upton, 2015). However, both concepts are multidimensional, interdependent, and include the same domains: physical, psychological, social, and environmental (Coleman, Morrison, Perkins, Brosco, & Schor, 2022; Hsieh, 2022; Skevingnton, & Böhnke, 2018). Moreover, both concepts include subjective and objective perspectives. Cognitive assessments of one's life, happiness, satisfaction, positive feelings like pride and joy, and negative emotions like pain and concern are all in one's subjective well-being (Stiglitz, Sen, & Fitoussi, 2009). Quality of life concept encompass the same subjective elements. Both concepts include objective elements such as material resources, income, education, and wealth (Camfield & Skevington, 2008; Selwyn & Wood, 2015; Skevington & Böhnke, 2018). According to Schalock (2004, 207), the subjective nature of quality of life reflects the personal appraisal of persons with disabilities concerning their services when they are asked to rate their satisfaction or dissatisfaction with services or happiness measures. Alternatively, the objective nature of quality of life refers to functional assessments, such as rating scales (level of functioning), participant observation questionnaires (external events and circumstances), engagement in everyday activities, self-determination and personal control, and role status (education, employment, living) (Schalock, 2004, 207).

As these concepts evolved, it was suggested that subjective well-being was merging with the concept of quality of life (Skevington & Böhnke, 2018). Thus, Camfield and Skevington (2008) stated that quality of life and well-being should be used as synonyms. Furthermore, Skevington and Böhnke (2018) suggested that there should be only one concept that would include all elements from quality of life and well-being. This concept was named as Life Quality and Well-being. However, both concepts - quality of life and well-being - have been still used in research (Coleman et al., 2022).

In terms of measuring both concepts, researchers have developed more instruments to measure quality of life, whereas well-being researchers have focused on theory formulation (Camfield & Skevington, 2008). However, in recent years, researchers and policy makers have become more interested in the design and development of instruments to measure well-being and well-being inequalities (Organisation for Economic Co-operation and Development, n.d.). Nonetheless, researchers have not agreed on a universal definition of well-being (Selwyn & Wood, 2015; Statham & Chase, 2010). Therefore, at this stage of concept and measure development, instruments designed to measure quality of life may produce more reliable and valid information about subjective quality of life than those under construction to measure well-being. Moreover, the quality of life definition (according to the WHO definition) excludes issues of functional (such as walking ability or hand function) or physical health and recommends that young people themselves evaluate and determine their own quality of life rather than parents or caregivers (Edwards, Huebner, Connell, & Patrick, 2002; Bjornson et al., 2008). However, the WHOQOL-BREF instrument includes questions about physical quality of life personal outcomes and this implies that a person can report himself or herself about his or her health-related quality of life as well as other quality of life domains. Thus, health care providers can gain important information also from physical health-related quality of life personal outcomes (Van Loon et al., 2010). In particular, Coleman et al., (2022) and Maguire, Davison, McLaughlin, and Simms (2022) emphasize the importance of focusing on measuring quality of life personal outcomes among young people with disabilities when developing different services (such as health care and education) for them. The change from a personal deficiency perspective to environmental factors that enhance individual self-determination, delivery of individualized services and supports, community and social inclusion, and self-empowerment is important in the quality of life framework (DeWaele & Van Hove, 2005; DeWaele, Van Loon, Van Hove, & Schalock, 2005). This change challenges organizations (such as educational and health care) to collect and analyze information on personal outcomes in subjective quality of life directly from persons with disabilities, because the services provided by these organizations can improve quality of life of persons with disabilities. In the quality of life framework, the subdomains of each quality of life domain (physical, psychological, social, and environmental) represent domain-related indicators (see Table 1). These domain-related indicators, which are also described in the quality of life framework (see Schalock et al., 2008) form personal outcomes in each quality of life domain. Thus, the personal outcomes in the quality of life framework provide important information to understand individual needs of young people with disabilities and to improve the delivery of the services for them (Coleman et al., 2022). Importantly, Camfield and Skevington (2008) state that subjective assessments are not less reliable than objective measures. In sum, quality of life is perceived as an outcome of interconnections between the individual, services, community, and society (Hoffman, Marquis, Poston, Summers & Turnbull, 2006; Lee, Harrington, Louie & Newschaffer, 2008; Schalock, Verdugo, Bonham, Fantova & Van Loon, 2008). Based on these considerations, the WHO`s WHOQOL-BREF instrument, with its subjective evaluations of personal outcomes in quality of life domains, provided a reliable instrument for collecting quality of life data in this PhD dissertation. Table 1 (World Health Organization, 1996) illustrates the domains and sub-domains of the WHOQOL-BREF instrument.

Table 1. WHOQOL-BREF Domains and Sub-domains

Domain	Sub-domain
General QOL	
General health	
1. Physical health	Pain and discomfort Energy and fatigue Sleep and rest Dependence on medication Mobility Activities of daily living Working capacity
2. Psychological health	Positive feelings Negative feelings Self-esteem Thinking, learning, memory and concentration Body image Spirituality, religion and personal beliefs
3. Social relationships	Personal relations Sex Practical social support
4. Environment	Financial resources Information and skills Recreation and leisure Home environment Access to health and social care Physical safety and security Physical environment Transportation

Note. Reprinted from "WHOQOL-BREF. Introduction, administration, scoring and generic version of the assessment. Field Trial Version." Field Trial Version. December 1996" by World Health Organization, 1996 (https://apps.who.int/iris/handle/10665/63529). Copyright (1996) by World Health Organization. Reprinted with permission.

The quality-of-life paradigm impacts on service quality, supports, personal outcome evaluation, and management strategies, as it has been operationalized into a measurable construct (Verdugo & Schalock, 2009). Quality of life can be measured at three levels: microsystem, mesosystem, and macrosystem. In this PhD dissertation, the quality of life assessment occurred at microsystem and mesosystem levels. The microsystem measurement occurred at the individual level when the study participants were asked to evaluate their subjective physical health, psychological state, social relationships, and personal beliefs and their connections to prominent environmental features (WHO, 1998). According to quality of life framework, quality of life can be measured by evaluating personal outcomes in the quality of life domains (physical, psychological, social, and environmental quality of life) of individuals with disabilities (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008; WHO, 2020). Because the upper secondary education and primary health care organizations are systems that have an impact on the quality of life for young adults with severe physical disabilities with or without a co-occurring intellectual disability, these organizations are included in the mesosystem level assessment of the environmental quality of life among the participants in this PhD dissertation (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008). The inclusion of upper secondary education in the mesosystem assessment is important since Faragher and Van Ommen (2017) state that education promotes quality of life among persons with disabilities. Primary health care must also be considered as part of the mesosystem assessment because it affects young adults with severe physical disabilities with or without a co-occurring intellectual disability in terms of their environmental and other domains of quality of life (Friedman & VanPuymbrouck, 2019; Schalock et al., 2018; Perrin, 2012).

The WHOQOL questionnaire used in this PhD dissertation provides individual's subjective appraisal of the personal outcomes in the domains of physical, psychological, social, and environmental quality of life. This quality of life personal outcomes related knowledge provides evidence for the strategic decision-making associated with the allocation of limited resources (Kober & Eggleton, 2009). Brown (2012) suggests that as the quality of life is a multidimensional concept, it can be used as a framework for service-related policy. According to him, it brings cohesion to research and practice, as it is both a research-paradigm and a means of professional and personal practice. Service providers and professionals are required to state explicitly what social, psychological, health, and education services they are going to implement to improve the quality of life of persons with disabilities (Brown, 2012). Brown (2012) also suggests that there should be a feedback model to be able to improve policies. This quality-of-life feedback model gives information on whether the changes made in the policies are addressing the difficulties that individuals with disabilities experience. Thus, the construct of quality of life is useful when trying to change policies (Brown, 2012). Furthermore, quality of life is an essential concept for disability service providers as it allows them to demonstrate the effectiveness of their services (Friedman, 2018).

As the quality-of-life concept is a holistic approach encompassing physical, psychological, social, and environmental domains, investigating those domains may provide valuable information on how severe physical and intellectual disabilities affect a young person's subjective quality of life after their transition from youth to adulthood (DeCamargo, 2011; WHO, 1997). For these reasons, transitions are critical for this group, as they must live with their disability for their entire life (Brown, Brown & Turnbull, 2003; Warren & Manderson, 2013).

2.2 Systems thinking and quality of life frameworks incorporating the individual, organization, and service delivery system

2.2.1 Implementation strategies in the systems thinking and quality of life frameworks

A recent study of Dori et al. (2020) mapped the different definitions of a system and concluded that the definition of a system is: "An arrangement of parts or elements that together exhibit behavior or meaning that the individual constituents do not." The systems thinking is a based on the general systems theory (Cioruta & Coman, 2019). Understanding a system entail studying the system relationships that exist between the various parts that work together to determine the system's behavior. Yawson (2012) stated that the workings of individual elements reveal very little about the overall system. Therefore, the entire system must be investigated (Yawson, 2012) to improve system learning (Stenvall & Virtanen, 2017). The system can include an individual, an organization and larger system (such as society) that interact with one another (Dori et al., 2020). The systems thinking framework provides a framework to integrate the individual, organization, and service delivery system. In Table 2 (p. 26), Schalock, Verdugo, Bonham, Fantova, and Van Loon (2008, 281) present their multisystem implementation strategies. This model shows how the single components are interrelated and interdependent. The systems-thinking framework can be implemented in three different levels: individual, organization, and systems levels. In the systems thinking framework, an individual can be empowered by asking him/her to provide information, such as quality of life's personal outcomes. Individuals are involved in the service delivery (e. g. upper secondary education and primary health care) when they are given the opportunity to share their perspectives (personal outcomes of domains of QoL) on their quality of life. In the systems-thinking framework, the organization is larger level than an individual. Quality of life principles can be the guiding approach. Quality of life principles include the concepts of quality of life domains and indicators. The organization (upper secondary education and health care services) should understand that quality of life domains (physical, psychological, social, and environmental) represent the individual's well-being and the range where the quality of life concept extends. On the other hand, the indicators reflect individual's behaviors, perceptions, and conditions in each quality of life domain. These quality of life indicators indicate a person's well-being and provide a foundation for assessing quality of life related personal outcomes (see Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008). When quality of life principles guide the organization, this means that the organization (e. g. upper secondary education services and adult health care services) is interested in and measures individual support needs, and the quality of life related personal outcomes (see Schalock, Verdugo, Bonham, Fantova, & Van Loon (2008, 279) of the young people who are using the upper secondary education and health care services.

These quality of life related personal outcomes guide organizational change and improvement. Quality improvement in the organization occurs when the organization has learning teams and uses evidence-based practices. These evidence-based practices are based on personal outcomes evaluation (Shogren, Luckasson, & Schalock, 2017). In the systems thinking framework, the larger service delivery system level training and organization development (upper secondary education services and primary adult health care services) are based on the internal evaluation of the organization. Internal evaluation refers to how these organizations assess how their services affect the personal outcomes of quality of life among young adults with severe physical disabilities with or without a co-occurring intellectual disability. If the assessed personal outcomes among these young adults are not satisfactory, the quality of life framework provides a foundation for quality improvement at the system level.

Furthermore, the process of quality of life and systems thinking framework provides four strategies for quality-of-life implementation: mental models, assessment, service delivery, and quality improvement. Mental models represent the organization's vision and culture. The organization's leadership, values training, service delivery, outcomes evaluation, and quality improvement are based on mental models (Schalock et al., 2008). These models are deep-rooted assumptions, images, and generalizations that help individuals understand the world (Senge 1990; 2006). Evidence-based practices and quality improvement in health care and educational organizations are based on assessment. Assessment can be carried out by measuring personal outcomes and individual support needs, as well as performance indicators (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012; Schalock et al., 2008). Schalock et al. (2008) describe the service delivery practices as “the services and supports that are provided to persons with disabilities”. The coordinated resources and strategies lead to best practices, which in turn produce enhanced personal outcomes (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012; Schalock et al., 2008). Quality improvement involves implementing action strategies based on systematically collected, analyzed, and synthesized data. As a result of this process, the organization or system improves its performance and accountability (Schalock et al., 2008). Quality improvement should aim at reducing bureaucracy and increasing new ideas in the organizations and systems (Orthner, Cook, Sabah, & Rosenfeld, 2006; Särkikangas, 2020).

Table 2. Multisystem Implementation Strategies

Implementation Level	Mental Model	Assessment	Service Delivery	Quality Improvement
Individual	Consumer Empowerment Consumer Involvement QOL (Concepts and Components)	Personal Outcomes (QOL Domains and Indicators) Assessment Methods	Consumer Involvement Consumer Equity & Empowerment	Shared Vision Involvement Self-Advocacy
Organization	QOL Principles Learning Organization Ethics	Supports Needs Assessment Performance Indicators Internal Evaluation System	Values Training Individualized Supports Provision Social Capital	Leadership Learning Teams Evidence-Based Practice Self-Evaluation
System	Training & Organization Development Activities (to support above models)	Organization Based Evaluation Manage for Results	Systems Thinking Flexibility and Innovation Incentives to Change	QOL Framework QI Methodology Evaluation-Reporting Standards

Note. Reprinted from "Enhancing personal outcomes: organizational strategies, guidelines, and examples" by R. L. Schalock, M. A. Verdugo, G. S. Bonham, F. Fantova, and J. Van Loon, 2008. *Journal of Policy and Practice in Intellectual Disabilities, 5*(4), 281. Copyright (2008) International Association for the Scientific Study of Intellectual Disabilities and Wiley Periodicals, Inc. Reprinted with permission.

This PhD dissertation adopted some concepts from two conceptual frameworks. Figure 1 (p. 28) illustrates the adopted concepts. It was not possible to study all concepts and measures from the systems thinking and quality of life frameworks in one PhD dissertation. Furthermore, Schalock et al., (2008) remind us that utilizing more measures and concepts does not necessarily result in better information. Therefore, measures and data should be concise and conceptually unambiguous (Schalock et al., 2008). Therefore, the concepts from the overarching framework of the Quality of Life framework were used, as this framework integrates quality of life personal outcomes, quality services, and quality improvement. Second, concepts from the Systems Thinking Framework were adopted since the framework views the interrelationships between the individual, organization, and wider service delivery system (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008). According to Schalock et al. (2008), both frameworks provide a framework for four Quality of Life-related implementation strategies which are: mental models, assessment, service delivery, and quality improvement. However, this PhD dissertation used some concepts (but not all) from the Systems Thinking Framework's individual, organization, and system levels. The concepts used from these levels included concepts from the four QoL-associated implementation strategies (mental model, assessment, service delivery, quality improvement) (see Schalock et al., 2008). This PhD dissertation aimed at examining the subjective quality of life and dissatisfaction with health care services among young adults with severe physical and intellectual disabilities by requesting them to provide information on their subjective quality of life and dissatisfaction with factors associated with health care services. Therefore, to provide evidence-based guidance for delivering health and social services for these young people, the adopted individual-level concepts were: user empowerment, user involvement in the form of quality of life concepts and components (mental model), personal outcomes in the form of quality of life domains and indicators (assessment), and user involvement (service delivery) described in the section 2.2.2. Furthermore, as the objectives of this PhD dissertation were to investigate the predictors of completion of upper secondary education and identify the factors associated with dissatisfaction with health care services among young adults with severe physical disabilities with or without a co-occurring intellectual disability, this PhD dissertation adopted the organization-level concepts: assessment (internal evaluation system) and quality improvement (evidence-based practice), training and organization elaborated in Section 2.2.3. Finally, since according to the systems thinking framework the quality of life of young adults with severe physical disabilities with or without a co-occurring intellectual disability is related to the broader systems of upper secondary educational and primary health care organizations and systems, this PhD dissertation used the system-level concepts: systems thinking (service delivery) and quality of life framework (quality improvement) described in Section 2.2.4. Figure 1 presents the conceptual and theoretical frameworks of this PhD dissertation.

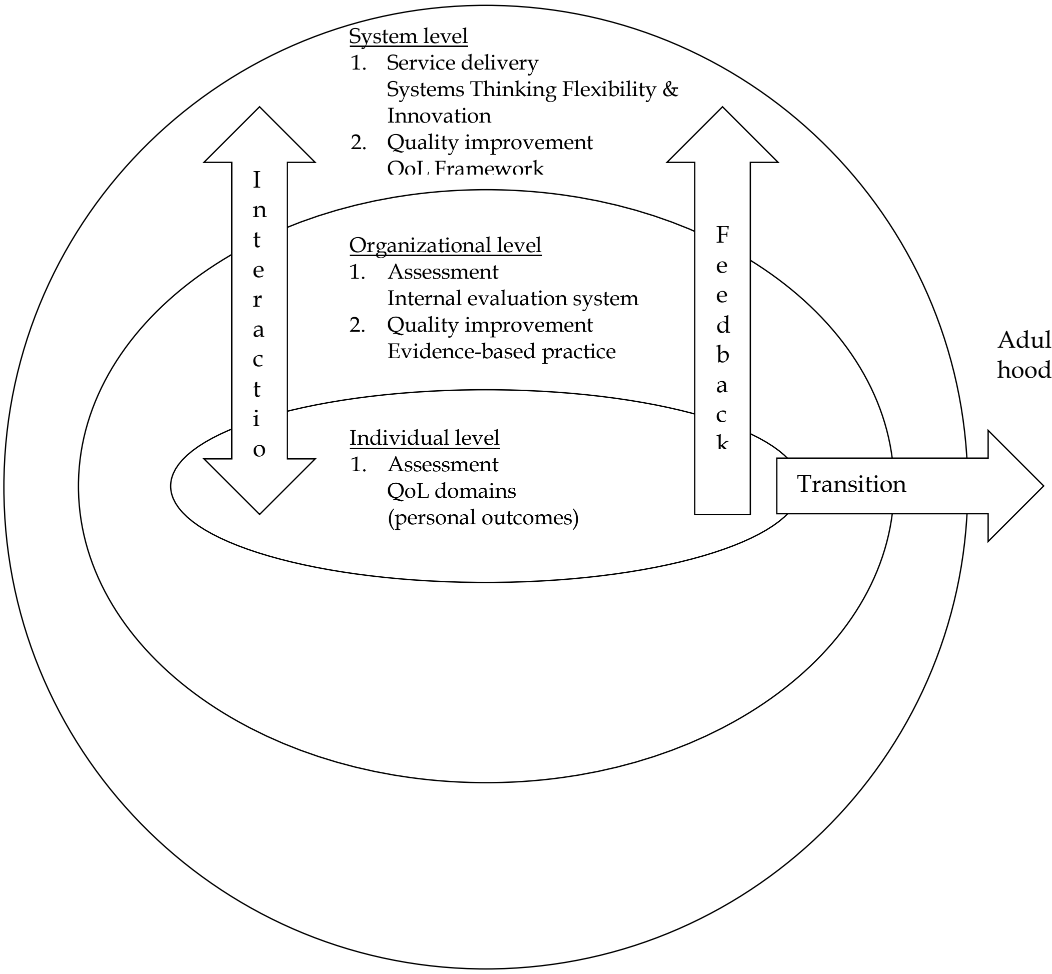

Figure 1 Conceptual and theoretical frameworks of the PhD dissertation

2.2.2 Individual level: quality of life among young adults with severe physical disabilities with or without a co-occurring intellectual disability

Mental model*. User empowerment. User involvement. Quality of life (concept and components).* The individual level of the systems-thinking relates to youth with severe physical and intellectual disabilities and their quality of life. As Schalock, Verdugo, Bonham, Fantova and Van Loon (2008) suggest, the individual level of the strategies encompasses consumer empowerment, consumer involvement, and quality of life with its concepts and components. However, upper secondary education and primary health care services, on the other hand, are free of charge in the Finnish society. Therefore, the concept consumer has been replaced with the concept user in this PhD dissertation. The two sub-studies aimed at user empowerment and involvement by asking young adults with severe physical and intellectual disabilities to provide their perspective on their subjective quality of life and their factors associated with dissatisfaction with adult health care services. Providing young adults the opportunity to give their perspective has been acknowledged as an important approach in the research (Gulati, Paterson, Medves, & Luce-Kapler 2011, 523). Thus, the collected information related to participants' lives (subjective quality of life, dissatisfaction with health care services) is not obtained from the professionals in the different disciplines. It is vital to gain knowledge from the young adults themselves since they are experts in their own lives. Requesting them to provide information about their life situation may lead to their empowerment. In addition, empowerment can improve young adults' quality of life (Shogren & Shaw, 2016, 10–11).

Assessment. *Personal outcomes (QoL domains and indicators)*. The study participants were requested to provide their perspectives on subjective quality of life domains: physical, psychological, social, and environmental because the concept of quality of life is multidimensional (Schalock et al., 2008). All quality of life domains included domain-related indicators. It is essential to understand that disability affects these young adults' lives in physical, psychological, social, and environmental dimensions. Physical impairments may restrict their participation in and access to local community activities, social activities, education, and employment (Brown, 2012). In addition, young adults with severe disabilities may be at risk of low psychological well-being (Biggs & Carter, 2016) as well as social participation problems and loneliness (Graf, Blankenship & Marini, 2009; Jalayondeja, Jalayondeja, Suttiwong, Sullivan, & Nilanthi, 2016; Palisano et al., 2009). Young adults' environmental quality of life (e.g., monetary resources, health and social care services accessibility and quality, possibilities to learn new skills and knowledge, opportunities to participate in recreational activities, physical environment, and transportation) may be compromised as well (WHO, 1996). Therefore, it is important to understand that personal and environmental factors, as well as their interaction, have an impact on quality of life whereas self-determination, resources, inclusion, and a sense of purpose in life improve it (Schalock et al., 2008). The measurement of quality of life indicates how much young adults with severe physical disabilities with or without a co-occurring intellectual disability value their life experiences. It includes the domains that are important for full and interconnected life physical, psychological, social, and cultural environments. It also encompasses common measurable experiences shared by all people as well as those special and subjective to specific individuals. Quality of life principles should be the leading paradigm in professional education and training as well, as they should be the basis for interventions and supports (Schalock et al., 2008, 277-278) in the upper secondary educational and health care services organizations.

Young adults with severe physical disabilities have a lower overall quality of life than young adults without disabilities (Ihara, Wolf-Branigin, & White 2012, 667; Lin, Ju, Lee, Yang, & Lo, 2011; Usuba, Oddson, Gauthier, & Young, 2014; Riquelme, Cifre & Montoya, 2011). As quality of life is a multidimensional construct incorporating physical, psychological, social, and environmental aspects, a holistic approach should be taken to address these various dimensions of life in efforts to increase the individual's quality of life (WHO, 1997). Up to now, far too little attention has been paid in studying the quality of life among young adults with severe physical disabilities. Some studies have suggested that children and adolescents with physical disabilities originally have fair or good quality of life (Böling et al., 2016; Domellöf et al., 2014; Colver & Dickinson, 2010; Shikako-Thomas et al., 2009). After adolescence, youth seem to experience a permanent deterioration in their subjective quality of life (Edwards et al., 2003; Lin et al., 2011; Roebroeck, et al., 2009). Although King et al. (2005, 196–198) have shown that young people with severe physical disabilities encounter difficulties that may influence their subjective quality of life, there is a lack of knowledge and understanding of the subjective quality of life and the factors related to or predicting it among these young people.

While there are some studies that focus on measuring quality of life among young adults with severe physical disabilities, the literature concerning the quality of life of young adults with multiple disabilities— such as the participants in this study, who have a severe physical disability with or without a co-occurring intellectual disability — is scarce. Overall, it appears that young adults with physical disabilities are rarely included in surveys on quality of life (Bagazgoïtia et al., 2021; Davidson, Irvine, Corman, Kee, Kelly, Leavey, & McNamee, 2017, 29; Ow, Appau, Matout, & Mayo, 2021). However, there are some studies which have demonstrated that environmental factors — such as educational and health care services — have an impact on the quality of life among young people with severe physical and intellectual disabilities (Schalock, Verdugo, Bonham, Fantova, & VanLoon, 2008). This PhD dissertation uses the term "young adults", since the participants are between the ages 19 and 22. Higley (2019) defines persons aged 18 to 25 as young adults.

2.2.3 Organizational level: upper secondary education and health care services

Mental model. *Quality of life principles. Learning organization. Ethics.* At the organizational level, quality of life principles, learning organization, and ethics represent the mental model suggested by Schalock et al. (2008). Educational (e.g., upper secondary education institutions) and primary health care organizations should understand quality of life principles (QoL domains and QoL indicators) because these organizations deliver services for young people with disabilities. Upper secondary educational and primary health care organizations need to be learning organizations to be able to improve quality of life related personal outcomes among young people with severe physical and intellectual disabilities (Schalock et al., 2008). In terms of ethics, these organizations should perceive young people with severe physical and intellectual disabilities equal human beings and keep the primary goal of intervention clear: improve quality of life personal outcomes and ensure participation in the society (Dekecki, 1992; Reinders, 1999).

Assessment. *Internal evaluation system.* Upper secondary education and primary health care organizations can use the measurement results of quality of life related personal outcomes as an organizational-level internal evaluation system (Schalock et al., 2008). Quality of life personal outcomes reflect the outcomes of the services delivered by upper secondary education institutions and primary health care organizations (Carbó-Carreté, Guàrdia-Olmos, & Giné, 2015; Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012; Dekecki, 1992; Friedman, 2022; Reinders, 1999; Schalock et al., 2008). Thus, these quality of life personal outcomes are feedback from the young people with severe physical and intellectual disabilities primary health care organizations and to the health care service delivery system. This feedback is one indication of how primary health care organizations have managed to support subjective quality of life among these young people (Schalock et al., 2008).

Moreover, satisfaction or dissatisfaction with these services is a subjective outcome of service delivery success to young people with severe physical and intellectual disabilities (see Felce & Perry, 2006; Walsh et al., 2006). This PhD dissertation investigated factors related to dissatisfaction with health care among young adults with severe physical disabilities with or without a co-occurring intellectual disability. As Schalock et al. (2008) stated, for research, objective indicators should be measured as well. This PhD dissertation determined the predictors of completion of upper secondary education among young people with severe physical and multiple disabilities in accordance with the instructions of Schalock et al. (2008), and they represented objective indicators of the upper secondary education internal evaluation system.

Upper secondary education and primary health care organizations can enhance quality of life personal outcomes by delivering their services based on the internal evaluation results. Best practices can be implemented and quality in operations can be manages using the results of internal evaluations (Schalock et al., 2008). Furthermore, upper secondary education and primary health care organizations can use the internal evaluation system as the foundation for change theory, which provides a framework for how these organizations construct their everyday activities to execute their strategic objectives. Finally, an internal evaluation system serves as a framework for upper secondary education and primary health care organizations to investigate what works or does not work and whether young people with severe physical and intellectual disabilities are satisfied with these organizations' services. Upper secondary education and primary health care organizations can improve quality of their services (provided for young people with severe physical and intellectual disabilities) based on the internal evaluation findings (Al-Abri & Al-Balushi, 2014; De Rosis, Barchielli, Vainieri, & Bellé, 2021; Hunter, 2006; Rijken et al., 2021; Schuh & Leviton, 2006; Walji, Carroll, & Haber, 2021). This is extremely important at least from two reasons. First, young people with severe physical and intellectual disabilities face difficulties in finding suitable upper secondary education options for themselves, as well as difficulties completing these studies (Rasalingam, Brekke, Dahl, & Helseth, 2021). Therefore, it is important to understand the factors that can create difficulties and obstacles for these young people in upper secondary education to develop these organizations to provide educational services that better meet their needs (Hill, 2013; Husny & Fasching, 2020). Second, objective measurement in upper secondary education (such as factors associated with completion of upper secondary education as in this PhD dissertation) can provide important information to guide the upper secondary organization change and quality improvement (Felce & Perry, 2006; Schalock & Felce, 2004). Understanding the factors that prevent or improve upper secondary education completion for young people with severe physical disabilities with or without a co-occurring intellectual disability in Finland can serve as a foundation for the development of upper secondary education for these young people. These organizations should work to remove or reduce barriers completing their upper secondary education.

Second, this is essential since these young people have transitioned from child health care (with multi-professional pediatric neurology clinics with regular follow-up appointments) to adult health care which is the same primary health care as other Finnish citizens use (Arvio et al., 2012; Ministry of Social Affairs and Health, n. d.). Earlier studies have shown that primary health care organizations may not provide such health care services that meet the needs of young people with severe physical and intellectual disabilities in Finland (ANED, 2014; EASD, 2017). Therefore, primary health care organizations may benefit from internal evaluation systems. These organizations can collect information about health care experiences in the form of satisfaction studies (Felce & Perry, 2006; Walsh et al., 2006). Satisfaction studies have been used as basis for quality improvement in health care organizations as they represent an internal evaluation system (DeRosis, Barchielli, Vainieri, & Bellé, 2021).

Service delivery. *Individualized supports provision*. Upper secondary education organizations and primary health care organizations should provide individualized supports for those young people who have severe physical disabilities or multiple disabilities. In Finland, the upper secondary education possibilities for these young people are restricted because upper secondary education institutions usually cannot provide sufficient individualized supports and services for young people with severe physical disabilities or those who have a co-occurring intellectual or other disability. Such upper secondary educational institutions that are equipped with needed resources and services are located mainly in bigger cities.

It is important to understand, that young people with severe physical disabilities and young people with severe physical and intellectual disabilities need different health care services than the average individual (Doucet, Luke, Splane, & Azar, 2019). However, once these young people have transitioned from child to adult health care, they do not have access to a specialist physician (neurologist) and the regular multi-professional follow-up appointments in Finland's neurology clinics. In Finland, physicians in primary health care are general physicians who may not have the skills and knowledge to manage complex health care needs of young people with severe physical disabilities or those who have severe physical disabilities and co-occurring intellectual disabilities.

Quality improvement. *Leadership. Learning teams. Evidence-based practice. Self-evaluation.* Quality improvement in upper secondary and primary health care organizations requires that leadership establishes these organizations' goals and strengthens endeavor as well as outcomes (Schalock et al., 2008). In these organizations, quality improvement leadership promotes learning. Leaders and entire (upper secondary and primary health care) organizations share a vision that outlines what the organization wants to accomplish. Leaders support all employees' personal mastery by assisting them to gain knowledge and skills (Schalock & Verdugo, 2013). They also emphasize systems thinking framework with feedback (Schalock & Verdugo, 2012). Leaders improve the quality of life aspect related to community and society participation and highlight the role of upper secondary education and primary health care organization in this participation. Finally, the leaders concentrate on measuring the quality of life personal outcomes (Schalock et al., 2008). They ensure that the quality of life personal outcomes information is conveyed all over the organization (Beadle-Brown, Bigby, & Bould, 2015). The leaders try to investigate and understand how the organization can achieve wanted outcomes (Schalock & Verdugo, 2012).

2.2.4 System level: development of activities to support quality of life

Mental model. *Training and organization. Development activities (to support above models)*. Quality of life as an outcome change when developing and implementing public services for persons with disabilities (Burgess & Gutstein, 2007, 84; Jenaro, Vega, Flores, & Cruz, 2013, 489—491). The perspectives of persons with disabilities as service users provides an opportunity to gain knowledge about service delivery and factors that could be useful when improving the quality of public services for them. When the opinions and quality of life personal outcomes of young people with severe physical and intellectual disabilities are known, this information guides the system level development and implementation of individualized and high-quality upper secondary education and primary health care services to improve their quality of life. As a result, the larger systems of upper secondary education institutions and primary health care organizations learn from the feedback of young people with severe physical and intellectual disabilities and develop their activities accordingly. This implies that interactions exist between the individual (young people with severe physical and intellectual disabilities) and the system level (entities of upper secondary education institutions and primary health care organizations).

Service delivery. *Systems thinking flexibility and innovation.* All upper secondary education institutions in Finland can be perceived as a larger system. These institutions deliver educational services for young people including those who have severe physical disabilities and those who have severe physical disabilities with a co-occurring intellectual disability. Because young people with severe physical disabilities with or without a co-occurring intellectual disability have multiple individual special educational needs, upper secondary education institutions as a system should be flexible and innovative in their efforts to serve these young people.

Quality improvement. *Quality of life framework*. At the system level, the subjective quality of life personal outcomes can be used as evidence-based information to guide organizational improvement (Gambrill, 1999) in upper secondary education and primary health care services, as discussed in this PhD dissertation. The quality of life personal outcomes serve as feedback from young people with severe physical and intellectual disabilities to organizations (upper secondary education institutions and primary health care organizations) and larger system (entities of upper secondary education system and primary health care system). Thus, when using quality improvement as a mechanism for organizational change, the first stage is to measure personal outcomes of quality of life as well as performance indicators (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008; Willis, Zeratkaar, ten Hove, Rosenbaum, & Ronen, 2021). The implementation of quality improvement involves four guidelines. First, quality improvement includes training of values of quality-of-life principles at the organization and system levels. In the organizations of education and health care services, professionals should understand the concept of quality of life with its core domains and the indicators (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008) that represent the quality-of-life values. The core domains (see Schalock et al., 2008) encompass physical, emotional, and material well-being. Furthermore, personal development, self-determination and interpersonal relations belong to the core domains. Finally, broader phenomena, such as rights and social inclusion, are included in the core quality of life domains (Schalock et al., 2008). In the research, the core quality of life domains may be presented in a shorter form to collect data from persons for whom longer instruments are not practical (e. g. see WHO, 1998). Second, staff training entails frontline supervisors in education and health care services monitoring employees and providing comments on the type of life that the young adult with severe physical and intellectual disabilities is leading. Moreover, the frontline supervisors provide feedback regarding how involved the young adult is in her or his life, and whether opportunities for continuing learning are available (Schalock et al., 2008). The objective of this training is to improve personal mastery and to prepare direct support personnel to play a significant role in learning teams. Third, to serve as community bridges, organizations in education and health care must reframe their roles and functions and implement organization-based evaluation mechanisms. Furthermore, education and health care organizations should develop partnerships with all stakeholders in the community and promote a research/evaluation mentality instead of a bureaucratized monitoring approach (Schalock et al., 2008). Fourth, education and health care organizations ought to have an internal evaluation system, according to Schalock and colleagues (2008). This system integrates the personal outcomes of quality of life and individual support needs of young adults with severe physical and intellectual disabilities as well as the education and health care organizations' performance indicators. Thus, evidence-based procedures and quality improvement in the education and health care organizations are based on this information (Schalock et al., 2008). Thus, the system-level strategies are based on the systems thinking framework.

The implementation of system-level strategies would ultimately lead to organizational change and improvement of quality in education and health care organizations to enhance the quality of life of young adults with severe physical and intellectual disabilities (Schalock et al., 2008).

2.3 Transitional outcomes

2.3.1 Quality of life outcomes after transition

According to the life course paradigm, every individual has several transitions across their whole life span. All young people experience the transition to adulthood. Transitions are significant life events (Alwin, 2012). From the individual's subjective point of view, transitions are usually related to an individual's age and involve changes in the individual's responsibilities, behaviors, expectations, and roles (Alwin, 2012). Levinson and Levinson (1996) use the concept of life structure to describe the fundamental pattern of human life. This pattern is maintained in stable times of life and changed in transitional times (Merriam, 2005). One of the transition models is Bridges's model (1980, 1991). Applying his model, the transition to adulthood is perceived as a process when something ends and people move to the "neutral zone" (see Bridges's model of transition, 1980, 1991), where the old life (childhood) is gone, and the new adulthood is not yet comfortable. As a result, transitioning from adolescence to adulthood is a difficult period of physical, psychological, and social transformation (Campbell et al., 2016) and changes in the young people's environments (Pandey & Agarwal, 2013). During the transition process to adulthood, young people may take turns in the transition process; they move forward and backward, in and out of the transition, and they can go through many transitions at once (Merriam, 2005).

New beginnings are the final phase of the model of transition. New habits, manners, and routines are adopted in the final phase of the model of transition (Bridges, 1980, 1991) when children have become young adults. After the transition to adulthood, young people are expected to take responsibility for their own lives, construct an adult identity, and take on an adult role (Eliason, Mortimer, & Vuolo, 2015). Importantly, young people with severe physical disabilities with or without a co-occurring intellectual disability experience the same transition from childhood to adulthood as their peers without disabilities. However, these young people also experience service-related transitions as well because they receive a greater number of services and support than young people without disabilities. The transition from basic education to upper secondary education and the transition from child to adult health care are two examples of major service-related transitions among young people with severe physical disabilities with or without a co-occurring intellectual disability. According to the quality of life and systems thinking frameworks, asking young adults with severe physical disabilities with or without a co-occurring intellectual disability to provide their opinion on their transitional outcomes empowers them as users of upper secondary education services and adult health care services by hearing and collecting their opinions and outcomes after organizational transitions.

Following these transitions, young adults are served by educational organizations and health care services that differ from those provided to children. Transitional outcomes in quality of life (subjective quality of life) can be assessed in young adults with severe physical disabilities with or without a co-occurring intellectual disability using the quality of life and systems thinking frameworks. The transitional outcomes provide individual-level feedback to the upper secondary education and adult primary health care organizational levels, because these organizations provide services for young adults with severe physical disabilities with or without a co-occurring intellectual disability. This individual-level feedback data (personal outcomes in quality of life) acts as organizational-level internal evaluation system data and system-level data to guide the development and quality improvement of upper secondary and adult health care service delivery for young adults with severe physical disabilities with or without a co-occurring intellectual disability (Shogren, Luckasson, & Schalock, 2017). Moreover, the individual-level information on factors associated with dissatisfaction with adult health care (subjective quality of life) can be perceived as health care transitional outcomes (young adults can be dissatisfied with certain factors associated with health care after their transition from child to adult health care). This dissatisfaction-related feedback information can be used as evidence-based outcomes (Van Loon et al., 2013) to guide health care quality improvement at both the organizational level and systems levels of adult health care. The feedback information at the adult health care system level can be used to guide quality improvement of service delivery (Van Loon et al., 2013). The quality improvement at the adult health organization and system levels can include leadership (goals and outcomes of organizations and system), learning teams, and evidence-based practices based on the subjective quality of life outcomes of young adults with severe physical disabilities with or without a co-occurring intellectual disability. Furthermore, dissatisfaction related information can be used to health care system training and organization to support subjective quality of life outcomes among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care.

Finally, the organizational level internal evaluation system information regarding predictors of completion of upper secondary education (objective quality of life) can be perceived as upper secondary transitional outcomes for young adults with severe physical disabilities with or without a co-occurring intellectual disability (certain factors can predict the completion of upper secondary education among these young adults). This feedback information (about predictors of completion of upper secondary education) can be described as evidence-based outcome (Van Loon et al., 2013) feedback for the upper secondary organizational level as well as evidence-based information (Van Loon et al., 2013) for the larger upper secondary system level to guide service delivery development and quality improvement at the upper secondary education system level. The quality improvement at the upper secondary education organizations and system can include leadership (goals and outcomes of organizations and system), learning teams, and evidence-based practices based on the subjective and objective quality of life outcomes of young adults with severe physical disabilities with or without a co-occurring intellectual disability. Furthermore, at the upper secondary education system level the feedback information can be utilized to training and organization of the system to support subjective and objective quality of life outcomes among young adults with severe physical disabilities with or without a co-occurring intellectual disability. Thus, in the quality of life and systems thinking frameworks, the transitional outcomes (quality of life personal outcomes, upper secondary outcomes, adult health care outcomes) of young adults with severe physical disabilities with or without a co-occurring intellectual disability interact with each other. However, from perspective of quality of life and systems thinking framework, it is important to note that the transitional outcomes of young adults with severe physical disabilities with or without a co-occurring intellectual disability may be poor (Pearson, Watson, Gangneux, & Norberg, 2020) in terms of their quality of life, educational outcomes, and health care outcomes.

According to studies (Edwards, Patrick, & Topolski, 2003; Ihara, Wolf-Branigin, & White, 2012, 667), young people with disabilities (including young people with physical and multiple disabilities, see Colquitt, Dipita, Kendall, Alfonso, & Walker, 2014; Usuba et al., 2014) have lower quality of life than their peers without disabilities. An important issue to consider is that it seems that the age of the person with disabilities impacts the quality of life. When compared to young people with disabilities, younger children and adolescents with disabilities may be more satisfied with their quality of life. According to prior studies, the transition period from youth to adulthood is a turning point when the quality of life of youth with severe disabilities deteriorates permanently (Lin, Ju, Lee, Yang, & Lo, 2011; Riquelme, Cifre, & Montoya, 2011; Usuba, Oddson, Gauthier, & Young, 2014). During and after the transition from child to adult health care, young people with severe disabilities may encounter health and health care system challenges (De Camargo, 2011; Gorter, Stewart, & Woodbury-Smith, 2011).

Previous research findings (8 cross-sectional and 4 longitudinal studies) suggest that there are several factors — such as age (Berástegui, Santos, & Suárez, 2021; Edwards, Patrick, & Topolski, 2003; Lin, Ju, Lee, Yang, & Lo, 2011; Riquelme, Cifre, & Montoya, 2011; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009; Usuba, Oddson, Gauthier, & Young, 2014), gender (Colver & Dickinson, 2010; Torres & Vieira, 2014), and intensity of pain (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2008; Hadden & von Baeyer, 2002; Miró et al., 2017; Riquelme, Cifre, & Montoya, 2011; Tarsuslu & Livanelioglu, 2010) — which may affect the subjective quality of life among youth with severe physical and intellectual disabilities. Moreover, the broader service systems – such as education and health care services – may have an impact on the subjective quality of life among these young people (Schalock et al., 2008). Regarding age, children and adolescents with physical disabilities have reported initially fair or good quality of life (Böling, Varho, Kiviranta, & Haataja, 2015; Colver & Dickinson, 2010; Domellöf, Hedlund, & Ödman, 2014; Shikako-Thomas, Majnemer, Nimigon, Cameron, & Shevell, 2009). Lin et al. (2009) found that adolescents (aged 13-19 years) with disabilities have better subjective quality of life than those without disabilities. However, no definitive conclusions can be drawn due to the limited number of studies regarding the impact of age on the subjective quality of life among adolescents with disabilities. Following adolescence, youth with disabilities seem to experience a permanent deterioration in their subjective quality of life (Edwards, Patrick, & Topolski, 2003; Lin, Ju, Lee, Yang, & Lo, 2011; Riquelme, Cifre, & Montoya, 2011; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009; Usuba, Oddson, Gauthier, & Young, 2014). When youth have transitioned to adulthood, the quality of life of individuals with disabilities is likely to be lower than for persons without disabilities (Kinne, 2008; Mittler, 2008) although some adults with disabilities report good quality of life (Albrecht & Devlieger, 1999).

Some studies indicate that the overall quality of life does not vary depending on gender of the person with disabilities (Domellöf, Hedlund, & Ödman, 2014; Edwards, Patrick, & Topolski, 2003; Lin, Ju, Yang, & Lo, 2011). However, Torres and Vieira (2014) found that female adolescents with disabilities aged 10-19 years returned lower global quality of life scores than males. Young females with disabilities may have lower psychological and environmental qualities of life (Torres & Vieira, 2014) but their social quality of life may be better than that of males with disabilities (Awasthi, Chauhan, & Verma, 2016). Overall, the gender differences concerning quality of life are understudied, since generally young people have been excluded from studies on quality of life (Hicks, Newton, Haynes, & Evans, 2011; Selwyn & Wood, 2015, 29). Studies about pain among young people with physical and intellectual disabilities have shown that recurring pain negatively affects all quality of life domains among these youths (Breau & Camfield, 2011; Colver et al., 2014; de la Vega et al., 2016; McDowell, Duffy, & Lundy, 2017; Miró et al., 2017; Miró, Solé, Gertz, Jensen, & Joyce, 2017). One important factor regarding pain is the intensity of pain. On one hand, Rapp et al. (2017) found that severe pain affects most the physical quality of life domain. On the other hand, Miró et al. (2017) and Riquelme, Cifre, and Montoya (2011) concluded that pain intensity is associated with lower personal outcomes and a lower level of function in all quality-of-life domains.

It appears that young adults with severe physical disabilities find themselves in the service system, but they have poor results in the primary domains that define adulthood. These domains include education, employment, and creating a family (Osgood, Foster, & Courtney, 2010). Young people with severe physical and intellectual disabilities undergo life transitions in all domains of their life (De Camargo, 2011). Thus, the transition occurs in the physical, psychological, social, and environmental domains of life (Colver & Longwell, 2013), which are also represented in the quality of life framework.

Young people with severe physical and intellectual disabilities may encounter problems related to their health, education, and welfare during and after their transition to adulthood (Gorter, Stewart, & Woodbury-Smith, 2011; Lindsay et al., 2018; Poppen, Sinclair, Hirano, Lindstrom, & Unruh, 2016; Shogren, Wehmeyer, Palmer, Rifenpark, & Little, 2015; WHO, 2011; Äikäs, 2012). Osgood, Foster, and Courtney (2010) remind that young people with severe physical and intellectual disabilities experience several changes and challenges in their lives after their transition to adulthood. They may face difficulties that influence their subjective quality of life (King, Baldwin, Currie, & Evans, 2005). First, the difficulties may be associated with physical quality of life, including pain and discomfort, energy and fatigue, sleep and rest, dependence on medication, mobility, activities of daily living, and working capacity. Furthermore, these young people need to plan for medical care and assistive devices (Osgood, Foster, & Courtney, 2010). Second, psychological quality of life challenges may be related to the extent to which a person has issues with negative feelings, self-esteem, thinking, learning, memory and concentration, body image, spirituality, religion, and personal beliefs. Third, social quality of life concerns may be associated with personal relations, sex, and practical social support. Fourth, issues associated with financial resources, information and skills, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment, and transportation may affect young adults' subjective environmental quality of life (WHO, 1996). However, young people with severe physical disabilities with or without a co-occurring intellectual disability encounter service-related environmental transitions that may affect of their quality of life after their transition to adulthood. The educational transition from primary to upper secondary education and the transition from child to adult health care are two examples of service-related transitions, which can be perceived as complex changes in external or social circumstances (Enz & Talarico, 2016) in the young people's environment.

2.3.2 Upper secondary education transition outcomes

Education is important for all people. However, persons with disabilities have a lower level of education than those without disabilities worldwide (WHO 2011, xi). For persons with disabilities, education provides academic skills, life and social development skills, individual autonomy, and independence through learning to express their own perspectives and views (Broderick, 2018, 33–34). Furthermore, adults with disabilities, are poorer than those without disabilities, but education reduces this disparity by increasing personal welfare. Education is essential for young people with disabilities, as it is for all young people, but it is also essential for participating in employment and other domains of social activity as well as promoting well-being (WHO, 2011) and quality of life (Addabbo, Sarti, & Sciulli, 2016) because education can be perceived as an objective indicator of quality of life (Davidson et al., 2017).

The WHO (2011, 169) states that enabling environments may support persons with disabilities to participate in different domains of the environment.

One of those domains is education. Physical, social, and attitudinal environments create opportunities for young people with disabilities to attain education (WHO, 2011, 169). Accessible buildings, roads, transportation, information, and communication (WHO, 2011, 169) are important features when including these young people in educational settings. The identification of attitudinal barriers about disabilities and education, such as ignorance and prejudice, should be included in the initial efforts in building a "culture of accessibility" (WHO, 2011, 169).

When compared to those without disabilities, children and young people with disabilities have lower educational outcomes, fewer mean years of education, lower rates of progression to higher levels of education, and difficulties completing education (Carter & Bumble, 2018; WHO, 2011, 206–208). Overall, individuals with disabilities have restricted opportunities to participate in education (Carter, Austin, & Trainor, 2012, 58–60; Test, Bartholomew & Bethune, 2015) and lower education levels compared to individuals without disabilities (Mithen, Aitken, Ziersch, & Kavanagh, 2014). All these issues should be considered when planning educational settings which promote inclusive and equitable societies (WHO, 2011, 206–208).

Aron and Loprest (2012) state that for young people with disabilities, a lack of education means fewer possibilities to live a socially fulfilling, intellectually stimulating, and economically productive life. Without education these individuals will have fewer abilities to manage their complex health conditions and health care and social service issues, as well as to advocate for themselves throughout their lives (Aron & Loprest, 2012). Education provides opportunities for young people with severe physical and intellectual disabilities to gain employment and live more independently (Test et al., 2009). Overall, education promotes quality of life among individuals with disabilities (Faragher & Van Ommen, 2017).

However, it seems that young people with disabilities have difficulties with finding a secondary education school and completing their secondary education. In particular, youths with intellectual disabilities are at risk of not having completed their upper secondary education (Shogren, Wehmeyer, Palmer, Rifenpark, & Little, 2015; WHO, 2011). Some studies have indicated that possible factors associated with the completion of upper secondary education may be both personal and environmental. Personal factors, such as having multiple disabilities, being a male, and possessing poor literacy skills, may be associated with problems in the completion of secondary education studies. In addition, environmental factors, such as the location of person with a disability (living in an urban or rural area), may be related to the completion of studies as well (Machalicek et al., 2010; McKissik, Diegelmann, & Parker, 2017). Nevertheless, the completion of studies among young people with disabilities involves a dynamic interaction between personal (disability) and environmental factors. Accordingly, environmental factors may facilitate or hinder young people with severe disabilities in the completion of their studies (WHO, 2007). One of those environmental factors is educational resources for young people with multiple disabilities. The concept of multiple disabilities refers to individuals who have more than one disability. It has been demonstrated that educational resources are not sufficient to meet the needs among this group. This hinders these youths' opportunities to complete their upper secondary education (Nganji & Brayshaw, 2017; Osgood, Foster, & Courtney, 2010). Multiple disabilities and educational services and resources are closely interconnected in determining the opportunities for these young people to complete their upper secondary studies.

Another factor which is related to the educational services for young people with severe physical and multiple disabilities is the location of the educational settings. There seems to be a lack of educational possibilities for young people with severe physical and multiple disabilities particularly in rural areas (McKissik, Diegelmann, & Parker, 2017; Pennington, Horn, & Berrong, 2009) which may be associated with not completing upper secondary education. Stanley and Lynn (2015) and Tait and Hussain (2016) have indicated that there is usually a greater range of educational services available in larger cities, whereas in small towns and rural areas such services are less developed and less likely to be offered. However, it has been shown that education leads to better psychological and environmental qualities of life (Addabbo, Sarti, & Sciulli, 2016; Winters, 2011). Educated persons with disabilities have better opportunities to gain employment, live in better environments, and acquire interpersonal skills (Addabbo, Sarti, & Sciulli, 2016; Nasir & Efendi, 2016; Ross & Van Willigen, 1997; Singal, Mahama Salifu, Iddrisu, Casely-Hayford, & Lundebye, 2015). Thus, their social and financial situations may be better when they are educated. Overall, education may promote better quality of life among persons with disabilities (Albrecht & Devlieger, 1999; Faragher & Van-Ommen, 2017; Ferrer-i-Carbonell, 2005). However, it seems that the social situation of persons with disabilities has not improved in Finland in accordance with their increased educational attainment (Kauppila, Niemi, & Mietola, 2018).

The comprehensive education provides education for all children in Finland. However, pupils with severe physical and intellectual disabilities are usually provided full-time special education in the special education class or special school (Takala, 2016). This means that these pupils have partly individualized or fully individualized curricula. After comprehensive education, all pupils with or without disabilities can continue to upper secondary education which is divided to vocational upper secondary education and general upper secondary education. This means that during their transition period to adulthood, young people transition from one educational setting to another. Usually at this point, young people complete school (Silva, 2012). In Finland, young people have the possibility to attend secondary education before transitioning to adulthood (Ministry of Education and Culture, n.d.).

Secondary education is important in shaping young people's further lives in the Nordic countries (Olofsson & Wadensjö, 2012, 6). Among other things, the completion of upper secondary education enhances the opportunities of young people to achieve employment and shape their career trajectories. Failure to complete upper secondary education may significantly increase unemployment and labor market exclusion, with serious societal and individual implications (Helgoy, Homme, Lundahl, & Rönnberg, 2019). For young people with disabilities, education may empower them, promote their societal inclusion (Faragher & Van Ommen, 2017; Peairson, Haynes, Johnson, Bergquist, & Krinhop, 2014), and provide opportunities to form social relationships (2011). Furthermore, a higher education level may assist persons with disabilities to understand their rights, get respect from others, find better work, and develop interpersonal skills (Nasir & Efendi, 2016; Singal, Salifu, Iddrisu, Casely-Hayford, & Lundebye, 2015).

However, students with severe physical and intellectual disabilities may have considerable difficulties to attend to general upper secondary education due to limited or non-existing special education arrangements in these educational institutions (Finnish Disability Forum, 2020). One possibility for these students is to apply to Preparatory education for work and independent living (Työhön ja itsenäiseen elämään valmentava koulutus, TELMA) which prepares students for vocational upper secondary education (Finnish Disability Forum, 2020). Another possibility is to apply to Preparatory education for vocational education (Ammatilliseen koulutukseen valmentava koulutus, VALMA) (Finnish Parliament, 7.3.2022). Both educations do not provide any degree for the students (Finnish Parliament, 7.3.2022; National Board of Education, n. d.). But it seems that students with severe physical and intellectual disabilities become segregated and marginalized within the educational system (Ministry of Education and Culture, n.d). One manifestation of segregation is that they do not attend to upper secondary education as often as those without disabilities (Hakala, 2018; Kirjavainen, Pulkkinen, & Jahnukainen, 2016, 14). When these pupils transition from primary to secondary education, there are not many educational opportunities for them in Finland (Hermanoff, Määttä, & Uusiautti, 2017). The few educational institutions for young people with severe physical and intellectual disabilities are concentrated in large cities in Finland, while secondary educational institutions are lacking in small towns or rural areas (Hermanoff, Määttä, & Uusiautti, 2017; Äikäs, 2012).

However, despite the increased educational attainment, the societal outcomes of individuals with disabilities remain lower than those of persons without disabilities (Kauppila, Mietola, & Niemi, 2018). For example, in Finland the socioeconomic situation of persons with disabilities has not improved (Sjöblom, 2016). Moreover, the employment rate of persons with disabilities is lower than among the general population in Finland. The employment rate of this group remains at 15–20% (Ekholm & Teittinen, 2014; Vesala, Klem, & Ahlstén, 2015). After all, education can improve the quality of life of persons with disabilities (Albrecht & Devlieger, 1999, Ferrer-i-Carbonell, 2005; Grabowska, Antczak, Zwierzchowski, & Panek, 2022).

2.3.3 Health care transition outcomes

In addition to educational services' impact on quality of life among young people with disabilities, other environmental factors, such as health care services, have an impact on the quality of life of this group according to the Systems Thinking

Framework (see Schalock et al., 2008). Young adults with severe physical and intellectual disabilities use various health care services, which may improve (Friedman & VanPuymbrouck, 2018) or potentially hinder their quality-of-life outcomes. Their quality-of-life outcomes may be lessened because they have unmet health care needs (Henry, Long-Bellil, Zhang, & Himmelstein, 2011) and they may be dissatisfied with the health care they receive (Arvio, Ajasto, Kiviranta, & Autti-Rämö, 2012; Zeng & Parmanto, 2004). An overall understanding of which factors cause dissatisfaction with health care services among persons with disabilities is lacking. However, studies have indicated, for example, that individuals with disabilities may be dissatisfied with their assistive devices (Benedict & Baumgardner, 2009; Henry, Long-Bellil, Zhang, & Himmelstein, 2011; Samuelsson, & Wressle, 2009), assistive devices services (Carlsson & Lundälv, 2019; Chen et al., 2011; Desideri et al., 2014; Gowran et al., 2020; Wressle & Samuelsson, 2008), and access to physician appointments (Academic Network of European Disability Experts (ANED), 2014; Bindels-de Heus, van Staa, van Vliet, Ewals, & Hilberink, 2013; European Association of Service Providers for Persons with Disabilities (EASD), 2017; Gibson & O'Connor, 2010; Lawthers, Pransky, Peterson, & Himmelstein, 2003; Oulton et al., 2016; Story, Schwier, & Isaacson, 2009; Yee & Breslin, 2010). In addition, persons with disabilities may be dissatisfied with physicians' knowledge and skills regarding their care (Kirschner & Curry, 2009; Minihan et al., 2011; Nishikawa, Daaleman, & Nageswaran, 2011; Shakespeare, Iezzoni, & Groce, 2009; WHO, 2011), and rehabilitative services (Lotstein, Inkelas, Hays, Halfon, Neal, & Brook, 2008; Majnemer et al., 2012; Mlenzana, Frantz, Rhoda, & Eide, 2013; Sixsmith, Callender, Hobbs, Corr, & Huber, 2014; WHO, 2011). Therefore, involving young adults with severe physical and intellectual disabilities by providing them an opportunity to express their opinions regarding their dissatisfaction with health care services can be used as a basis for quality improvement in the health care services (see Schalock et al., 2008). When a young adult with severe physical and intellectual disabilities is satisfied with her/his health care services, it can have a positive impact on their quality of life and personal outcomes (Schalock et al., 2008).

After their transition to adulthood, young adults with severe physical and intellectual disabilities are served by multiple public service systems in Finland. Among others, these service systems include upper secondary education services and primary health care services. As a result, young adults with severe physical and intellectual disabilities have experienced an educational transition from comprehensive to upper secondary education and health care transition from child to adult primary health care. Both services may affect the quality of life among young adults with severe physical and intellectual disabilities (Perrin, 2012; Van Loon, Claes, Vandevelde, Van Hove, & Schalock, 2010). Furthermore, these services enable young adults to function in their everyday lives. Therefore, developing services and practices of personnel working in the field is important in efforts to improve the quality of life among young people with disabilities (Brown 2007; Brown 2012, 79). Health care, education and social services have an essential role when young people with severe physical and intellectual disabilities are transitioning from child services to adult services (Stewart, 2009). Brown (2012) states that young people would need the right, appropriate and individualized services that address their special, individual, and complex needs. However, the current services are not responding to special needs and requirements of these individuals (Brown, 2012; McColl, Jarzynowska, & Shortt, 2010; Oulton et al., 2016; Särkikangas, 2020; Äikäs, 2012). For this reason, a feedback model would be important to effectively improve services. A feedback model implies that services can be measured, assessed, and modified to meet the needs of young adults with severe physical disabilities (Brown, 2012, 80).

Health care services are very important for young adults with severe physical and intellectual disabilities. In Finland, these young adults use the same health care services as other citizens. Municipalities are responsible for arranging health care services, which are divided into two types: primary health care and specialized medical care (Ministry of Social Affairs and Health, 2019). Young adults with severe physical and intellectual disabilities require primary health care services; in addition, they need diverse specialized health care services (National Academies of Sciences, Engineering, and Medicine Division, 2018, 91). Moreover, young adults with severe physical and intellectual disabilities transition from child to adult health care services. At this point, it has been suggested that the health care services are not prepared to manage the complex and long-term health care needs of young adults with severe physical and intellectual disabilities (Colver et al., 2018). However, these young people have a reliance on health care services as some of them need a range of such services daily and others need them regularly. Thus, health care services are crucial for them.

In general, persons with disabilities experience various problems and barriers with health care services. They may encounter inadequate care, lack of knowledge about their disability and associated conditions, and difficulties with communication (Chan et al., 2008; Iezzoni et al., 2003; Lin et al., 2010; Nocon & Sayce, 2008; Shin & Moon, 2008). As regards young adults with severe physical and intellectual disabilities, challenges and barriers with health care services are endangering their health and quality of life (Cheak-Samora & Thullen, 2017, 37; Rosenbaum & Ronen, 2013, 371–374). These young people are transitioning from child health care to adult health care services while they may be encountering problems with their health (Colver et al., 2018; Coyne, Hallowell, & Thompson, 2016; Gorter et al., 2011; Merrick et al., 2015; Poppen et al., 2016). To meet the health care needs of young adults with severe physical and intellectual disabilities during their transition from child to adult health care services requires knowledge and skills from doctors and other health care professionals (Kirschner & Curry 2009; Minihan et al., 2011; Shakespeare et al., 2009), as well as coordinated and individualized health care services (Parish, Roderick, Andrew, & Shattuck, 2009; Särkikangas, 2020, 196–203; Zhou, Roberts, Dhaliwal, & Della, 2016).

In particular, it has been suggested that tailoring or individualizing health care services could improve them to better meet the needs of users (Nocon & Sayce, 2008; Radwin & Alster, 2002; Schalock, Gardner, & Bradley, 2007; Suhonen, Leino-Kilpi, & Välimäki, 2005) and possibly decrease or overcome the physical, communication, attitudinal, financial, administrative, and organizational barriers (Lawthers et al., 2003; Lin et al., 2010; Petry, Maes, & Vlaskamp, 2009) that persons with disabilities face in health care settings. Removing barriers and providing needed health care services to young people with disabilities improves their satisfaction with health care services and overall quality of life (Friedman & VanPuymbrouck, 2018).

Given that the need for and reliance on health care services is high, patient or user dissatisfaction with these services should be measured. User perceptions and experiences about health care services provide essential information for service providers. Identifying factors associated with dissatisfaction with health care services provides useful information to develop the quality of health care services (Fadyl, McPherson, & Kayes, 2010, 87—88) for persons whose health-related quality of life may depend on those services. However, obtaining valid and reliable responses from individuals with intellectual disabilities may be difficult. Due to cognitive and communication difficulties, the wording of the questions should be carefully planned, bearing in mind that answering complex or abstract questions may be challenging (Finlay & Lyons, 2002; Rapley & Antaki, 1996). In addition, the service systems may restrict persons with intellectual disabilities from developing autonomy because these individuals are dependent on other people who meet their needs. Consequently, persons with intellectual disabilities may be compliant (Biklen & Moseley, 1998) and provide answers which please persons in positions of authority when they are asked for their opinions about services (Lotan & Ells, 2010).

Despite the challenges in asking persons with intellectual disabilities about their experiences regarding their health care services, collecting information about their health care experiences is a part of person-cantered service delivery (Stancliffe, Emerson, & Lakin, 2004). Moreover, persons with intellectual disabilities who receive health care services have the right to express their opinions about the services delivered to them. This information is important when developing, planning, and implementing health care services for persons with disabilities (Lotan & Ells, 2010). To improve the quality of health care services provided to young adults with severe physical and intellectual disabilities, it is important to collect information on the issues with which these young people are dissatisfied.

Previous research has shown that there are at least five factors which may be associated with dissatisfaction with health care services among young adults with severe physical and intellectual disabilities. These are dissatisfaction with: the assistive devices situation (Ajasto et al., 2012; Henry et al., 2011), assistive devices services (Terveyskylä.fi 2018), access to a physician's appointment (WHO 2011, 57-65), physicians' expertise regarding the youth's disability (Shakespeare et al., 2009, 1815; WHO, 2011, 77–78), and rehabilitative services (Crossley, 2015;

European Commission, 2019; Finlex, 2007; Social Insurance Institution of Finland, 2019). By improving these health care-related services at the organization level, satisfaction with health care services could increase and lead to better quality of life among young people with severe physical and intellectual disabilities.

Another important transition is the transition from child to adult health care services for young people with severe physical and intellectual disabilities. All Finnish citizens –including young people with severe physical and intellectual disabilities - have the possibility to use public primary health care (organized by municipalities, see Ministry of Social Affairs and Health, n.d.) as well as specialized medical services (Ministry of Social Affairs and Health, n.d.). Moreover, paediatric neurology clinics provide children with neurological conditions multiprofessional and regular follow-up appointments usually until the child reaches the age of 16 (Arvio, Ajasto, Kiviranta, Autti-Rämö, 2012; Craiu et al., 2020; Rosqvist, Harri-Lehtonen, Airaksinen, Ylinen, & Kallinen, 2009; Sillanpää, Saarinen, & Lähdesmäki, 2020). Thus, young people with severe physical and intellectual disabilities experience health care transition from child to adult health care usually at the age of 16 in Finland. After this health care transition, there are not any regular or multiprofessional follow-up appointments since these young people use the same primary health care and specialized medical services as other Finnish people (Arvio et al., 2012; Ministry of Social Affairs and Health, n.d.). There are different health and social care services for persons with disabilities (see Nurmi-Koikkalainen et al., 2020). However, these services may be uncoordinated (see Särkikangas, 2020) and complicated. Furthermore, since young people with severe physical and intellectual disabilities have complex health care needs, they would need multiprofessional follow-up appointments after their childhood as well (Cornec et al., 2022). Thus, it seems that there is a lack of continuity of care for young people with neurological conditions in Finland.

After the transition to adult health care, young adults with severe physical and intellectual disabilities may confront obstacles since they must contend with considerable changes in the care they require and the way it is delivered (Campbell et al., 2016). These barriers include, for example, a lack of and unmet needs regarding assistive devices (Ajasto, Arvio, & Arvio, 2012; Benedict & Baumgardner, 2009; Henry, Long-Bellil, Zhang, & Himmelstein, 2011), problems accessing health care services (Krahn, Klein, Walker, & Correa-De-Araujo, 2015), and a lack of physicians who understand the complex health care needs of young people with severe physical and intellectual disabilities (Kirschner & Curry, 2009; Minihan et al., 2011; Nishikawa, Daaleman, & Nageswaran, 2011; Shakespeare, Iezzoni, & Groce, 2009; WHO, 2011).

Young people with disabilities usually have functional limitations, use high rates of health care services and rehabilitative and social services, and consider their health as poor (Crowley, Wolfe, Lock, & McKee, 2011; Dejong, Palsbo, Beatty, Jones, Knoll, & Neri, 2002; Joly, 2015). Transitioning from pediatric to adult health care is recognized to be a phase of increasing healthcare costs, poor clinical results, and unmet health care needs (Solanke, Colver, & McConachie, 2018). Expenses are incurred because of visits to emergency care, intensive care admissions, and hospitalizations (Baines, 2009; British Columbia Medical Association, 2012; Crowley, Wolfe, Lock, & McKee, 2011; Goodman, Hall, Levin, Watson, Williams, Shah, & Slonim, 2011). Health care services fail to meet the needs of young individuals with disabilities who have transitioned from child to adult health care services (Pearson, Watson, Gangneux, & Norberg, 2021). This significant health care transition failure may result in a worsening of health, which can have long-term negative repercussions (Campbell et al., 2016) in young peoples' adulthood. Transitioning from child to adult health care services can result in deterioration of health and a decrease in quality of life for young people with disabilities (Gorter et al., 2021). Thus, it would be important to plan for and implement health care services transition in a coordinated, holistic, and continuing way (Brown, Macarthur, Higgins, & Chouliara, 2018; Särkikangas, 2020; Solanke, Colver, & McConachie, 2018). After the transition to adult healthcare, it could be useful to study the user dissatisfaction with health care services (Lee, Moriarty, Borgstrom, & Horwitz, 2010; Tomkins, Siyambalapitiya, & Worrall, 2013). The factors causing dissatisfaction may be perceived as supports needs assessment: the health care organization (organizational level assessment) assesses experiences of adult health care at the individual level. Moreover, when the health care organization collects information about the personal outcomes in the subjective quality of life domains (physical, psychological, social, environmental), this information can be used to guide organizational change and improvement in the health care services. Thus, the health care organization can receive information about what kind of support young adults with severe physical and intellectual disabilities need in the adult health care. This is important because these young people may experience health deterioration, functional capacity impairment, and unmet health care needs (Arvio et al., 2012; Campbell et al., 2016; Menezes, Robinson, Harkins, Sadikova, & Mazurek, 2021; Solanke, Colver, & McConachie, 2018). Given that these young peoples' quality of life is deteriorating (Arvio et al., 2012; Campbell et al., 2016; Gorter et al., 2021; Perrin, 2012), it is essential to better understand their experiences with health care as well as their subjective perceptions of the domains of quality of life (physical, psychological, social, environmental). To meet the health care needs of young adults with severe physical and intellectual disabilities, the information on the topics can be used to guide quality improvement and organizational change in the delivery of health care services.

However, it seems that at least in 2015 there were no health care transition policies or research in action in Finland (Hepburn, Cohen, Bhawra, Weiser, Hayeems, & Guttmann, 2015). Considering earlier studies regarding the transition from child to adult health care, some findings are presented. First, it would be beneficial to educate the health care professionals to implement an appropriate transition to meet the complex health care needs of young adults with severe physical disabilities (Stewart, 2009). Second, as Bolger, Vargus-Adams, and McMahon (2017) suggest, establishing an interdisciplinary clinic in adult health care facilities could be a possible solution to transitional difficulties among young adults with severe disabilities.

3 AIM OF STUDY AND RESEARCH QUESTIONS

The main aim of this PhD dissertation was to develop a quality of life feedback implementation model for upper secondary education and public health care organizations using the quality of life and systems thinking frameworks to enhance quality of life outcomes for young adults with severe physical disabilities. To that end, three independent research studies were conducted. Study I (Heräjärvi, Leskinen, Pirttimaa, & Jokinen, 2020) explored the subjective quality of life among youth with severe physical disabilities and determined the predictive factors for the subjective QoL. Study II (Heräjärvi, Leskinen, Pirttimaa, Jokinen, & Arvio, 2020) aimed at identifying the factors that are associated with completion of upper secondary education among young adults with severe physical and multiple disabilities. In addition, the purpose of this study was to determine which factors predict the completion of upper secondary education of these young adults. Study III (Heräjärvi, Leskinen, Pirttimaa, Virtanen, & Jokinen, 2023) aimed to identify the factors associated with negative public health care experiences of young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland. The main empirical research questions of this PhD dissertation were:

1. What kind of subjective quality of life do youth with severe physical disabilities have once they have transitioned to adulthood in Finland (Study I)?
2. Which are the predictors of completion of upper secondary education among young adults with severe physical and multiple disabilities in Finland (Study II)?
3. How do young adults with severe physical disabilities with or without a co-occurring intellectual disability experience adult health care services in Finland? Are there any factors that are associated with a negative experience with adult health care services among these young adults? (Study III)?

The PhD dissertation consisted of three original studies. The first research question was addressed in Study I. The second research question was addressed in Study II. Study III addressed the third research question.

4 METHODOLOGY

4.1 Procedure

The studies of this PhD dissertation are part of a larger research project initiated by five child neurology clinics in Finland and the Social Insurance Institution of Finland in 2010. Those organizations started a study called “Vaikeasti liikuntavammaisten nuorten elämäntilanne ja palvelujärjestelmien toimivuus Suomessa” (Severely Disabled Youths' Life Situation and the Functioning of Service Systems in Finland) (Arvio, Ajasto, Kiviranta, & Autti-Rämö, 2012). The project aimed to assess the life situation of young people with severe physical disabilities as well as the services provided for them. A further objective was to explore the subjective quality of life of young people with severe physical disabilities after their transition from child to primary (adult) health care. The project obtained research permits from the Ethical Committee of the Päijät-Häme Joint Authority for Health and Wellbeing in Lahti, Finland. Participants with their proxies (parents, caregivers, personal assistants) were contacted via letters of invitation accompanied by consent forms.

4.2 Participants

All participants (*N* = 74) had a severe physical disability, and they were former patients of five neurological clinics in Finland. Of the participants, 39 (53%) had a physical and an intellectual disability. They were recruited by purposeful sampling by Päijät-Häme Central Hospital's Department of Child Neurology. Participants ranged in age between 19 and 22 years (*M* = 20.2, SD = 1.16). Thirty-two (43.2%) were female and 42 (56.8%) were male. Sixty-one (82.4%) of the participants had another disability in addition to severe physical disability. The most common additional disabilities included speech disability and visual disability. Thirty-nine (52.7%) subjects had a severe physical disability with co-occurring intellectual disability. The respondents had mild to moderate intellectual disability according to the parents, carers, or personal assistants. The inclusion criteria of the study were that participants had to be at least 16 years old (thus, facing major life transitions) and classified by the Gross Motor Function Classification System Expanded and Revised (GMFCS—E & R) as belonging to level IV or level V. Persons in level IV use wheeled mobility in most settings. In level V, a manual wheelchair is needed to transport individuals in all settings (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). Individuals belonging to these levels are considered to have a severe physical disability. Descriptive information about the participants is presented in Table 3.

Table 3. Description of Participants

Variable	*n*	%
Age		
19	30	28.30
20	14	21.70
21	15	25.00
22	15	25.00
Gender		
Female	32	43.20
Male Impairment	42	56.80
Severe physical disability	74	100.00
Severe physical disability with co-occurring intellectual disability	39	52.70
Cerebral palsy	47	63.51
Speech disability	31	41.89
Visual disability	24	32.43
Other (e.g. visual processing disorder, learning disability)	21	28.35
Education		
Mainstream education (completely individualized)	52	70.27
Mainstream education (partly individualized)	7	27.03
Mainstream education (at comprehensive school)	13	17.57
Preparatory education	17	22.97
Special vocational school	20	27.03
Vocational school	8	10.81
Other (e.g. folk high school, special folk high school, upper secondary school)	18	24.32
Occupational status		
Disability pension	35	47.30
Daytime activity center	29	39.19
Other	10	13.51
Housing situation		
Home with parents	36	48.65
Nursing home	13	17.57
Residential care	12	16.22
Home with parents and respite care	7	9.46
Other	6	8.11

Note. Reprinted from “Subjective quality of life among youth with severe physical disabilities during the transition to adulthood in Finland.”, by N. Heräjärvi, M. Leskinen, R. Pirttimaa, and K. Jokinen, 2020, *Disability and Rehabilitation, 42*(7), p. 2. (https://www-tandfonline-com.ezproxy.jyu.fi/doi/full/10.1080/09638288.2018.1511756). Copyright 2018 by Taylor & Francis. Reprinted with permission.

4.3 Instruments

The WHO Quality of Life brief scale (WHOQOL-BREF) was used to gather data about the study participants' subjective quality of life. For this purpose, Päijät-Häme Central Hospital's Department of Child Neurology translated the WHOQOL-BREF instrument into Finnish. The WHOQOL-BREF is a cross-culturally valid and multidimensional international instrument for assessing personal outcomes of quality of life in 26 aspects of life. All 26 items are rated on a five-point (from 1 to 5) Likert interval response scale. Even though WHOQOL-BREF is based on the WHO's definition of quality of life as “the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (The WHOQOL Group, 1995, 1405), there are no specific questions about an individual's goals and expectations. Rather, the questionnaire includes questions about the individual's current life situation and environment. Higher scores in each quality of life domain indicate a better quality of life (WHO, 1997). Following that, examples of all response option scales are provided. An example of one item in physical quality of life domain is: “To what extent do you feel that physical pain prevents you from doing what you need to do?” The respondents rated this item (1) not at all, (2) a small amount, (3) a moderate amount, (4) a great deal, (5) an extreme amount. One item example from the psychological quality of life is: “How well are you able to concentrate?”, to which the participants answered as follows: (1) not at all (2) slightly (3) moderately (4), very, (5) extremely. Another item example from the psychological quality of life is: “How often do you have negative feelings such as blue mood, despair, anxiety or depression?” The participants rated this item (1) never, (2) infrequently, (3) sometimes, (4) frequently, (5) always.

One item example from environmental quality of life domain is: “How satisfied are you with your access to health services?” The participants rated the item on the following answer options: (1) very dissatisfied, (2) fairly dissatisfied, (3) neither satisfied, nor dissatisfied, (4) satisfied, (5) very satisfied. Another example from environmental quality of life is: “Have you enough money to meet your needs?” The respondents rated this item on the following response options: (1) not at all, (2) slightly, (3), somewhat, (4) to a great extent, (5) completely.

Of the 26 items, the first two global quality of life items relate to global quality of life and overall health; the remaining 24 items are analyzed to produce a quality-of-life score from 0 to 100 across 4 domains: physical (7 items), psychological (6 items), social (3 items), and environmental (8 items) (WHO, 1996). According to the WHOQOL-BREF scoring manual, the domain scores were calculated by multiplying the mean score of each domain by four.

Hawthorne, Herrman, & Murphy (2006) have presented preliminary norms for the self-reported quality of life by age and gender when using WHOQOL-BREF questionnaire. The norms for persons without disabilities, for the age group 20–29 are as follows (with 95% CI). For males, the norms are: physical domain (*M* = 88.7, *SD* = 9.8, CI = 83.7–93.7), psychological domain (*M* = 74.3, *SD* = 16.8, CI = 65.7–82.9), social domain (*M* = 68.1, *SD* = 23.4., CI = 56.1–80.1), and environmental domain (*M* = 77.2, *SD* = 10.6, CI = 71.8–82.7). For females, the norms are: physical domain (*M* = 83.6, *SD* = 11.3, CI = 79.4–87.8), psychological domain (*M* = 69.7, *SD* = 17.9, CI = 63.0–76.4), social domain (*M* = 75.6, *SD* = 15.3, CI = 69.9–81.3), and environmental domain (*M* = 72.7, *SD* = 15.6, CI = 66.9–78.5). The domain norms for all are: physical (*M* = 85.4, *SD* = 10.9, CI = 82.2–88.6,), psychological (*M* = 71.4, *SD* = 17.5, CI = 66.3–76.5), social (*M* = 72.9, *SD* = 18.8, CI = 67.4–78.4), and environmental (*M* = 74.3, *SD* = 14.0, CI = 70.2–78.4). The above norms were used as reference values when comparing the domain-related quality of life scores between young adults without and with severe physical and intellectual disabilities.

In this PhD dissertation, reliability for the WHOQOL-BREF instrument was 0.85 (Cronbach's alpha), which aligns with previous studies, in which alpha values ranged between 0.70 and 0.89 (Agnihotri, Awasthi, Chandra, Singh, & Thakur, 2010; Jalayondeja, Jalayondeja, Suttiwong, Sullivan, & Nilanthi, 2016; Skevington, Dehner, Gillison, Mcgrath, & Lovell, 2014). Alpha values for the respective domains were 0.57 (physical), 0.80 (psychological), 0.44 (social), and 0.59 (environmental). The low alpha value for the physical domain may result from the absence of item 15, which relates to the respondent's mobility. The social domain’s low alpha value could be related to the domain's limited number of items (3).

The Severely Disabled Youths' Life Situation and Functioning of the Service Systems in Finland (Arvio, Ajasto, Kiviranta, & Autti-Rämö, 2012) instrument was used to collect information about the participants' education and functioning of the health services. This non-standardized and adapted (Emerson, Felce, & Stancliffe, 2012; Kooijmans, Mercera, Langdon, & Moonen, 2022) questionnaire has been developed by Finnish health care professionals who knew the participants well since they had treated the participants in the five child neurology clinics. The questionnaire contains 104 items covering six areas of life of persons with disabilities. These are: health, physical functioning, housing, studying/occupation, service systems (education, health care, and social care), and social relations. Simple and clear vocabulary was used in the questionnaire, and yes-no response scale options (Fang et al, 2011; Kooijmans, Mercera, Langdon, & Moonen, 2022) were designed to meet the needs of young adults with severe physical disabilities with a co-occurring intellectual disability. This questionnaire was piloted by two young adults with severe physical disabilities with co-occurring intellectual disabilities. For the purposes of the first study of this PhD dissertation, the intensity of pain item from the health section was assessed on a 10-point numerical Visual Analogue Scale, where 0 indicates no pain and 10 indicates unbearable pain (Boonstra, Schiphorst Preuper, Balk, & Stewart, 2014; Kooijmans, Mercera, Langdon, & Moonen, 2022).

4.4 Data collection

Between 2010 and 2012, two researchers from Päijät-Häme Central Hospital collected data from 74 participants at home using a cross-sectional design. Data collection at home provided participants with a familiar, distraction-free environment as well as enough time to answer questions in a conversational style (Kooijmans, Mercera, Langdon, & Moonen, 2022) because visits lasted between 1.5 and 6 hours. The two researchers (who had been caring young people in Finnish child neurology clinics) collected data from 60 young individuals and the author of this PhD dissertation collected the data from 14 young persons. This PhD dissertation's author was a researcher in a larger project called "Vaikeasti liikuntavammaisten nuorten elämäntilanne ja palvelujärjestelmien toimivuus Suomessa" (Severely Disabled Youths' Life Situation and the Functioning of Service Systems in Finland) and collected data from 14 participants for this PhD dissertation as a part of this larger project. Most of the data (from 60 participants) was collected by two researchers from Päijät-Häme Central Hospital, and the author was granted permission to use that data in her PhD dissertation. From 2010 to 2023 the author of this PhD dissertation worked thirteen different full-time jobs while working on this PhD dissertation. As a result, the publication process has taken a long time after the data collection.

If necessary, parents, carers, or personal assistants facilitated (Holt et al., 2018) young adults with severe physical disabilities with a co-occurring intellectual disability in answering the questions in the two paper questionnaires. However, all responses came straight from the young adults. When assisting participants with intellectual disabilities in understanding the questions, proxies used picture communication symbols (PCS) (Boardmaker, 2022) to make the survey accessible (Frankena et al., 2019). Proxies also used the PCS symbols to assist the participants with visual, speech or other disabilities (e. g., visual processing disorder, learning disability) answer the questions. The participants had used PCS symbols in their daily lives and thus understood their meaning. Furthermore, the researcher frequently checked to see if the participant understood the question by requesting him or her to elaborate or clarify it (Kooijmans, Mercera, Langdon, & Boonen, 2022). Proxies also provided background information for the participants and for the interviewers because proxies had daily contact with the young adult and were aware of their situation and needs. When the proxy's opinion and the participant's response differed, the participant's response took priority.

4.5 Statistical analyses

4.5.1 Associations

All statistical analyses were performed using IBM's Statistical Package for the Social Sciences (SPSS) for Windows. In all studies, the data were first screened for outliers and missing values (Bennett, 2001). In some analyses, the missing values existed but they did not exceed 6 values. A significance level of $p < 0.05$ was adopted for all tests. In Study I, the Shapiro-Wilk test was used to confirm data normality. In Study I, Pearson correlation coefficient was used to measure the strength of association in continuous variables. Moreover, one- sample *t*-tests and independent samples *t*-tests were used to compare means between groups. In Studies II–III, chi-squared tests for independence and Fisher's exact tests for independence were used for analyzing associations in nominal information. In Study I, sequential multiple regression analysis was used to identify predictors. To determine predictor variables in Studies II and III, binary logistic regression analyses were used. This section describes the statistical analyses in two categories. First, I will present the analyses that sought to identify associations and to compare the means of groups. Second, I will present the predictive analyses. Table 4 provides a summary of the variables and methods used in Studies I–III.

Table 4. Summary of Variables and Methods Used in Studies I—III

		Study I	Study II	Study III
Statistical methods		One-sample *t*-tests	Chi-squared tests for independence	Fisher's exact tests for independence
	Variables			
	IV	Males with and without severe physical disabilities, females with and without severe physical disabilities	Disability type, gender, location, literacy skills	Negative experience with 1. need for assistive devices, 2. need for assistive device repair/maintenance, 3. ease of obtaining a physician's appointment, 4. physicians' disability skills and knowledge, 5. need for rehabilitative services
	DV	Physical, psychological, social, environmental QOL	Completion of upper secondary education	Negative experience with health care
Statistical methods		Independent samples *t*-tests	Binary logistic regression	Binary logistic regression
	IV	Males with severe physical disabilities, females with severe physical disabilities	Location, literacy skills	Negative experience with 1. need for assistive devices, 2. need for assistive device repair/maintenance, 3. ease of obtaining a physician's appointment, 4. physician's disability skills and knowledge, 5. need for rehabilitative services. The 6th independent variable in the 1st binary regression analysis was intellectual disability.
	DV	Physical, psychological, social, environmental QOL	Completion of upper secondary education	Negative experience with health care
Statistical methods		Sequential multiple linear regression		
	IV	Age, gender, intensity of pain		
	DV	Physical, psychological, social, environmental QOL		

Note. QOL=quality of life ; IV= independent variable ; DV=dependent variable

In Study I, the Pearson correlation coefficient was used to measure the strength of association between age, gender, intensity of pain, and quality of life domains (physical, psychological, social, and environmental). One-sample *t*-tests were used to examine the statistically significant mean differences between the physical, psychological, social, and environmental quality of life scores for all young people with severe physical disabilities (42 males, 32 females; $N = 74$) and all young people without severe physical disabilities. The mean quality of life scores of youth with severe physical disabilities were compared to the WHOQOL-BREF population norms (Hawthorne et al., 2006, 44–48). Independent samples *t*-tests were used to compare the quality-of-life domains' (physical, psychological, social, environmental) mean scores between male and female youth with severe physical disabilities.

In Study II, the chi-squared tests of independence were used to determine whether there was a statistically significance association between descriptive variables (disability type, gender, location, and level of reading and writing skills) and the completion of upper secondary education. A Bonferroni correction was used to adjust the P value for multiple tests.

In Study III, Fisher's exact tests for independence were used to determine whether a negative experience with any of the following five variables was significantly associated with a negative experience with health care services: the need for new assistive devices, the need for assistive devices services, the ease of obtaining a physician's appointment, the physician's disability skills and knowledge, and the need for rehabilitative services.

4.5.2 Predictive analyses

In Study I, a three-stage sequential multiple linear regression with three blocks was used to predict the subjective quality of life among youth with severe physical disabilities. The dependent variables were physical, psychological, social, and environmental qualities of life. The independent variables with significant P-values ($P < .05$) were entered in the following order. Age was entered as a control variable in block one, gender (female = 0, male = 1) was entered in block two, and intensity of pain was entered in block three. The validity of model assumptions was evaluated by using regression diagnostics.

In Study II, a binary logistic regression was performed to identify the strongest predictors and to determine to what extent they explained the outcome variable: completion of upper secondary education among young adults with severe physical and multiple disabilities. The dependent variable was the completion of upper secondary education (0 = no upper secondary education, 1 = upper secondary education). The final model contained two predictors (both with $P < .05$) that were entered as a single block into the model. The predictors were location (0 = rural, 1 = urban) and level of reading and writing skills (0 = not at all, 1 = moderate or good). Gender and disability type were not included in the logistic regression model as they were not significant predictors of completion of upper secondary education. Ensuring the regression model's validity, logistic regression assumptions were reviewed.

In Study III, three binary logistic regressions were carried out to detect the statistically significant predictors for a negative experience with health care services among young adults with severe physical disabilities with or without a co-occurring intellectual disability. The purpose of the first binary logistic regression was to determine if a negative experience with the independent variables (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician possesses disability skills and knowledge, the need for rehabilitative services, and an intellectual disability) can predict a negative experience with health care among study participants. The experience with three significant independent variables: the need for new assistive devices (0 = negative experience, 1 = positive experience), the ease of obtaining a physician's appointment (0 = negative experience, 1 = positive experience), and the physicians' disability skills and knowledge (0 = negative experience, 1 = positive experience) were measures with $P < .05$, and they were included in the binary logistic regression model to predict a negative experience with health care services among young adults with severe physical disabilities with or without a co-occurring intellectual disability ($N = 74$). The independent variables were selected from literature that indicates that persons with disabilities may be dissatisfied with these factors. Because 39 respondents reported an intellectual disability, it was determined to be an important factor to be included in the binary logistic regression even though it was not a measure with $P < .05$. The binary logistic regression model was created using experience with health care (0 = positive experience, 1 = negative experience) as the outcome variable. A negative experience with health care services (= 1) was used as a reference category. The results are presented as odds ratios (OR) and their 95% confidence intervals. According to the literature (Shakespeare et al., 2009, 1815; WHO, 2011, 77–78), physician's disability skills and knowledge (0 = negative experience, 1 = positive experience) was an important independent variable associated with a negative experience with health care.

The second binary logistic regression was conducted to examine whether a negative experience with the independent factors (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining physician's appointment, the physician possesses disability skills and knowledge, the need for rehabilitative services) can predict a negative experience with health care in young adults with severe physical disabilities without a co-occurring intellectual disability ($n = 35$). The third binary logistic regression was carried out to test whether a negative experience with the independent factors (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician possesses disability skills and knowledge, the need for rehabilitative services) could predict a negative experience with health care in young adults with severe physical disabilities with a co-occurring intellectual disability ($n = 37$). Odds ratios (OR) and their 95% confidence intervals are used to present the binary logistic regression results.

5 OVERVIEW OF ORIGINAL STUDIES

5.1 Study I

The aim of Study I was to investigate the subjective quality of life among seventy-four youth with severe physical disabilities in Finland during their transition to adulthood. The data were collected using a cross-sectional design with the WHOQOL-BREF (World Health Organization Quality of Life-Brief) instrument and a Finnish health care professionals' instrument called Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland instrument after the participants had transitioned from child to primary (adult) health care. Two researchers from Päijät-Häme Central Hospital (one of whom was the author of this PhD dissertation and the other a neurological nurse) collected data from 74 young adults with severe physical disabilities with and without co-occurring intellectual disabilities. The neurological nurse collected data from sixty respondents, whereas the author of this PhD dissertation collected data from fourteen participants. One-sample *t*-tests were conducted to identify any statistically significant differences between the physical, psychological, social, and environmental quality of life scores for all young people with severe physical disabilities and all young people without severe physical disabilities. The participants' quality of life scores were compared using one-sample *t*-tests to the preliminary quality of life population norms of young people without severe physical disabilities obtained from the Hawthorne, Herrman, and Murphy study (2006). Furthermore, males and females with severe physical disabilities were compared using independent samples *t*-tests in terms of quality of life domains. A three-stage sequential multiple regression analysis was used to determine whether age, gender, and intensity of pain could explain a significant amount of the variance for physical, psychological, social, and environmental qualities of life among youth with severe physical disabilities.

All youth with severe physical disabilities reported a significantly lower physical, psychological, social, and environmental quality of life than all youth without severe physical disabilities, as found in the previous studies (Lin et al., 2011; Torres & Vieira, 2014; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009; Moreira et al., 2013). Male youth with severe physical disabilities had lower physical, psychological, and environmental quality of life domains compared to male youth without disabilities. Females with severe physical disabilities scored lower only in the physical domain compared to those without severe physical disabilities.

Gender-related differences in physical, psychological, social, and environmental quality of life domains were not found among youth with severe physical disabilities. However, when age and intensity of pain were included in the sequential multiple linear regression analysis predicting quality of life, males with severe physical disabilities had lower psychological and social qualities of life than females with severe physical disabilities.

Age, gender, and intensity of pain were associated with and predicted quality of life among youth with severe physical disabilities. These results showed that physical quality of life among all youth with severe physical disabilities is negatively affected by intensity of pain. Moreover, the results indicate that younger youth experience worse quality of life in physical, psychological, and social quality of life domains than older youth. The environmental quality of life did not increase with age; younger respondents scored higher for environmental quality of life than older respondents. This implies that the environmental quality of life of the younger participants was better than that of the older ones. The age range of the respondents was from 19 to 22 years. The question about environmental quality of life included the items of financial resources, information and skills, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment, and transportation. One explanation for the result that younger respondents scored higher points in environmental quality of life could be that the younger participants may receive support from their family members regarding their financial situation and information about issues that the young people need in their daily lives. Family members can also help the young person with severe physical and intellectual disabilities to move around in their environment and provide opportunities to participate in recreation and leisure time. Furthermore, younger participants may receive more support from their families in accessing health and social services. On the other hand, this suggests that older youth may be dissatisfied with their financial situation if they do not have enough money to meet their needs. Moreover, the older respondents may face challenges in moving around in their residential area as well as problems with participating in recreation and leisure. They may not get enough information about the issues they need in their daily lives. Finally, they may face challenges in accessing health and social care. It is possible that after years of caring for the young people with severe physical and intellectual disabilities, the family members will no longer be able to provide as much support as they used to do.

Finally, in addition, the qualities of life in psychological and social quality of life domains did not increase when males grow older. Furthermore, increasing age did not have a positive influence on the participants' financial situation. Overall, the results indicate that these young people (aged from 19 to 22) have pain, difficulties in social participation, and loneliness, all of which have an impact on their adult quality of life (Jalayondeja, Jalayondeja, Suttiwong, Sullivan, & Nilanthi, 2016; Graf, Blankenship, & Marini, 2009; Palisano et al., 2009). In particular, young males with severe physical disabilities may be more disadvantaged in terms of social participation difficulties and loneliness compared to females with severe physical disabilities.

5.2 Study II

The purpose of this study was to investigate whether young adults with severe physical and multiple disabilities have completed upper secondary education in Finland. Specifically, it was examined whether the type of disability, gender, rural or urban location, and the level of literacy skills were associated with completion of upper secondary education among young people with severe physical and multiple disabilities. The data used in this study was the same data as in Study I. Respondents' ages ranged from 19 to 22 years, and they were expected to have attended and completed some upper secondary education, as upper secondary education in Finland usually ends when students are 18 or 19 years old. All participants ($N = 74$) had a severe physical disability but 44 of them also had another disability. Thus, they had multiple disabilities.

Chi-squared tests of independence with Bonferroni correction were employed to identify whether a significant association existed between disability type, gender, location, and level of reading and writing skills and the completion of upper secondary education. A binary logistic regression analysis was performed to identify the strongest predictors and to analyze to what extent they explained whether a participant had completed upper secondary education.

The results of this study showed that the completion of upper secondary education among young adults with severe physical and multiple disabilities was associated with disability type, the young adult's location, and the level of literacy skills. The results indicated that 66.2% (49 out of 74) had completed some kind of upper secondary education (preparatory education, special vocational school, vocational school, folk high school, special folk high school, upper secondary school) and 34% (25) had not completed any upper secondary education. Young adults with severe physical disabilities (other than cerebral palsy) and intellectual disabilities were not as likely as young adults with other types of disabilities to complete their upper secondary education. In contrast, young adults with cerebral palsy were more likely to have completed upper secondary education than those who did not. The completion of upper secondary education was not associated with gender. Young adults living in the urban areas were more likely to have completed upper secondary education than those living in the rural areas. Young adults with moderate or good reading and writing skills were more likely to have completed upper secondary education than not. Among all participants (*N* = 74), urban location and moderate or good literacy skills predicted the completion of upper secondary education.

Consequently, the results are partly consistent with earlier studies (Nganji & Brayshaw, 2017; Osgood, Foster, & Courtney, 2010), which found that the severity of the youths' problems and the lack of services provided to youths with disabilities may account for the poor educational outcomes among them. Moreover, the results (urban location was associated with completion of upper secondary education) reinforce the findings of Äikäs (2012) and Hermanoff, Määttä, and Uusiautti (2017), who found that there seems to be a lack of local educational services for young adults with intellectual disabilities and that the services available in Finland for these students do not meet their personal needs and hopes. Overall, these findings imply that young adults with severe physical and multiple disabilities in Finland have significant challenges and experience educational inequality in completing upper secondary education. Therefore, focusing on delivering evidence-based practical services and processes that address students' academic, career, and personal goals would enhance the opportunities for these young people to complete their upper secondary education (Ferretti & Eisenman, 2010). Creating a disability-aware environment and community to provide such services would promote equal participation and the human right to education for these individuals (Nganji & Brayshaw, 2017).

5.3 Study III

Study III aimed at investigating the experiences of young adults with severe physical and intellectual disabilities after their transition to adult health care services in Finland, with the goal of identifying factors associated with negative experiences with these services. Thus, the first objective was to investigate whether a negative experience with the following six independent factors — the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician possesses disability skills and knowledge, the need for rehabilitative services, and an intellectual disability — were associated with a negative experience with health care services among young adults with severe physical disabilities with or without a co-occurring intellectual disability after they had transitioned from child to adult health care services in Finland. The second objective was to explore whether a negative experience with any of the five independent factors (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician possesses disability skills and knowledge, and the need for rehabilitative services) could predict a negative experience with health care services in young adults with severe physical disabilities without a co-occurring intellectual disability (*n* = 35). The third aim was to investigate whether any of the five independent factors (the need for new assistive devices, the need for assistive device repair/maintenance, the ease of obtaining a physician's appointment, the physician possesses disability skills and knowledge, and the need for rehabilitative services) could predict a negative experience with health care services in young adults with severe physical disabilities with a co-occurring intellectual disability (*n* = 37).

Fisher's exact tests of independence revealed that a negative experience with the three independent factors - the need for new assistive devices, the ease of obtaining a physician's appointment, and the physician's disability skills and knowledge - was associated with a negative experience with health care services among all participants (*N* = 68). Furthermore, 41 participants had a negative experience with health care. Fisher's exact tests of independence showed that negative experiences with the ease of obtaining a physician's appointment, and the physician possesses disability skills and knowledge, were associated with negative experiences with health care among young adults with severe physical disabilities (without a co-occurring intellectual disability) (*n* = 32). Finally, Fisher's exact tests of independence indicated that a negative experience with the need for new assistive devices was associated with a negative experience with health care among young adults with severe physical disabilities with a co-occurring intellectual disability (*n* = 37–38).

The first binary logistic regression indicated that among young adults with– severe physical disabilities with or without a co-occurring intellectual disability (*N* = 68), that a negative experience with the following three independent factors – the need for new assistive devices situation, the ease of obtaining a physician's appointment, and the physician possesses disability skills and knowledge – predicted a negative health care experience. According to the second binary logistic regression results, a negative experience with the independent factor: physician possesses disability skills and knowledge predicted a negative experience with health care among young adults with severe physical disabilities without a co-occurring intellectual disability. The third binary logistic regression results showed that a negative experience with the need for new assistive devices predicted a negative health care experience among young adults with severe physical disabilities with a co-occurring intellectual disability.

In conclusion, findings suggest that young adults with severe physical disabilities with or without a co-occurring intellectual disability experience dissatisfaction with accessing and obtaining the health care services they need. The results conform with the perception that the Finnish health care services for persons with disabilities are uncoordinated (see Särkikangas, 2020). The findings also add to previous research indicating that individuals with disabilities have difficulties in the ease of obtaining a physician's appointment (see Academic Network of European Disability Experts, ANED, 2014; European Association of Service Providers for Persons with Disabilities, EASD, 2017). Finally, the result that young adults with severe physical disabilities with or without a co-occurring intellectual disability had a negative experience with their physicians' disability skills and knowledge was understandable since there are only 14 physicians in Finland with expertise in intellectual disability medicine (Suomen Lääkäriliitto, 2019). Therefore, it is very likely that many young adults with severe physical disabilities with or without a co-occurring intellectual disability have difficulties gaining access to a physician with this kind of expertise. In sum, these results suggest that adult health care services for young adults with severe physical disabilities with or without a co-occurring intellectual disability should be developed to be more accessible and person-centered. This could be implemented by requesting young adults with severe physical and intellectual disabilities to provide feedback about those services to be used to improve the quality of health care services (Gal, Weisberg-Yosub, Shavit, & Doron, 2010). Overall, the results of Studies I–III are summarized in Table 5, which indicates the quality of life outcomes of young adults with severe physical disabilities after their transition from childhood to young adulthood.

Table 5. Quality of Life Outcomes of Young Adults with Severe Physical Disabilities

Study	Level	Quality of Life and Domain	Transition Phase	Quality of Life Outcome
I	Individual Organization	Subjective Domains: -physical -psychological -social -environmental	After the transition from childhood to young adulthood	Low quality of life domains (personal outcomes): -physical -social -environmental Predictors of quality of life: -age -gender -pain
II	Organization System Upper secondary education	Objective Domain: -environmental	After the transition from basic education to upper secondary education	Predictors of low likelihood of completion of upper secondary education: -no literacy skills -rural residence
III	Individual Organization System Primary health care	Subjective Domain: -environmental	After the transition from child to adult primary health care	Predictors of negative experience with health care: Negative experience with -need for new assistive devices -ease of obtaining a physician's appointment -physician's possession of disability skills and knowledge

6 DISCUSSION

The main aim of this first Finnish PhD dissertation on the subject was to use systems thinking and quality of life frameworks to develop a quality of life implementation feedback model for upper secondary and health care organizations to improve quality of life, upper secondary, and health care transition outcomes for young adults with severe physical disabilities in Finland. Related to this, the first aim was to examine the subjective quality of life among young adults with severe physical disabilities in Finland after their transition to adulthood (Study I). The second objective was to investigate which are the predictors of completion of upper secondary education among young adults with severe physical and multiple disabilities in Finland (Study II). Finally, this PhD dissertation aimed to identify the factors associated with a negative health care experience of young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland (Study III). To answer these questions, the key findings were: 1) Young adults with severe physical disabilities returned lower values in physical, social, and environmental qualities of life compared to young adults without disabilities (Study I). 2) There were no gender differences in the subjective quality of life among young adults with severe physical disabilities (Study I). 3) Among young adults with severe physical disabilities, age, gender, and intensity of pain were associated with quality of life (Study I). 4) Completion of upper secondary education was associated with having a severe physical disability (other than cerebral palsy) with an intellectual disability, location, and literacy skills (Study II). 5) Young adults with severe physical and multiple disabilities who lived in urban location and had moderate or good literacy skills were more likely to complete upper secondary education than those who lived in rural location and had no literacy skills (Study II). 6) A negative experience with the following three factors— the need for new assistive devices, the ease of obtaining a physician's appointment, and the physician's possession of disability skills and knowledge—were associated and predicted a negative health care experience among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland (Study III). Next, these results are discussed in more detail.

6.1 Subjective quality of life among youth with severe physical disabilities after the transition to adulthood in Finland

Comparison of youth with and without severe physical disabilities. Supporting the findings of previous studies (Lin, Ju, Lee, Yang, & Lo, 2011; Moreira et al., 2013; Torres & Vieira, 2014; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009), the results of Study I recognized that the subjective quality of life in the physical, social, and environmental domains is lower than those of youth without severe physical disabilities (Study I). The lower scores in physical quality of life among youth with severe physical disabilities may result from the health and functional difficulties among these individuals in their transition to adulthood. These secondary conditions refer to various physical, psychological, social, and emotional problems that result from the person-environment interaction (Rimmer, Chen, & Hsieh, 2011; WHO, 2007). Moreover, lower physical quality of life was associated with the intensity of pain among youth with severe physical disabilities. In Study III, it was found that youth (with severe physical disabilities with or without a co-occurring intellectual disability) who had a negative experience with the ease of obtaining a physician’s appointment had a negative experience with their health care. An important finding was that youth had pain and the intensity of pain was associated with low subjective quality of life. Those who had pain may have had difficulty obtaining an appointment with a physician who could have helped them with treating the pain. Furthermore, the finding of Study III indicated that young adults with severe physical disabilities with or without a co-occurring intellectual disability had a negative experience with their physicians' disability skills and knowledge. Thus, this finding may indicate that the low physical quality of life was at least partially influenced by the general physician's (who may not always be the same in all appointments in the health centres in Finland) lack of skills and knowledge, because the young people used the same primary health care services as the rest of Finnish people after transitioning from child to adult health care. Thus, the regular multiprofessional follow-up appointments in the child neurology clinics had ended. Children had a physician, usually a child neurologist, who knew them and their specific disability-related requirements at their child neurology appointments. However, a general physician in primary health care may not have had some ways to help the young people with energy and fatigue, dependence on medication, assistive devices, and mobility, given that the young adults had a negative experience with their need for new assistive devices as well. All of these factors may have influenced young adults' negative experience with their physician's disability skills and knowledge.

In Study I, youth with severe physical disabilities reported lower social quality of life than those youth without disabilities. This finding may reflect that youth with severe disabilities may have restricted opportunities to form supportive social relationships. Moreover, the lower social quality of life among youth with severe physical disabilities (compared to those without disabilities) found in Study I may be related to the finding that 25 (of 74 participants) participants did not have any kind of upper secondary education (Study II). In educational settings, youth may establish social relationships with peers. Thus, those who did not have any upper secondary education may lack this kind of opportunity to form friendships. In addition to limited important personal relationships, youth with severe physical and multiple disabilities may experience a lack of practical social support (see Table 1 WHOQOL-BREF domains and sub-domains) that may be available in upper secondary education settings.

Youth with severe physical disabilities scored lower in terms of environmental quality of life compared to those youth without disabilities. The quality of life in environmental domain consists of the questions (items) about financial resources, information and skills, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment, and transportation. There are several explanations for this finding. First, young persons with severe physical disabilities may experience financial difficulties (see Hughes & Avoke, 2010); most were not receiving any income from employment, as Study I revealed. Second, the lower environmental quality of life may be related to information and the skills (subdomain of environmental quality of life; see WHO, 1996,) among participants. In the WHOQOL-BREF instrument, question 13 reads as follows: How available to you is the information you need in your day-to-day life? Related to this was Study II finding that youth who had moderate or good literacy skills were more likely to have completed upper secondary education. This may indicate that those youth who did not have moderate or good literacy skills lacked opportunities to learn and develop new skills and information (see WHO, 1996, 7). On the one hand, the school environment could provide more other means of conveying information. For example, digital solutions could be one possibility to assist persons with intellectual disabilities to understand educational texts and contents. Fajardo, Ávila, Delgado, Gómez-Merino, and Salméron (2022) suggest that video-blogs and linguistic simplifications could be used to improve abilities of reading comprehension among students with intellectual disabilities. Furthermore, teaching functional digital literacy skills could help students with intellectual disabilities. These skills include emailing, saving, and accessing bookmarked pages, and cloud storaging (Cihak, Wright, McMahon, Smith, & Kraiss, 2015). On the other hand, literacy skills are important in society; the information needed in our daily lives is usually written in text format. Therefore, upper secondary education institutions should aim to provide young people with severe physical and intellectual disabilities multiple literacy skills that will help these people to cope their studies and everyday live. The low level of environmental quality of life can be explained by Study III results which showed that young adults with severe physical and intellectual disabilities had a negative experience with their assistive devices situation. They may not have provided information related to assistive devices (question 13). De Camargo (2011) also showed that information about services and support for young people with severe physical disabilities is not adequately provided.

Third, the lower environmental quality of life (compared to youth without disabilities) can be explained by the Study II finding: youth with severe physical disabilities who lived in urban areas in Finland were more likely to have completed their upper secondary education than those living in rural areas in Finland. In Finland, most educational opportunities for youth with severe physical disabilities exist in larger cities. Fourth, the participants' environmental quality of life may be lower due to challenges and barriers in enjoying leisure time activities and obstacles in the built environment (Powrie, Kolehmainen, Turpin, Ziviani, & Copley, 2015) since many buildings are not yet accessible in Finland. Overall, the accessibility of leisure time activities may be poor (Powrie, Copley, Turpin, Ziviani, & Kolehmainen, 2020), which excludes individuals with disabilities from participation in some activities (Finnish Disability Forum, 2019). Furthermore, the lack of personal assistants, interpreters, transportation, and support from public sector impede young people with disabilities to participate in leisure time activities in Finland (Armila, Rannikko, & Torvinen, 2018). This type of exclusion reduces the well-being of young people with disabilities as well as fosters a sense of social otherness in them (Armila, 2016; Armila, Rannikko, & Torvinen, 2018). Participation in leisure activities would promote quality of life and it is important in terms of inclusion in the community and society (Badia, Orgaz, Verdugo, Ullán, & Martínez, 2011). Fifth, the lower environmental quality of life can be explained by difficulties in access to health care and social services in Finland (Academic Network of European Disability Experts (ANED), 2014; Bindels-de Heus et al., 2013; European Association of Service Providers for Persons with Disabilities (EASD), 2017; Gibson & O´Connor, 2010; Gorter et al., 2021; Oulton et al., 2016; Solanke, Colver, & McConachie, 2018; Yee & Breslin, 2010). This finding may be related to the Study III findings that participants had a negative experience with the ease of obtaining a physician's appointment and the need of new assistive devices. Assistive devices would enable these young people to access to their environments. Furthermore, appropriate assistive devices would mitigate the functional limitations that often restrict employment and income from employment among young people with physical disabilities (She & Livermore, 2009). In sum, all these difficulties may lower the environmental quality of life among youth with severe physical disabilities with or without a co-occurring intellectual disability compared to young people without disabilities.

Gender differences among youth with and without severe physical disabilities. According to the results of Study I, there were some gender-related differences in qualities of life between youth with and without severe physical disabilities. The findings showed that compared to youth without disabilities, male youth with severe physical disabilities had a lower quality of life in three quality of life domains: physical, psychological, and environmental. On the other hand, female youth with severe physical disabilities scored lower than females without severe physical disabilities in one quality of life domain: physical. When compared to youth without severe physical disabilities, it appears that the quality of life of males with severe physical disabilities is more widely negatively influenced than the quality of life of females with severe physical disabilities.

Several possible explanations can be provided considering the low physical, psychological, and environmental quality of life among males with severe physical disabilities. For instance, it is possible that young males with disabilities would like to participate more in physical activities, but their severe physical disability restricts their opportunities to participate in those activities (Maher, Williams, Olds, & Lane, 2007). This, in turn, may negatively affect the physical, psychological, and environmental qualities of life of those males.

Although it has not been fully proven, the lower psychological quality of life among youth with severe physical disabilities compared to those without disabilities may result from the threat to males' self-esteem in the context where males perceive devaluation toward themselves (Brown, 2014). Males with physical disabilities may also have low body esteem. In particular, it has been suggested that males with physical disabilities devalue their legs (Taleporos & McCabe, 2005). Negative body esteem may be increased by negative stigma and attitudes associated with having a disability (Gorter, 2009; Reel, & Bucciere, 2010). All these issues may negatively affect the psychological quality of life of males with physical disabilities. Among young males with severe physical disabilities, physical, psychological, and environmental qualities of life may be interconnected, but this possible association warrants further investigation.

Females with and without disabilities. Comparison between females with and without severe physical disabilities showed that only physical quality of life was lower among females with severe physical disabilities. As physical quality of life mainly relates to health, this finding could be consistent with prior research indicating poorer health among young girls in the general population (Cavallo et al., 2006). Surprisingly, no differences were found in psychological, social, and environmental qualities of life between females with and without severe physical disabilities. This outcome is contrary to that of Tarsuslu and Livanelioglu (2010), who found that all quality-of-life domains among females with physical disabilities are lower compared to young female adults without physical disabilities. In terms of the psychological quality of life, negative attitudes toward females with severe physical disabilities could have less impact than for males with severe physical disabilities (Kostanjsek et al., 2013). This could explain the finding that there were no differences in psychological quality of life between females with and without severe physical disabilities.

There were no differences in social quality of life between females with and without severe physical disabilities. A possible explanation for this could be that females with severe physical disabilities may have some social networks that offer them support (Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011). This support may have a positive impact on their social quality of life. The environmental quality of life did not differ between females with and without severe physical disabilities. Recalling that males with severe physical disabilities had a lower environmental quality of life compared to males without disabilities, it is difficult to explain the absence of differences in environmental quality of life between female youth with and without severe physical disabilities. However, it might be that females participate more in leisure-time activities than their male counterparts, which may enhance their environmental quality of life. In addition, females with severe physical disabilities may have a support person who is able to bring them to those activities (Tonkin, Ogilvie, Greenwood, Law, & Anaby, 2014).

Gender differences between youth with severe physical disabilities. The absence of differences in quality of life and quality of life domains by gender among youth with severe physical disabilities aligns with earlier studies. However, earlier studies have identified such differences. Yet, when age and intensity of pain were included in the sequential multiple regression analysis, weak gender differences emerged. These differences suggested that males with severe physical disabilities scored lower in terms of the psychological and social qualities of life than females with severe physical disabilities. In addition, an important finding was that when males grow older, their psychological and social qualities of life do not increase. It is worth bearing in mind that gender may have reached statistical significance in other quality of life domains if more background information about the participants had been included in the analysis. In Study I, the association of gender with quality of life became stronger when included with age. However, one possible explanation for almost nonexistent gender differences relates to Finnish society's fundamental commitment to gender equality and the nonexistence of gender discrimination in institutions, services, and decision-making (Ministry of Social Affairs and Health, 2020). There were no gender-differences in upper secondary education completion among young adults with severe physical and multiple disabilities in Study II. Thus, regardless of gender, students in Finland have equal opportunities to receive education in Finnish educational institutions (Ministry of Social Affairs and Health, 2017).

Age, gender, and pain. According to the results of sequential multiple regression analysis, age, gender, and intensity of pain explained the variability of subjective quality of life among all 74 participants. Thus, age, gender, and intensity of pain together explained 26% of physical, 19% of psychological, 22% of social, and 13% of environmental quality of life among youth with severe physical disabilities. In all quality-of-life domains, intensity of pain was the most important predictor. Rimmer, Chen, and Hsieh (2011) also found that people with disabilities experienced pain that affects their physical and environmental qualities of life and represents a significant barrier to functioning and participation. The findings of Study I indicated that pain contributed negatively to subjective quality of life in a holistic way, as it also influences psychological and social qualities of life. The finding that age was moderately associated with physical, psychological, and social quality of life, but not with environmental quality of life, suggests that the older the youth, the higher their quality of life.

This conflicts with earlier studies showing that quality of life decreases with age, and that youth entering adulthood report lower subjective quality of life than adolescents (Torres & Vieira, 2014). One possible explanation is that the older youth were more adjusted than the younger ones in terms of physical, psychological, and social qualities of life. Another factor influencing the higher quality of life of older youth might be that they were more self-determined, and they accomplished their tasks and objectives. This, in turn, led to increased quality of life (McDougall, Evans, & Baldwin, 2010). However, the study participants here (*N* = 74) had an age range of four years. The influence of age on subjective quality of life could have been different if the participants' age range was wider than four years.

Environmental quality of life and age. Age alone was not associated with environmental quality of life. This suggests that age did not positively or negatively affect to environmental quality of life among young people with severe physical disabilities. However, one aspect of environmental quality of life (environmental quality of life includes a question of financial situation) that should improve as people age is their financial situation. Usually, when young people age, their financial situation gets better after they graduate and get employed. However, Study II findings showed that 49 (66.2%) of 74 youths had completed some upper secondary education. Thus, 25 (34%) of the youths with severe physical and multiple disabilities had not completed any upper secondary education. Furthermore, Study I indicated that increasing age (as it was not associated with environmental quality of life) may not have a positive influence on young people's financial situation. Almost half of the study participants received a disability pension (*n* = 35, or 47.30%) or attended a daytime activity center (*n* = 29, or 39.19%), with no income from employment. As Finland's system allows youth with severe physical disabilities to apply for a disability pension (Social Insurance Institution of Finland, 2019), education and employment of youth is not incentivized. However, it is important to remember, that when age was included in the sequential multiple regression model, along with gender and intensity of pain, it was a significant predictor of quality of life.

6.2 Completion of upper secondary education

Study II aimed to test the hypotheses that disability type, gender, location, and literacy skills are associated with the completion of upper secondary education among young adults with severe physical and multiple disabilities. The second objective was to test the hypothesis that disability type, gender, location, and literacy skills can predict the completion of upper secondary education among these youth. The findings of Study II are in line with those of Lindsay et al. (2018), who found that after comprehensive education, youth with severe physical and multiple disabilities have challenges in completing the subsequent educational levels. The results of Study II showed that 25 (34%) of the study participants (*N* = 74) had not completed any upper secondary education. Considering the completion of upper education, young adults with multiple disabilities (severe physical disabilities (other than cerebral palsy) and intellectual disabilities) was the group that had the lowest number of young adults who had completed upper secondary. From this group, 5 individuals (6.8% of all the 74 study participants) had completed upper secondary education. In terms of completing upper secondary education, the group of young adults with multiple disabilities (cerebral palsy with co-occurring intellectual disability) did not differ from the group of young adults with a single disability (cerebral palsy or a severe physical disability).

Location (urban or rural residence) and literacy skills (reading and writing skills) were associated with and predicted upper secondary education. Those who had moderate or good literacy skills and lived in urban areas were more likely to have completed their upper secondary education than those who had no literacy skills and lived in rural areas in Finland. This finding is in line with earlier studies which indicate that individuals with disabilities have restricted educational opportunities (Carter, Austin, & Trainor, 58–60; Test, Bartholomew & Bethune, 2015). Moreover, after comprehensive education, these youths have challenges in completing the subsequent educational levels (Lindsay et al., 2018). In particular, youths with intellectual disabilities are at increased risk of not completing their upper secondary education (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015, 263; WHO, 2011, 214). Therefore, it may be that recurring pain and mobility challenges (indicators of low physical quality of life found in Study I), which may be related to dissatisfaction with assistive devices: the participants were in need for new assistive devices (found in Study III), at least partially restricted the completion of upper secondary education among young adults with severe physical disabilities with or without a co-occurring intellectual disability. The environmental QoL includes the indicator of information and skills. Thus, due to a lack of information and skills (compared to young adults without disabilities), a lack of reading and writing skills, and a lack of possibilities to complete upper secondary education in rural areas of Finland (as the findings of Study II indicated), these young adults may experience low scores in terms of environmental QoL.

Usually, young people form important social relationships and friendships in educational settings. These social relationships are essential for young people with disabilities (Carter, Asmus, & Moss, 2013). However, the finding of Study I that young people with disabilities had a lower social quality of life than those without disabilities, may be associated with the findings of Study II. Young adults with severe physical and intellectual disabilities may have a low social quality of life, as they experience social isolation, loneliness, and a lack of supportive social relationships (the results of Study I); this is because not all of them had an opportunity to form social relationships in upper secondary education settings. The finding of a low social quality of life supports evidence from the previous observations of Kauppila, Niemi and Mietola (2018) that the social situation of persons with disabilities may not improve even though their educational level has increased.

6.3 Identifying factors associated with negative experience with health care

The aim of Study III was to identify factors associated with negative public health care experiences of young adults with severe physical disabilities with or without a co-occurring intellectual disability after they transitioned from child to adult health care in Finland. The results showed that all 74 participants had a negative experience with the following factors: the need for new assistive devices, the ease of obtaining a physician's appointment, and the physician possesses disability skills and knowledge. The result that participants had a negative experience with their need of new assistive devices may be related to the Study I result that young people with severe physical disabilities had lower physical and environmental quality of life than those without disabilities. Mobility restrictions caused from a lack of appropriate assistive devices create barriers in moving in the environment and may lead a decrease in physical and environmental quality of life among young people with severe physical disabilities. Furthermore, the finding that young adults with severe physical disabilities with or without a co-occurring intellectual disability had a negative experience with the ease of obtaining a physician's appointment can be associated with the Study I result that participants had a low environmental quality of life. One of the indicators of environmental quality of life is access to health and social services. A negative experience with the need for new assistive devices may be related to low social quality of life (indicated in Study I) as young adults may need several assistive devices to be able to participate in leisure time activities and social situations. With respect to the negative experiences with physician's disability skills and knowledge, this finding may have an impact on the overall QoL since young adults have complex health care needs and pain (Study I indicated that participants' intensity of pain decreased physical, psychological, social, and environmental QoLs). Thus, general physicians should have the requisite skills and knowledge to understand the overall health situation and the complex health care needs of young adults with severe physical disabilities with or without a co-occurring intellectual disability when they have transitioned from child to adult health care.

The experiences of users of health care services are an essential part of person-centered service delivery (Finlay & Antaki, 2012; Lotan & Ells, 2010). Young adults with severe physical and intellectual disability regularly use various health care services (Houtrow, Valliere, & Byers, 2018) but their opinions about those services are seldom heard, even though health care services impact their quality of life. Furthermore, young adults' opinions about health care services are important in planning and implementing health care services for them, as they are at risk of major health and functional impairments in adulthood (Perrin, 2012). Yet, very little is known about these young adults' experiences regarding their health care services (Gal, Weisberg-Yosub, Shavit, & Doron, 2010) even though these services impact on their quality of life.

6.4 Young adults and transitional outcomes

Young adults with severe physical disabilities with or without a co-occurring intellectual disability who have transitioned from comprehensive education to upper secondary education and from child to adult primary health care have lower physical, social, and environmental quality of life compared to young adults without disabilities.

It seems that these young people are disadvantaged in terms of upper secondary education because 25 participants (out of 74) did not have completed any upper secondary education. Therefore, their opportunities to gain income is not as good as other young people who have completed upper secondary education. However, it is notable, that although 49 young people had completed upper secondary education, none of the 74 participants had income from employment. Overall, of the participants, 35 (47.30%) were on a disability pension and 29 (39.19%) participated in daytime activity center. Ten participants stated that they received some other monetary benefit.

These young adults also may be at risk of not accessing and completing upper secondary education in Finland if they have moderate or no literacy skills at all and if they live in the rural areas of Finland. Because young adults with severe physical disabilities with or without a co-occurring intellectual disability would need new assistive devices, have trouble getting a physician's appointment, and have a negative experience with the doctor's disability skills and knowledge, their health care needs and hopes should be heard in primary healthcare.

6.5 Theoretical synthesis of dissertation

To conclude, Figure 2 (p. 79) shows how the findings of this PhD dissertation's transitional outcomes among young adults with severe physical disabilities with or without a co-occurring intellectual disability interact with and combine the concepts from the existing theoretical models of quality of life and the systems thinking framework by showing, how Study I: subjective quality of life domains (personal outcomes) provides individual level assessment feedback and organizational-level internal evaluation system feedback for primary health care in the quality of life and systems-thinking frameworks, and how Study II: predictors of completion of upper secondary education among young people with severe physical and multiple disabilities provides organizational-level internal evaluation system feedback on upper secondary education outcomes in the quality of life and systems thinking frameworks. Furthermore, Study III: identifying the factors associated with negative public health care experiences of young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland generates health care organizational-level assessment information and individual-level feedback on health care transition outcomes in the quality of life and systems thinking frameworks.

Figure 2 indicates how Study I (personal outcomes in quality of life domains), Study II (predictors of completion of upper secondary education), and Study III (identifying the factors associated with negative public health care experiences) provide assessment information for the internal evaluation system and quality improvement feedback for upper secondary education and primary health care organizational and system levels to use in improving quality of service delivery for young adults with severe physical disabilities with or without a co-occurring intellectual disability.

The main links found in this PhD dissertation are indicated in Figure 2. The paths in the theoretical synthesis of this PhD dissertation figure labeled with the red Greek letter beta indicate pathways whose direction can be predicted. This model (Figure 2) suggests that at the individual level of the systems-thinking framework, assessment of quality of life personal outcomes indicated that youth with severe physical disabilities with or without a co-occurring intellectual disability experience lower physical, social, and environmental quality of life compared to those without disabilities. Moreover, a participant's higher age predicted higher physical, psychological, and social qualities of life, but not higher environmental quality of life. Male gender predicted low scores in the psychological and social quality of life. Intensity of pain predicted low scores in all four quality of life domains.

The model (Figure 2) also suggests that in the systems thinking framework, assessing the objective quality of life outcomes young adults with severe physical disabilities with or without a co-occurring intellectual disability are the foundation for evidence-based practices and quality improvement at the organizational level of upper secondary education. These subjective quality outcomes are the predictors of completion of upper secondary education. The results of this study showed that the participant's urban location and moderate or good literacy skills (reading and writing skills) predicted the completion of upper secondary education. On the other hand, those participants who had multiple disabilities (a severe physical disability, other than cerebral palsy, with an intellectual disability) were not as likely as those with other types of disabilities to complete their upper secondary education. Moreover, the findings of this PhD dissertation suggest that those young adults with severe physical and multiple disabilities (a severe physical disability with a co-occurring intellectual disability) who lived in the rural areas of Finland and had no literacy skills at all were more likely to have not completed their upper secondary education. Overall, the assessment of the educational support needs of young adults with severe physical and multiple disabilities during their upper secondary education is important because education may increase their quality of life in later adulthood.

The findings of this study also suggest that according to the quality of life and systems thinking framework, assessing the personal outcomes in quality of life domains and identifying the factors associated with negative public health care experiences of young adults with severe physical disabilities with a co-occurring intellectual disability according to the internal evaluation system provides a foundation for evidence-based practices and quality improvement at the organizational level of their adult health care services. The findings showed that a negative experience with the following factors: the need for new assistive devices, the ease of obtaining a physician's appointment, and the physician’s proficiency in disability skills/knowledge predicted a negative experience with health care. Thus, using this information when implementing evidence-based practices at the health care services' organizational level could lead to improvement in the quality of health care services delivery to young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland. It is important to remember that these health care services may have an impact on the young adults' quality of life in the later adulthood.

Finally, at the system level, the participants of this study are considered as users of educational and health care services. Their involvement and empowerment when planning and implementing educational and health care service delivery is important from perspectives of systems-thinking and quality of life frameworks, since the individual, organizational, educational, and health care service delivery systems are interconnected (see Schalock et al., 2008).

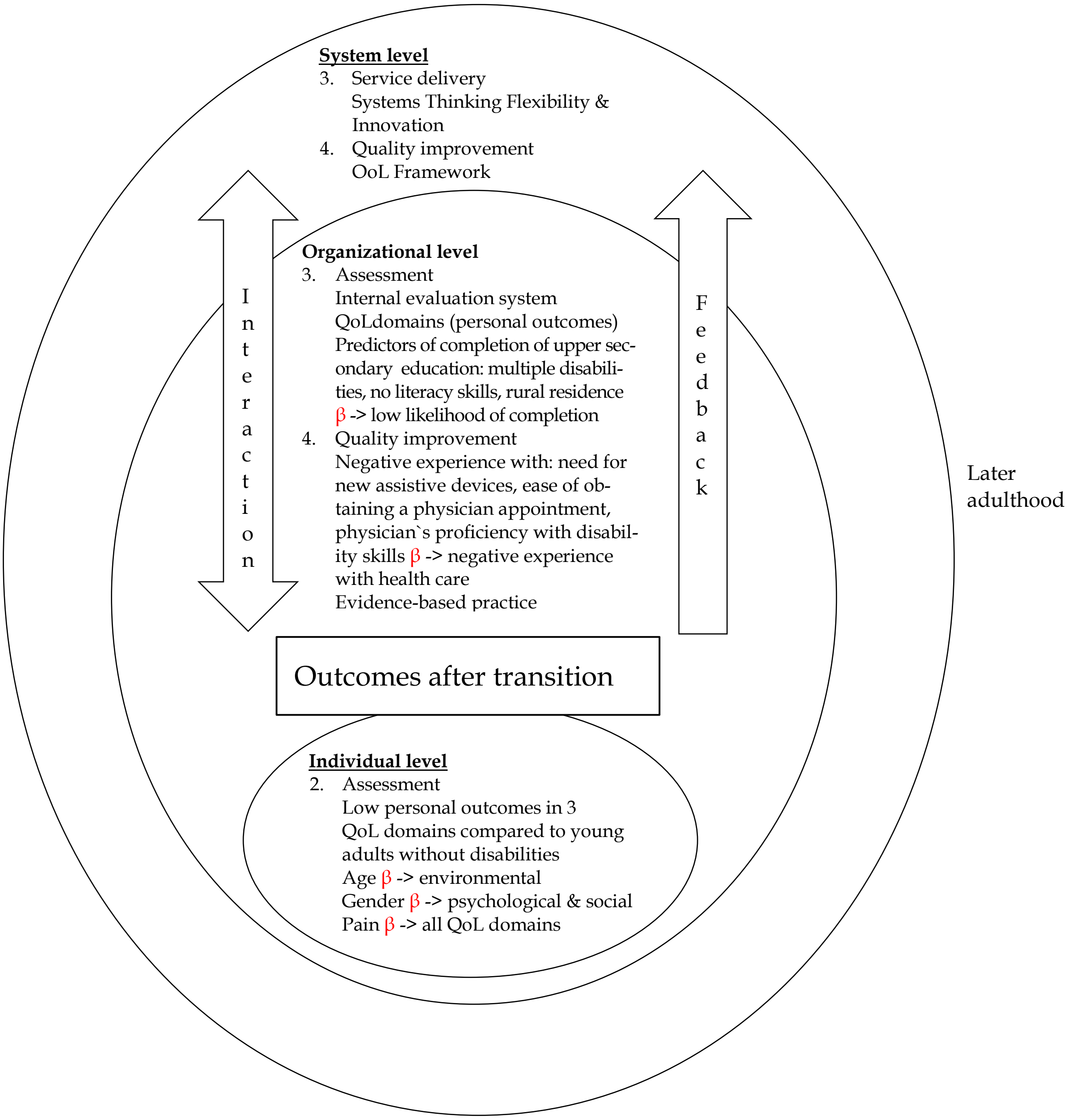

Figure 2 Conceptual and theoretical synthesis of the PhD dissertation's main findings

6.5.1 Contextualizing the dissertation

The context and contributions of this PhD dissertation to the field of transitional quality of life research are illustrated in Table 6 (p. 82). In Study I, the quality of life among youth with severe physical disabilities (with or without a co-occurring intellectual disability) was compared to that of youth without severe physical disabilities. Recent (within 10 years) studies on the quality of life of children and young people have focused on slightly different topics. On one hand, quality of life studies related to persons without disabilities have concentrated on exploring the associations between specific factors and quality of life. The review of literature on the quality of life of children and adolescents conducted by Ow, Appau, Matout, and Mayo (2021), included primarily children and adolescents. However, some studies have had young adults and adults as participants. One study has investigated the quality of life among young Finnish adults who are not in the education system or engaged in employment. Moreover, another study aimed to provide normative data to assess internal consistency and construct validity of the Pediatric Quality of Life Inventory Young Adult Generic Core Scales (PEDSQL_YA). On the other hand, quality of life research related to persons with disabilities has been investigating the quality of life of persons with different disabilities. Most studies have concentrated on children and adolescents. One study has compared the determinants of participation and quality of life between young adults with disabilities and the general population. There has been a study that operationalized the concept of quality of life for adults with severe disabilities. The only Finnish study has investigated the quality of life of adolescents with cerebral palsy. However, many previous studies have not requested young adults with physical disabilities to provide information about their own quality of life (Bagazgoïtia et al., 2021; Davidson, Irvine, Corman, Kee, Kelly, Leavey, & McNamee, 2017, 29; Ow, Appau, Matout, & Mayo, 2021. In many cases, the quality of life information has been collected from other people than young people themselves. Thus, this PhD dissertation contributes significantly to research on subjective quality of life outcomes, outcomes after transition to upper secondary education, and outcomes after transition from child to adult health care among young adults with severe physical disabilities with or without a co-occurring intellectual disability in Finland. In addition, this PhD dissertation develops a quality of life feedback implementation model for upper secondary education and public health care organizations in an effort to improve the quality those services and quality of life for young adults with severe physical disabilities.

As presented in Table 6, previous studies of the educational transition among persons with various disabilities (such as autism spectrum disorder, Down syndrome, physical disabilities) have concentrated on the factors influencing successful transition, transition practices, experiences of transition, school connectedness related to transition, and evaluation and experiences of transition programs. At least one study has included young people with complex disabilities when investigating the economic consequences of the transition. Most studies have covered the transition from primary/basic school transition to secondary school. The experiences of Finnish young adults with severe disabilities and their transition phase after graduation have only been investigated in one study. Far too little attention has been paid to the transition period from the viewpoint of completion of upper secondary education among those young adults who have severe physical disabilities with or without a co-occurring intellectual disability. Therefore, this PhD dissertation provides new information about the predictors of completion of upper secondary education among young adults with severe physical and intellectual disabilities in Finland.

This evidence-based knowledge can be used to guide upper secondary education development, quality improvement, and implementation.

Earlier studies on the health care transitions of persons with disabilities (see Table 6) have investigated such various topics as the features and determinants of effective, efficient, and successful transitional care, features of transitional care associated with better outcomes for young people, and health-care-transition-related concepts, topics, and themes. The views, experiences, and recommendations of parents concerning the transition have been studied as well. Moreover, the evaluation of the effectiveness of interventions targeted to improve the transition from pediatric to adult health care has been investigated. A study has also been conducted to determine whether the needs of young people with cerebral palsy were met during the transition. Prior health care transition studies have included at least young people with cerebral palsy, intellectual disabilities, and special health care needs. However, there is a lack of studies in Finland that ask young adults with severe physical disabilities with or without a co-occurring intellectual disability to tell their opinions about health care services and rate their satisfaction with these services after transitioning from child to adult health care services. Thus, this PhD dissertation provides valuable information about the personal outcomes in quality of life domains and the factors associated with negative experiences with health care among these young people after their transition from child to adult health care in Finland. This knowledge is useful in efforts to improving, developing, and implementing evidence-based and person-centered adult health care services for young adults with severe physical disabilities with or without a co-occurring intellectual disability in Finland.

Table 6. Contextualization of PhD Dissertation

Earlier Studies of QoL		Aim of Dissertation	Research Questions	Contribution to Field
Persons without Disabilities	*Persons with Disabilities*			
Associations of factors with HRQoL/QoL *Children and adolescents* -physical activity, sedentary behavior, and fitness[1] -socio-demographic variables and predictor roles of negative and positive dimensions[2] -self-efficacy, self-esteem, loneliness, stress[3] -school-based mindfulness intervention[4] -24-h movement guidelines[5] *Young adults and adults* -educational level[6] -school-absenteeism, happiness[7] -effects of yoga-based activity – stress, anxiety, QoL[8] *QoL/assessment of instrument* -QoL of Finnish NEET adults[9] -provide normative data to assess internal consistency and construct validity of QoL instrument[10]	*Children and adolescents* -severe DD[11] -Finnish adolescents with CP[12] -self-reported QoL of adolescents with CP: cross-sectional and longitudinal analysis[13] -adolescents with Down syndrome[14] -parent-reported effect of physical, social, and attitudinal environment on QoL of adolescents with CP[15] -changes in QoL in children and adolescents with PD — longitudinal design[16] -QoL of children with CP and ID: identifying the important domains of life[17] -functionality and QoL of children with disability[18] - QoL in children and adolescents with physical disabilities[19] *Young adults and adults* -determinants of participation and QoL of young adults with CP: comparison with the general population[20] -operationalization of QoL for adults with severe disabilities[21]	To use quality of life and systems thinking frameworks to develop of a quality of life implementation feedback model for upper secondary and health care organizations to improve quality of life among young adults with severe physical disabilities after their transition to adulthood.	1. What kind of subjective quality of life do youth with severe physical disabilities have during their transition to adulthood in Finland?	This PhD dissertation provided new information about personal outcomes of quality of life, completion of upper secondary education, and factors associated with negative experiences with health care among young adults with severe physical and intellectual disabilities. This knowledge resulted in the development of a quality of life implementation feedback model that can be used as evidence-based information when improving the quality of upper secondary education and primary health care services to improve the quality of life of young adults with severe physical disabilities.
Earlier studies of educational transitions of persons with disabilities				
Primary/basic to secondary school -factors influencing the successful transitioning of YP with Down syndrome[22] -targeted transition practices and associated opportunities for YP with special educational needs[23] -YP with high-functioning autism and Asperger's syndrome: experiences of moving to college[24] -YP with special educational needs and their experiences about transition[25]			2. Which factors are associated with completion of upper secondary education among young adults with severe	

Earlier Studies of QoL	Aim of Dissertation	Research Questions	Contribution to Field
-evaluation of transition program targeted to children with ASD[26] -school-connectedness and the primary to secondary school transition for YP with ASD[27] *Secondary to further education* -students with disabilities and their experiences of self-determination in a transition program[28] -experiences of youth with PD and clinicians who support them in their transition to post-secondary education[29] -experiences of YA about upper secondary education and transition after graduation[30] -transition pathways for YP with complex disabilities: economic consequences[31]		physical and multiple disabilities?	
Earlier studies of health care transition of persons with disabilities			
-transition from paediatric to adult health care services in Scotland for YP with CP[32] -identifying features of potentially effective and efficient transitional care for YP with complex health care needs[33] -ecological model as a framework for organizing concepts and themes related to health care transition[34] -features of transitional healthcare associated with better outcomes for YP with long-term conditions[35] -views and experiences of families of young adults with ID about transition to adult health care[36] -transitions from child to adult health care for YP with ID: a systematic review[37] -parents' experiences and recommendations about transferring YP with profound ID and multiple disabilities from pediatric to adult health care[38] -development of the concept of successful transition and identifying determinants that are associated with it[39] -evaluation of effectiveness of interventions which aim to improve the health care transition of adolescents with chronic conditions (review)[40] -evaluating whether the needs of YP with CP are met during health care transition[41] -transition-related interventions and post-transition outcomes of health care transition among youth with special health care needs[42]		3. Which factors are associated with negative health care experiences among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition from child to adult health care in Finland?	

Note. QoL = quality of life; HRQoL = health-related quality of life; NEET = not in employment or education; DD = developmental disability; CP = cerebral palsy: PD = physical disability; ID = intellectual disability; YA = young adults; YP = young people; ASD = autism spectrum disorder.

1 Bermejo-Cantarero et al., 2017; 2 Freire & Ferreira, 2018; 3 Mikkelsen, Haraldstad, Helseth, Skarstein, Småstuen, & Rohde, 2020; 4 Lassander, Hintsanen, Suominen, Mullola, Vahlberg & Volanen, 2021; 5 Khan, Lee, & Tremblay, 2021; 6 Gil-Lacruz, Gil-Lacruz, & Gracia-Pérez, 2020; 7 van den Toren, van Grieken, Mulder, Vanneste, Lugtenberg, de Kroon, Swan Tan, & Raat, 2019; 8 Yuce & Muz, 2020; 9 Kivijärvi, Aaltonen, Forma, Partanen, Myllylä, & Rissanen, 2020; 10 Limperg, Haverman, van Oers, van Rossum, Maurice-Stam, & Grootenhuis, 2014; 11 Ncube, Perry, & Weiss, 2018; 12 Böling, Varho, & Haataja, 2018; 13 Colver, Rapp, Eisemann, Ehlinger, Thyen, Dickinson, Parkes, Parkinson, Nystrand, Fauconnier, Marcelli, Mihcelsen, & Arnaud, 2015; 14 Sheridan, O Malley-Keighran, & Carroll, 2020; 15 Badia, Orgaz, Gómez-Vela, Verdugo, Ullán, & Longo, 2016; 16 Lin, Ju, Lee, Yang & Lo, 2011; 17 Davis, Reddihough, Murphy, Epstein, Reid, Whitehouse, Williams, Leonard, & Downs, 2017; 18 Dos Santos, da Silva, Sousa, Pires, Iop, Ferreira, & Silva, 2018; 19 Ow, Appau, Matout, & Mayo, 2021; 20 Arnaud, Duffaut, Fauconnier, Schmidt, Himmelmann, Marcelli, Pennington, Alvarelhao, Cytera, Rapp, Ehlinger, & Thyen, 2021; 21 Gómes, Arias, Verdugo, Tassé, & Brown, 2015; 22 Mullan, Prendeville, & Kinsella, 2018; 23 Kalalahti, Niemi, Varjo, & Jahnukainen, 2020; 24 Mitchell & Beresford, 2014; 25 Lawson & Parker, 2019; 26 Mandy, Murin, Baykaner, Stanton, Cobb, Hellriegel, Anderson, & Skuse, 2016; 27 Hebron, 2018; 28 Ankeny & Lehmann, 2011; 29 Lindsay, Duncanson, Niles-Campbell, McDougall, Diederichs, & Menna-Dack, 2018; 30 Äikäs, 2012; 31 Knapp, Perkins, Beecham, Dhanasiri, & Rustin, 2008; 32 Wright, Robb, & Shearer, 2016; 33 Colver, Merrick, Deverill, LeCouteur, Parr, Pearce, Rapley, Vale, Watson, & McConachie, 2013; 34 Wang, Burns Mc Grath, & Watts, 2010; 35 Colver, McConachie, LeCouteur, Dovey-Pearce, Mann, McDonagh, Pearce, Vale, Merrick, & Parr, 2018; 36 Brown, Higgins, & McArthur, 2020; 37 Brown, McArthur, Higgins, & Chouliara, 2018; 38 Bindels-de Heus, van Staa, van Vliet, Ewals, & Hilberink, 2013; 39 Oswald, Gilles, Cannady, Wenzel, Willis, & Bodurtha, 2012; 40 Campbell, Biggs, Aldiss, O´Neill, Clowes, McDonagh, While, & Gibson, 2016; 41 Solanke, Colver, & McConachie, 2017; 42 Bloom, Kuhlthau, Van Cleave, Knapp, Newacheck, & Perrin, 2012.

6.6 Policy and practical implications

This PhD dissertation provides novel insights into the interrelationships between transition outcomes in quality of life, transition outcomes in upper secondary education, and transition outcomes in primary health care services of young adults with severe physical disabilities with or without a co-occurring intellectual disability in the quality of life and systems thinking frameworks. The results suggest that individual-level assessment of quality of life personal outcomes (subjective quality of life), organizational-level internal evaluation system assessment of factors associated with negative health care experiences (subjective quality of life), and organizational-level assessment of predictors of completion of upper secondary education (objective quality of life) are interconnected in the quality of life and systems thinking frameworks because they provide feedback to guide evidence-based practice, quality improvement, and innovation for service delivery in the upper secondary education and primary health care organizations and systems. These organizations and systems deliver services for young adults with severe physical disabilities with or without a co-occurring intellectual disability. The significance of this work is that it is the first PhD dissertation in Finland that allows young adults with severe physical disabilities with or without a co-occurring intellectual disability to express their perspectives on their quality of life and opinions after their transition from child to adult primary health care, as well as outcomes following their educational transition to upper secondary education. In the quality of life and systems thinking frameworks, this new evidence-based knowledge can be used to develop quality of life enhancing upper secondary educational services and primary health care services for young adults with severe physical disabilities with or without a co-occurring intellectual disability.

Overall, three approaches and different methodological solutions were used in this PhD dissertation to capture the phenomena of quality of life, completion of upper secondary education, and experiences with primary health care services among young adults with severe physical disabilities with or without a co-occurring intellectual disability after their transition to adulthood. All concepts were related to the quality of life and systems-thinking frameworks (Figure 3). The findings of this PhD dissertation have multiple policy and practical implications for policymakers and for upper secondary educational and primary health care service developers.

Enhancing quality of life. Policy makers should develop coordinated and individualized efforts to improve the subjective quality of life among these young adults. It is important to remember, from a service-delivery perspective, that the services and supports provided to young people with disabilities typically decrease after their transition to adulthood (King, Baldwin, Currie, & Evans, 2006). When it comes to health care, the emphasis should be on the primary prevention of secondary conditions, such as pain, fatigue, depression, sleep problems, and obesity. Unless treated or managed, secondary conditions commonly restrict participation in activities (Rimmer, Chen, & Hsieh, 2011) and lead to decreased quality of life among young adults. Furthermore, young males with severe physical and intellectual disabilities would need preventive support to promote psychological and social qualities of life in adulthood, since it seems that they are at risk of living in social isolation. For example, young males would benefit from leisure time activities that prevent social isolation and to increase social support and forming of close relationships. Moreover, social care services should be developed so that the poor financial situation (see WHO, 2011) of these young adults could improve, increasing opportunities for them to participate in social or leisure time activities. Physical and built environments should be developed in an accessible manner for persons with mobility restrictions, in order to enable them to participate in life situations (see Colver & Dickinson, 2010). In summary, to better recognize these social and environmental restrictions, a holistic and evaluative approach should be adopted, as the limited opportunities for social participation will continue into adulthood if they are not addressed at the policy-making level.

Upper secondary education. The results further suggest that more services and support strategies should be implemented to enable young adults with severe physical disabilities with or without a co-occurring intellectual disability to attend and complete upper secondary education in their local school system. As the results showed, the educational services should be planned to support those who have severe or multiple disabilities, since their needs may be complicated. Moreover, the educational services and forms of support should cover the rural areas in Finland, as the results indicated that those young adults who live in rural areas are less likely to complete upper secondary education than those who live in urban areas in Finland. Finally, the results suggest that young adults with severe physical and multiple disabilities would need more special educational support to achieve moderate or good reading and writing skills, which would help them to complete upper secondary education.

Currently, the educational services and supports do not meet these young adults' needs and hopes (see Hermanoff, Määttä, & Uusiautti, 2017, 30; Äikäs, 2012, 136, 147). The support strategies and other interventions needed may include interpreters, classroom assistants, enabling technologies, and accessible educational materials. In rural areas, technological solutions could be implemented to bolster upper secondary education completion rates for young individuals with severe physical disabilities with or without a co-occurring intellectual disability. One option is to train and support to special education teachers in rural areas by providing real-time eCoaching while they are teaching (Horn, 2021), for example, from vocational special education institutions (Finland has seven vocational special institutions) and universities in Finland. The idea behind eCoaching is that a coach provides continuous and regular remote instructional support and advice to a rural special education teacher on how teach students with disabilities in upper secondary education institutions using evidence-based methods (Horn, 2021). Moreover, efforts to support the transition from comprehensive education to secondary education for young persons with severe physical and intellectual disabilities should be improved. Furthermore, as

Collins (2007) suggested, special education teachers in rural areas could benefit from mentors or being part of a network of other special education teachers, which would promote the sharing of knowledge and resources. Implementing the same kinds of support services that Valteri Schools provide for neighborhood schools to support students with special education needs in basic education (see Opetushallitus, n.d.) could increase the chances of young people with severe disabilities attending their local upper secondary schools. Strong professional assistance to support neighborhood education principle in upper secondary education would enhance teachers' ability to instruct students with severe physical impairments. Finally, teachers and schools should establish a context for learning instruction and use evidence-based instructional methods to teach writing strategies and word-, sentence-, and paragraph-level skills for young adults with severe physical and intellectual disabilities. By focusing on delivering these evidence-based support and service strategies, the opportunities for these young people to attend and complete upper secondary education could be improved.

Health care services. The present study suggests that adult health care services for young adults with severe physical and intellectual disabilities should be developed with consideration of the complex health care needs of young adults with severe physical disabilities with or without a co-occurring intellectual disability after they have transitioned from child to adult health services in Finland. First, the assistive devices situation of these young adults should be updated regularly as the results of this study indicated that participants are dissatisfied with their assistive devices situation. Moreover, maintenance services for assistive devices should be developed. Furthermore, increasing the understanding of general physicians on the complex health care needs of young adults with severe physical disabilities with or without a co-occurring intellectual disability would be useful by adding disability-related contents to the physicians' medical education curriculum. Thus, the adult health care services could be developed more person-centered for these young adults.

The results indicated that young adults with severe physical and intellectual disabilities were dissatisfied with their assistive devices situation, access to a physician's appointment, and physicians' expertise with their disability (as assessed by the young adults and their proxies). An important implication is that young adults with severe physical and intellectual disabilities should be given a possibility to express their opinions about the health care services provided for them. In Finland, these young people experience a health care services-related transition from child to adult health care services and their voices should be heard after that transition process. This information about young adults' experiences and the personal outcomes of quality of life can be used to guide the development of person-centered, individualized, and evidence-based health care services for them (Shogren, Luckasson, & Schalock, 2017; Willis, Zeratkaar, ten Hove, Rosenbaum, & Ronen, 2021). Furthermore, as Bolger, Vargus-Adams, and McMahon (2017) suggest, a possible solution to improve the transition from child to adult health care settings for young adults with severe physical and intellectual disabilities could be the implementation of a multi-professional clinic in the adult health care settings to ensure continuity of care after the health care transition from child to adult health care (Cornec et al., 2021). These multi-professional clinics could provide regular follow-up appointments for young people with severe physical disabilities with or without a co-occurring intellectual disability in the same way that child neurologic services and units in Finland function. Policymakers can use the current PhD dissertation findings to develop and implement evidence-based upper secondary educational and health care services based on the quality of life implementation feedback model developed in this PhD dissertation to improve the quality of life for young adults with severe physical and intellectual disabilities (see Figure 3 Quality of life implementation feedback model).

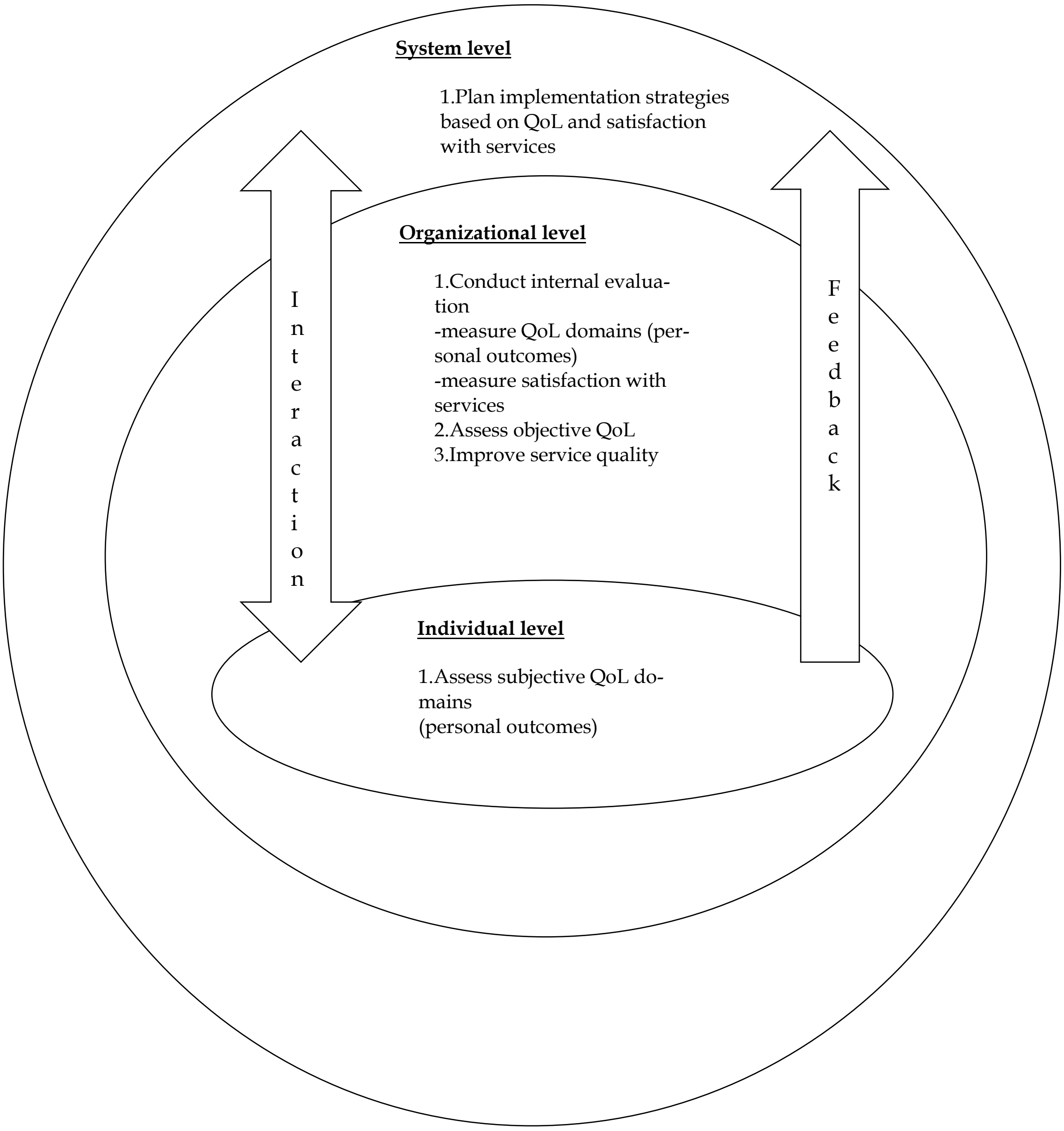

Figure 3 Quality of life implementation feedback model

6.7 Strengths, limitations, and future research

A strength throughout the PhD dissertation process comprised the theoretical frameworks used to approach the quality of life among young adults with severe physical and intellectual disabilities. The quality-of-life framework encompassed social, environmental, psychological, and physical (Suárez, Tay, & Abdullah, 2018) perspectives, whereas the systems-thinking framework incorporated the individual and organization (upper secondary educational services, and health care services organizations) level aspects. Thus, subjective quality of life was approached holistically by requesting young adults to provide information about their quality of life, completion of upper secondary education, and experiences with health care services after their transition from youth to adulthood as well as after their transition from the child's educational services to those of an adult. Moreover, participants were asked to tell their experiences on health care services after their transition from child to adult health care services. First, the subjective quality of life data collected from youth included information about their physical, psychological, social, and environmental qualities of life. Moreover, young adults provided information about the intensity of their pain. Thus, these data were broad and provided a multidimensional (WHOQOL Group, 1995) understanding about young adults' subjective quality of life. Furthermore, the data was collected via WHO' s Quality of Life-Bréf instrument and the health care professionals' instrument Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland. WHOQOL-Bréf instrument produces information on quality of life indicators based on the literature (see Schalock et al., 2008; WHO, 1998) and quality of life and systems-thinking frameworks (Schalock et al., 2008 for upper secondary education and health care organizations. The Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland instrument, on the other hand, provides more information on respondents' satisfaction with the functioning of educational and health care service systems (subjective quality of life, see Schalock et al., 2008). This adapted instrument includes questions about satisfaction with specific factors of health care and health care in general. These aspects belong to subjective quality of life at the individual level in the systems thinking framework. However, the instrument contains, for example, questions about participants' residence and level of education, which may have an impact education completion. These types of questions reflect the objective quality of life in the quality of life and the systems thinking frameworks (Schalock, et al., 2008). Furthermore, this questionnaire includes individual-level background information (such as type of disability, age, gender, and intensity of pain) about the participants. These factors may impact on the participants' subjective quality of life and completion of upper secondary education. Thus, this instrument provides a wide range of adapted questions from which upper secondary education providers and health care providers can gain valuable information for improving service delivery and improving respondents' quality of life using the quality of life and systems thinking frameworks.

Data collection occurred in the broader project (Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland) of five central hospitals and the Social Insurance Institution of Finland. Second, when data related to completion of upper secondary education were collected directly from young adults, it increased understanding about the factors behind young adults' completion of upper secondary education. In addition, knowing that in Finland, education shapes the futures of young adults in terms of employment (Hakkarainen, Holopainen, & Savolainen, 2015), this knowledge allows reflection on how the completion of upper secondary education may affect the quality of life of young adults with severe physical and intellectual disabilities (Canha, Simões, Owens, & De Matos, 2015, 160; Rohana, Alias, & Tumin, 2020). Third, young adults provided their perspective in terms of dissatisfaction with factors associated with adult health care services; this information provided insight into how adult health care services affecting young adults' subjective quality of life. Given that the transition phase from youth to adulthood is crucial for young adults' future in terms of their quality of life, education, and health, this study demonstrated that difficulties in the lives of young adults with severe physical and intellectual disabilities may accumulate and continue into later adulthood unless addressed.

This PhD dissertation has several limitations that must be considered when interpreting and generalizing the results. Limitations include the small sample of young adults with severe physical disabilities (*N* = 74). Moreover, the sampling method, which was a purposeful sample, may limit the generalizability of the findings. However, the participants of the present PhD dissertation may be perceived to have special knowledge and experience with the phenomenon of disability-related issues (Cresswell & Plano Clark, 2011). From this sample, 39 (53%) had a severe physical disability with a co-occurring intellectual disability. Obtaining valid and reliable responses from individuals with intellectual disabilities may be difficult. However, all participants (*N* = 74) had a proxy (parent, carer, personal assistant) who provided background information for the participant and the researcher during the data collection. The proxy knew the young adult and his/her needs and challenges very well. The WHOQOL-BREF and the Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland instruments included at least some abstract questions; parents, caregivers, or personal assistants facilitated those young adults whose disabilities were so significant that they could not respond to the questions without assistance. In particular, the WHOQOL-BREF was not adapted for persons with intellectual disabilities. Thirty-nine (53%) of the respondents had a severe physical disability with a co-occurring intellectual disability. Valid and reliable information regarding their quality of life can be difficult to gain. However, the indicators, domain-related personal outcomes, and concepts in quality of life may not apply differently to young adults with intellectual disability than to the general population (Moonen, Mercera, Langdon, &

Kooijmans, 2021). Moreover, the nurse who collected the data from 60 respondents was very familiar with the participants and their reliability in answering the questions. Instead, the author of this PhD dissertation collected the data from 14 participants of whom four needed facilitation with answering the questions. Consequently, the author of this PhD dissertation did not know the participants or their disability-related limitations to answer reliably to the questions.

Furthermore, the WHOQOL-BREF also has only three questions about the social quality of life. As a result, it is unclear, whether the instrument adequately capture the issues of social inclusion and opportunities to participate in social activities, which are indicators of objective quality of life in the systems thinking framework (see Schalock et al., 2008) among young adults with severe physical disabilities with or without a co-occurring intellectual disability. A further limitation is the use of WHOQOL-BREF population norms. Even though the population norms for the WHOQOL-BREF were international, cross-cultural, and intended to be used by researchers, it is worth noting that these norms were derived from an Australian population. Thus, population norms derived from the Finnish population could be somewhat different. Given that the Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland instrument was not specifically designed for measuring organizational level (upper secondary education and health care) supports needs assessment or key performance indicators (according to the systems thinking framework), this type of information would have provided more profound foundation for organizational-level quality improvement.

Furthermore, the Moreover, the questions in Study II and Study III did not allow multilevel modeling, although that would have provided more detailed information about the phenomenon of completion of upper secondary education and experiences of dissatisfaction with health care services among young adults with severe physical and intellectual disabilities. However, Study II and Study III did provide important and useful information, considering that the sample size was 74 participants and the total number of young adults with severe physical and intellectual disabilities in Finland is small. The Finnish early birth cohort is less than 60, 000 children (Statistics Finland, 2020) and 1.3% of them (about 730 children) have a physical disability (Kivelä, Nurmi-Koikkalainen, Ristikari, & Hiekkala, 2019). The exact number of those young people who have a severe physical disability with a co-occurring intellectual disability is estimated to be smaller than 1.3% of the yearly birth cohort, but the exact number of those young people is not known. Thus, the sample size was relatively good in terms of representation and, consequently, the analyses provided reliable information about the study phenomena. However, it would have been useful to collect new data to support the results of this study but it is very challenging to collect information from young adults with severe physical disabilities with or without a co-occurring intellectual disability. The results of this study are still relevant because the services provided to these young adults following the transition from basic to upper secondary education, as well as the transition from child to adult health care, have not yet changed.

Finally, when the concepts of the quality of life and systems thinking frameworks are compared to concepts in the Finnish health care system, there is one conceptual difference. The frameworks employ the term "consumer", which does not correspond to the Finnish health care system. All Finnish citizens are entitled to free public health care; users pay only a small user fee (Kela, 19.12.2022). The term "consumer" is not used in this PhD dissertation. Instead, young adults with severe physical disabilities with or without a co-occurring intellectual disability have been described as health care users.

Future studies on quality of life in Finland should consider this and strive to collect even larger samples with instruments and methods designed to include young adults with all kinds of disabilities. Future studies should also focus more on gaining information about social services and the loneliness of young adults with disabilities. It would also be important to investigate the topics of this PhD dissertation in longitudinal design from childhood to adulthood. It would be essential to study transitions of education, health care, and social services from child to adult services to provide longitudinal, evidence-based information to guide policymakers and the developers of these services.

6.8 Ethical considerations

The present study was initiated in the context of a broader research project: Severely disabled youths' life situation and the functioning of the service systems in Finland (Vaikeasti liikuntavammaisten nuorten elämäntilanne ja palvelujärjestelmien toimivuus Suomessa). Thus, the Ethical Committee of Päijät-Häme Joint Authority for Health and Wellbeing in Lahti, Finland, had approved the project study protocol. Most of the data collections (*N* = 60) and data sets were gathered during this project. Furthermore, the Ethical Committee of Päijät-Häme Joint Authority for Health and Wellbeing in Lahti, Finland, obtained the research permits for the author to collect data from 14 young adults during her employment as a researcher in the Päijät-Häme Central Hospital. The author of this PhD dissertation only collected the data from 14 participants, by applying the principle that data collection must not cause any damage, distress, or risks to study participants (Intersoft Consulting, n.d.). Immediately after the data collection, the author delivered the data to the Päijät-Häme Central Hospital to be stored in their information system using Secure Sockets Layer (SSL) connection. Consequently, all personal information was processed in accordance with the General Data Protection Regulation 2016/679 (Finnish National Board on Research Integrity TENK, 2023). The hospital followed the guidelines for medical research ethics in Finland (Finnish National Board on Research Integrity, 2018). In addition, this PhD dissertation was conducted by applying the guidelines for responsible conduct of research (Finnish National Board on Research Integrity, 2023). All the procedures related to data collection, management, storage, archiving, and handling have been managed by the Päijät-Häme Central Hospital. The author used the data which was stored in the information system of the Päijät-Häme Central Hospital. After conducting the analyses in SPSS, the author deleted the datasets from her computer.

SUMMARY IN FINNISH

Elämänlaadun käsite fyysisine, psykologisine, sosiaalisine ja ympäristön elämänlaadun osa-alueineen on hyväksytty keskeisenä viitekehyksenä ja päämääränä suunniteltaessa ja toteutettaessa vaikeasti liikuntavammaisten ja älyllisesti kehitysvammaisten nuorten koulutus-, terveydenhoito- ja sosiaalipalveluja (McDougall et al., 2016). Nämä nuoret kokevat transitiovaiheen kaikilla eri elämänlaadun osa-alueilla. Lisäksi nuoret kokevat palvelujärjestelmiin (koulutus-, terveydenhuolto- ja sosiaalipalveluiden) liittyvät transitiot siirtyessään lasten ja nuorten palvelujärjestelmistä aikuisten palvelujärjestelmiin. Elämänlaadun kytkeytyessä ja ollessa yhteydessä palvelujärjestelmiin tämän tutkimuksen teoreettisina viitekehyksinä hyödynnettiin käsitteitä elämänlaadun (Quality of Life) ja systeemiajattelun (Systems Thinking Framework) viitekehyksistä. Vaikeasti liikuntavammaisten nuorten elämänlaatu sen jälkeen, kun he ovat siirtyneet nuoruudesta aikuisuuteen, on tärkeä tutkimuskohde. Nuorten itse arvioimat elämänlaadun osa-alueet, fyysinen, psyykkinen, sosiaalinen ja ympäristö, vaikuttavat kokonaiselämänlaatuun. Maailman terveysjärjestö määrittelee elämänlaadun yksilön käsitykseksi omasta elämäntilanteestaan suhteessa omiin päämääriin, tavoitteisiin ja odotuksiin oman kulttuurin ja arvomaailman määrittelemässä viitekehyksessä. Elämänlaatu on moniulotteinen käsite, johon vaikuttavat monimutkaisesti yksilön fyysinen terveys, psykologinen terveys, riippumattomuus, sosiaaliset suhteet ja niiden suhde ympäristön keskeisiin piirteisiin (WHOQOL Group, 1995, 1405). Yksilön henkilökohtaiset tulokset elämänlaadussa edustavat yksilön käsitystä hänen fyysisestä, psykologisesta, sosiaalisesta ja ympäristön elämänlaadusta. Nämä osa-alueet sisältyvät elämänlaadun viitekehykseen subjektiivisesta ja objektiivisesta näkökulmasta. Campbell, Converse ja Rogers (1976) määrittelevät subjektiivisen elämänlaadun yksilön arvioksi omasta elämästään. Yksilön tekemä arvio voi sisältää fyysisen, psykologisen, sosiaalisen ja ympäristön elämänlaadun osa-alueet (WHO 2020). Ympäristön elämänlaadun osa-alueet edustavat objektiivista elämänlaatua. Nämä osa-alueet voidaan käsittää moninaisiksi ympäristöiksi ja ulkoisiksi tekijöiksi, jotka vaikuttavat yksilön subjektiiviseen elämänlaatuun ja henkilökohtaisiin tuloksiin elämänlaadusta (Campbell, ym., 1976; Claes, Van Hove, Van Loon, Vandevelde, & Schalock 2010, 62). Näin ollen, vaikeasti liikunta- ja älyllisesti kehitysvammaisten nuorten henkilökohtaisiin tuloksiin elämänlaadussa vaikuttavat laajempi ympäristö ja heille tarjotut palvelut ja palvelujärjestelmät: esimerkiksi koulutus- ja terveydenhuoltojärjestelmä (Friedman & VanPuymbrouck 2019; WHO, 2007, xvii).

Vähäiset aikaisemmat tutkimukset ovat osoittaneet, että vaikeasti liikunta- ja kehitysvammaisten nuorten elämänlaatu voi heikentyä sen jälkeen, kun he ovat siirtyneet nuoruudesta varhaisaikuisuuteen. Vaikeasti liikuntavammaisten nuorten elämänlaatua ei kuitenkaan ole tutkittu kokonaisvaltaisesti huomioiden kipujen ja toisen asteen koulutuksen suorittamisen vaikutus sekä nuorten kokemuksia terveydenhuollosta heidän siirryttyään lasten terveydenhuollosta aikuisten terveydenhuoltoon. Aiemmin ei ole myöskään tutkittu niitä tekijöitä, jotka aiheuttavat kielteisiä kokemuksia terveydenhuollosta ja jotka saattavat vaikuttaa nuorten elämänlaatuun. Tiedetään kuitenkin yksittäisiä tekijöitä, joihin vammaiset henkilöt saattavat olla tyytymättömiä terveydenhuollossa. Tämän tutkimuksen tavoitteena käyttää elämänlaadun ja systeemiajattelun viitekehyksiä kehitettäessä elämänlaadun toimeenpanon palautemalli toisen asteen koulutuspalveluiden ja perusterveydenhuollon laadun kehittämiseksi, jotta ne edistäisivät paremmin vaikeasti liikuntavammaisten nuorten elämänlaatua heidän siirryttyään toisen asteen koulutukseen ja lasten terveydenhuoltopalveluista aikuisten terveydenhuoltopalveluihin. Tätä varten ensimmäiseksi tutkittiin vaikeasti liikuntavammaisten nuorten subjektiivisen elämänlaadun tuloksia. Toiseksi tutkittiin tekijöitä, jotka olivat yhteydessä ja ennustivat nuorten toisen asteen koulutuksen suorittamista. Kolmanneksi tutkittiin sitä, mitkä tekijät olivat yhteydessä ja ennustivat nuorten kielteisiä kokemuksia terveydenhuoltopalveluista heidän siirryttyään lasten terveydenhuoltopalveluista aikuisten terveydenhuoltopalveluihin. Tutkimuksen tavoitteina oli tuottaa tietoa a) nuorten subjektiivisesta elämänlaadusta, b) toisen asteen koulutuksen suorittamiseen vaikuttavista tekijöistä sekä tekijöistä, jotka olivat yhteydessä kielteisiin kokemuksiin terveydenhuollosta. Näihin tutkimuskysymyksiin vastattiin kolmella osatutkimuksella, joissa vastaajina olivat 74 vaikeasti liikuntavammaista (joista 39 nuorella oli liitännäisvammana kehitysvamma) 19–22-vuotiasta nuorta. Aineisto kerättiin terveydenhuollon asiantuntijoiden kehittämällä Vaikeasti liikuntavammaisten nuorten elämäntilanne ja palvelujärjestelmien toimivuus Suomessa -kyselylomakkeella sekä WHO:n Quality of Life-Bréf-kyselylomakkeella.

Ensimmäisen osatutkimuksen tavoitteena oli selvittää, onko vaikeasti liikuntavammaisten nuorten ja vammattomien nuorten subjektiivisessa elämänlaadussa eroja. Lisäksi tutkittiin, onko vaikeasti liikuntavammaisten nuorten miesten ja naisten subjektiivisen elämänlaadun välillä eroja. Tutkimuksessa tarkasteltiin myös sitä, miten ikä, sukupuoli ja kipujen voimakkuus ovat yhteydessä subjektiiviseen elämänlaatuun. Yhden otoksen *t*-testi osoitti, että vaikeasti liikuntavammaisten nuorten fyysinen, sosiaalinen ja ympäristön elämänlaatu on matalampi kuin vammattomien nuorten. Riippumattomien otosten *t*-testit osoittivat, että vaikeasti liikuntavammaisten nuorten välillä ei ole sukupuolesta johtuvia eroja elämänlaadussa. Kuitenkin pieniä eroja löytyi, kun hierarkkisessa logistisessa regressioanalyysissa otettiin kipujen voimakkuus mukaan. Hierarkkisen logistisen regressioanalyysin tulosten mukaan vaikeasti liikuntavammaisilla miehillä oli matalampi psykologinen ja sosiaalinen elämänlaatu kuin vaikeasti liikuntavammaisilla naisilla, eikä nuoren korkeampi ikä vaikuttanut siihen, että vanhemmat nuoret olisivat saaneet korkeampia pisteitä kuin nuoremmat miehet näillä elämänlaadun osa-alueilla. Regressioanalyysi myös osoitti, että kipujen voimakkuus vaikutti kaikkiin elämänlaadun osa-alueisiin alentavasti: fyysiseen, psykologiseen, sosiaaliseen ja ympäristön elämänlaatuun. Regressioanalyysin tulosten mukaan vanhemmat nuoret (ikäjakauma 4 vuotta) saivat korkeampia fyysisen, psykologisen ja sosiaalisen elämänlaadun pisteitä kuin nuoremmat vastaajat. Ympäristön elämänlaatu ei noussut nuorten vanhentuessa. Tutkimuksen tulokset lisäsivät ymmärrystä siitä, millainen on vaikeasti liikuntavammaisten nuorten subjektiivinen elämänlaatu ja mitkä tekijät siihen vaikuttavat.

Toisen osatutkimuksen tavoitteena oli tutkia, mitkä tekijät ovat yhteydessä ja ennustivat vaikeasti liikunta- ja älyllisesti kehitysvammaisten nuorten toisen asteen koulutuksen suorittamista. Tutkimuksessa pyrittiin selvittämään, miten nuoren vammatyyppi, sukupuoli, asuinpaikka sekä luku- ja kirjoitustaito ovat yhteydessä toisen asteen koulutuksen suorittamiseen. Lisäksi tutkittiin, voivatko nuoren vammatyyppi, sukupuoli, asuinpaikka sekä luku- ja kirjoitustaito ennustavat nuoren toisen asteen koulutuksen suorittamista. Toisen osatutkimuksen tulokset osoittivat, että 66 % (49 nuorta 74 nuoresta) vaikeasti liikunta- ja monivammaisista nuorista oli suorittanut jonkin toisen asteen koulutuksen. Näin ollen 25 (34%) nuorella ei ollut mitään toisen asteen koulutusta. Fisherin tarkka testi osoitti, että vaikeasti liikuntavammaiset (muut kuin cp-vammaiset) nuoret, joilla oli myös kehitysvamma, eivät olleet yhtä suurella todennäköisyydellä suorittaneet toisen asteen koulutusta kuin nuoret, joilla oli jokin muu vammatyyppi. Nuoret, joilla oli cp-vamma, olivat todennäköisemmin suorittaneet toisen asteen koulutuksen kuin nuoret, joilla oli jokin muu vammatyyppi. Sukupuolella ei ollut yhteyttä toisen asteen koulutuksen suorittamiseen. Khiin neliö -testit osoittivat seuraavat kaksi tutkimustulosta. Ensinnäkin nuoren asuinpaikka oli yhteydessä toisen asteen koulutuksen suorittamiseen. Nuoret, jotka asuvat kaupungissa, olivat todennäköisemmin suorittaneet toisen asteen koulutuksen kuin maaseudulla asuvat nuoret. Toiseksi luku- ja kirjoitustaito oli yhteydessä toisen asteen koulutuksen suorittamiseen. Nuoret, joilla oli kohtalainen tai hyvä luku- ja kirjoitustaito, olivat todennäköisemmin suorittaneet toisen asteen koulutuksen kuin ne, joilla ei ollut luku- ja kirjoitustaitoa lainkaan. Binäärinen logistinen regressio osoitti, että nuoren asuinpaikka (kaupunki) ja kohtalainen tai hyvä luku- ja kirjoitustaito ennustivat toisen asteen koulutuksen suorittamista. Aiemmissa tutkimuksissa on havaittu, että nuoren ongelmien vakavuus ja koulutuspalveluiden puute selittävät vaikeavammaisten nuorten heikkoja koulutustuloksia (Nganji & Brayshaw, 2017; Osgood, Foster, & Courtney, 2010). Lisäksi on osoitettu, että älyllisesti kehitysvammaisten nuorten asuinpaikkakunnilla tarjottavista koulutuspalveluista on pula eivätkä koulutuspalvelut vastaa heidän tarpeitaan ja toiveitaan (Hermanoff, Määttä, & Uusiautti, 2017; Äikäs, 2012). Tämän tutkimuksen tulokset antavat tärkeää tietoa siitä, mitkä tekijät vaikuttavat vaikeasti liikunta- ja älyllisesti kehitysvammaisten nuorten toisen asteen koulutuksen suorittamiseen ja miten toisen asteen koulutuspalveluiden tarjontaa tulisi kehittää palvelemaan paremmin näitä nuoria. Tutkimuksen tulokset ovat linjassa aiempien tutkimustulosten kanssa osoittaen, että maaseudulla asuvien vaikeasti liikuntavammaisten ja älyllisesti kehitysvammaisten nuorten koulutuspalveluita tulisi suunnitella tukemaan nuorten toisen asteen kouluttautumista kotipaikkakunnalla. Toisen asteen koulutuspalveluita tulisi olla tarjolla myös pienemmillä paikkakunnilla, eikä vain isoissa kaupungeissa. Vammaisia nuoria pienemmillä paikkakunnilla ja maaseudulla opettaville erityisopettajille voidaan tarjota esimerkiksi säännöllistä eCoach-tukea (Horn, 2021) ammatillisten erityisoppilaitosten ja yliopistojen taholta. eCoach-konseptin idea on tukea opettajaa verkkovälitteisesti reaaliaikaisesti, kun hän opettaa vammaista nuorta (Horn, 2021). Tulokset vahvistavat myös aiempia tutkimuksia siitä, että vaikeasti liikunta- ja älyllisesti kehitysvammaisten nuorten luku- ja kirjoitustaidon oppiminen on keskeistä, jotta nuoret saisivat toisen asteen koulutuksen suoritettua.

Kolmannen osatutkimuksen tavoitteena oli tunnistaa tekijöitä, jotka ovat yhteydessä ja ennustavat vaikeasti liikuntavammaisten nuorten (joilla oli tai ei ollut liitännäisvammana älyllistä kehitysvammaa) kielteisiä kokemuksia terveydenhuoltopalveluista. Fisherin eksaktit testit osoittivat, että nuorten kielteiset kokemukset apuvälineiden saatavuudesta (nuorilla oli tarve uusille apuvälineille), kielteiset kokemukset pääsystä lääkärin vastaanotolle sekä heidän kielteiset kokemuksensa lääkärin tietämyksestä heidän vammastaan olivat yhteydessä kielteiseen kokemukseen terveydenhuoltopalveluista. Lisäksi binäärisen logistisen regression tulokset osoittivat, että nuorten kielteiset kokemukset apuvälineiden saatavuudesta (tarve uusille apuvälineille), lääkärin vastaanotolle pääsystä ja kielteiset kokemukset lääkärin tietämyksestä nuoren vammasta ennustivat kielteistä kokemusta terveydenhuoltopalveluista nuorten siirryttyä lasten terveydenhuollosta aikuisten terveydenhuoltoon. Binäärisen logistisen regression tuloksista ilmeni myös, että vaikeasti liikuntavammaisten nuorten (joilla ei ollut liitännäisvammana kehitysvammaa) kielteiset kokemukset lääkärin tietämyksestä heidän vammastaan ennustivat tyytymättömyyttä terveydenhuoltoon heidän siirryttyään lasten terveydenhuollosta aikuisten terveydenhuoltoon. Tutkimuksen tulokset painottavat sitä, että yleislääkäreiden koulutukseen tulisi lisätä vammaisuuteen liittyviä oppisisältöjä sekä sairaaloihin pitäisi perustaa näille nuorille kohdennettuja moniammatillisia poliklinikoita tai yksiköitä, joissa tapahtuisi nuorten säännöllinen ja moniammatillinen seuranta. Liikunta- ja kehitysvammaisten terveydenhuoltopalveluita tulisi kehittää yksilökeskeisemmiksi ja saavutettavimmiksi. Lisäksi on tärkeää tutkia säännöllisesti nuorten kokemuksia terveydenhuoltopalveluista, jotta terveydenhuoltopalveluita voidaan kehittää elämänlaadun toimeenpanon palautemallin mukaisesti edistämään vaikeasti liikuntavammaisten nuorten elämänlaatua.

Kokonaisuudessaan tutkimuksen tulokset osoittivat yhdenmukaisesti aiempien tutkimusten kanssa sen, että vaikeasti liikuntavammaisten, joilla oli tai ei ollut kehitysvammaa liitännäisvammana, nuorten subjektiivinen elämänlaatu on alhaisempi kuin vammattomilla nuorilla. Lisäksi tutkimuksen tulokset valottivat aikaisempaa ymmärrystä siitä, miten laajemmalla koulutus- ja terveydenhuoltojärjestelmällä on vaikutusta näiden nuorten subjektiiviseen ja objektiiviseen elämänlaatuun, toisen asteen suorittamiseen ja tyytymättömyyteen terveydenhuoltopalveluihin. Nämä tiedot ovat keskeisiä, sillä nuoret kokevat siirtymävaiheen koulutus- ja terveydenhuoltopalveluissa lasten palveluista aikuisten palveluihin, jolloin on tärkeää ottaa huomioon vaikeasti liikunta- ja kehitysvammaisten nuorten palveluihin liittyvät yksilölliset erityistarpeet. On tärkeää, että jatkotutkimuksissa näiden nuorten henkilökohtaisen elämänlaadun tuloksia ja palvelujärjestelmiin tyytyväisyyttä ja niiden toimivuutta tutkitaan lisää. Henkilökohtaisen elämänlaadun tuloksia ja tietoa tekijöistä, jotka ennustavat toisen asteen koulutuksen suorittamista sekä tietoa terveydenhuoltopalveluihin tyytymättömyyttä aiheuttavista tekijöistä voidaan hyödyntää päätöksenteossa suunniteltaessa ja toteutettaessa toisen asteen koulutuspalveluita ja terveydenhuoltopalveluita, jotka tukevat nuorten subjektiivista ja objektiivista elämänlaatua aikuisuudessa. Palveluilla on vaikutusta näiden nuorten subjektiiviseen ja objektiiviseen elämänlaatuun aikuisuudessa.

Tutkimuksen tulokset vahvistavat käsitystä siitä, että vaikeasti liikunta- ja älyllisesti kehitysvammaisten nuorten henkilökohtaisen elämänlaadun tuloksia tulisi käyttää toisen asteen koulutuspalveluiden ja terveydenhuoltopalveluiden suunnittelussa ja toteutuksessa näyttöön perustuvana tietona, jotta huomioidaan tämän ryhmän elämänlaatu sen jälkeen, kun he ovat siirtyneet toisen asteen koulutukseen ja aikuisten terveydenhuoltopalveluihin. Näin nuoret saisivat tarvitsemansa yksilölliset, esteettömät ja saavutettavat toisen asteen koulutuspalvelut ja terveydenhuoltopalvelut. Toisen asteen koulutuksessa ja terveydenhuoltopalveluissa tulisi olla vammaisuuteen liittyvää tietoa, taitoja ja osaamista enemmän, jotta koulutus-, ja terveydenhuoltopalvelut voidaan toteuttaa huomioiden liikunta- ja kehitysvammaisten nuorten aikuisten palvelutransitiovaiheen jälkeiset tarpeet ja toiveet. Nuorten elämänlaatua aikuisuudessa edistävien palveluiden suunnittelu ja toteuttaminen edellyttävät vammaisuudesta tietoisen ympäristön ja yhteisön perustamista. Jotta vaikeasti liikunta- ja kehitysvammainen nuori voisi osallistua toisen asteen koulutukseen kotipaikkakunnallaan, toisen asteen koulutuspalveluita voitaisiin pienemmillä paikkakunnilla tukea säännöllisillä tukikäynneillä esimerkiksi erityisammattioppilaitoksiin perustettujen tiimien toimesta sekä verkkovälitteisesti eCoaching-konseptin avulla (Horn, 2021). Terveydenhuoltoon tulisi Bolgerin, Vargus-Adamsin ja McMahonin (2017) sekä Mäenpään (ks. Kauppinen, 2022) ehdotuksen mukaisesti perustaa moniammatillinen klinikka tai yksikkö, jossa vaikeasti liikunta- ja älyllisesti kehitysvammaisten terveydenhuoltopalveluita voitaisiin koordinoidusti ja säännöllisesti hoitaa.

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ORIGINAL PAPERS

I

SUBJECTIVE QUALITY OF LIFE AMONG YOUTH WITH SEVERE PHYSICAL DISABILITIES DURING THE TRANSITION TO ADULTHOOD IN FINLAND

by

Heräjärvi, N., Leskinen, M., Pirttimaa, R., & Jokinen, K. (2020).

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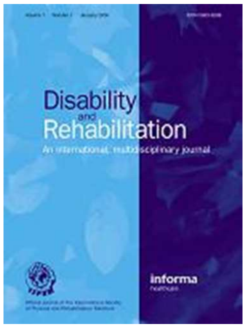

Subjective Quality of Life among Youth with Severe Physical Disabilities during the Transition to Adulthood in Finland

Journal:	*Disability and Rehabilitation*
Manuscript ID	Draft
Manuscript Type:	Research Paper
Keywords:	youth, severe physical disability, subjective quality of life, transition to adulthood, gender differences, pain

Implications for Rehabilitation

- youth with SPD experienced pain that affects their subjective QoL during the transition to adulthood
- youth with SPD would benefit from participation in social activities to promote their social and psychological QoL

Subjective Quality of Life among Youth with Severe Physical Disabilities during the Transition to Adulthood in Finland

Abstract

Purpose: Prior studies have shown that young people with severe physical disabilities (SPD) are at risk of diminished subjective quality of life (QoL) during the transition from youth to adulthood. Increasing age is associated with deterioration in QoL; gender differences in QoL may exist, and pain can negatively influence QoL. The study examined the subjective QoL of youth with SPD during the transition to adulthood to investigate any association with age, gender, and intensity of pain.

Method: A purposive sample of 42 males and 32 females (mean age 20.19) with SPD completed World Health Organization Quality of Life – Brèf (WHOQOL-BREF) to measure QoL; the Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland to measure health issues.

Results: One sample t-tests results indicated that physical, social, and environmental QoL of youth with SPD was lower than for those without disabilities. Independent samples t-tests showed that QoL of youth with SPD did not differ by gender. Sequential multiple regression analysis indicated that age, gender, and intensity of pain were correlated to subjective QoL.

Conclusions: Results suggest that youth with SPD need more education, health, and social care support services to promote their QoL during the transition to adulthood.

Keywords: youth, severe physical disability, subjective quality of life, transition to adulthood, gender differences, pain

Introduction

The aim of this research was to study the subjective quality of life (QoL) of young people with severe physical disability (SPD) during the transition to adulthood. The study adopts the United Nations definition of youth [1] as individuals between the ages 15 and 24 and quality of life is defined as ”the individual`s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [2]. Encompassing physical, psychological, social, and environmental domains [3], the subjective QoL of youth with SPD depends largely on the provision of relevant health, educational, and social services during their transition to adulthood [4]. In Finland, public sector takes care of citizens' health and wellbeing, with health and social services organised by statutory insurance [5]. Education services from pre-primary to higher level are publicly funded and organised by municipalities [6]. All of these services are also available to youth with SPD. Nevertheless, while undergoing normal life transitions in education, employment, and social relations [7], these young people may also experience problems related to their health and welfare [8–10].

During these transitions, they are at risk of dropping out of everyday support services, which may lead to decreased subjective QoL. For that reason, these transitions are critical for this group, as they must live with their disability for their entire life [11,12]. That being so, it is useful for a number of reasons to explore their QoL in transition. First, youth with SPD may experience lower subjective QoL than their peers without disabilities [13–16]. Second, in general population, female youth may experience poorer QoL than male youth [17–19]. As indicated by the WHOQOL-BREF's population norms (see Table 5) [18] used as criterion values in this study, young females between the ages of 20 and 29 return lower scores in physical, psychological, and environmental domains than young males of the same age. Most earlier studies suggest that the overall QoL of young males and females with disabilities does not differ by gender [20,13,21,14]. However, Torres and Vieira [22] found that female adolescents with disabilities aged 10–19 years have lower global QoL than males. While young females with disabilites may have lower psychological and environmental QoL [22], their social QoL may be better than young males with disabilities [23]. One of this study aim was to detect any differences by gender in QoL domains.

A third important variable is age; children and adolescents with physical disabilities have reported initially fair or good QoL [24,25,20,26], and Lin et al. [21] found that adolescents (aged 13–18 years) with disabilities have better subjective QoL than those without disabilities, although the limited number of studies prevent any definitive conclusions. Following adolescence, however, youth with disabilities seem to experience a permanent deterioration in subjective QoL [13,14,15,16,27]. In adulthood, the QoL of individuals with disabilities is likely to be lower than for persons without disabilities [28,29], although some adults with severe disabilities experience good QoL [30].

Frequently recurring pain adversely affects subjective QOL among youth with SPD by preventing them from attending physical activities and causing distress [31,15,32]. A few existing studies have shown that children and youth with cerebral palsy aged between 1 and 19 years experienced monthly pain at an intensity of 1.4 on a 0–5 scale [33], and children and youth with physical disabilities aged between 8 and 21 years experienced chronic pain at an intensity of 3.2 on a 0–10 scale [34]. On investigating the association of pain with QoL among youth with physical disabilities, Riquelme et al. [15] concluded that these young people had a lower QoL as compared to healthy youth experiencing occasional pain.

In Finland, little is known about subjective QoL among youth with SPD during the transition to adulthood. According to Böling et al. [24], Finnish children with cerebral palsy have fairly good QoL, but some Finnish evidence suggests that youth with disabilities do not receive the health, educational, and social supports they need and are excluded from education and employment. Moreover, their health deteriorates rapidly, resulting in lowered QoL [35,10]. The present study aims to contribute to a fuller understanding of subjective QoL among youth with SPD by addressing four primary objectives: 1) to explore subjective QoL among youth with SPD during the transition to adulthood; 2) to identify any differences in subjective QoL between young males and females with SPD; 3) to investigate how age and gender relate to subjective QoL among youth with SPD; and 4) to determine whether intensity of pain is associated with subjective QoL among youth with SPD.

Transitional challenges

When entering adulthood, youth with disabilities typically face the same major life transitions in education, employment, and social relations as all young people

[36]. In addition, however, youth with disabilities experience health, health service, and social service transitions [8,37] that may impact on physical, psychological, social, and environmental aspects of their subjective QoL. In Finland, one such transition occurs when basic education ends at the age of sixteen or seventeen (depending on whether the pupil has extended compulsory education) [38]. At this point, youth with SPD may have restricted opportunities to participate in secondary education, and dropout is a possibility [39–41], which may affect their future employment [42]. Additionally, their social context may change, as they may not move to the same educational context as their peers without disabilities [43]. Opportunities to practice social skills with nondisabled youth therefore diminish, increasing the probability of social difficulties and isolation [44]. In addition to educational transition, youth with disabilities experience health service transitions and changes in health status.

In Finland, the transition from child to adult health services for this group occurs on reaching the age of sixteen [45]. At this point, access to specialist consultation may become difficult, leading to drop-out from adult health services unless sufficient information has been provided [46,47,16]. Another potential problem is that because adult health services are not usually equipped to manage a young person with disabilities [46–50] and other health concerns can therefore emerge (e.g. obesity, deconditioning, joint problems, cardiovascular disease, emotional difficulties, respiratory problems).

Deterioration of physical functioning with the loss of walking ability and emerging activity limitations may be accompanied by premature ageing and frequent pain in the muscles and joints [51,52,32]. Additionally, medical procedures can lead to increased pain [53–55]; it seems that pain is more common in females, but the lack of comparative studies of pain in this context prevents any definitive conclusions [20,56,27].

In Finland, these health-related concerns occur at the same time as the transition from the children's to the adult social system, with the associated issue of ensuring that youth with SPD obtain all requisite social services [45]. Meeting these transition goals, and ensuring good QoL for youth with SPD depends on proactive service provision. To understand the life situation and needs of these young people, the present study investigated their subjective QoL during the transition from youth to adulthood.

Methods

Setting and design

In 2010, the Social Insurance Institution of Finland and five central hospitals embarked on a project entitled Severely disabled youths' life situation and the functioning of the service systems in Finland which aimed to assess the life situation of youth with severe physical disabilities and the services provided for them. A further objective was to explore the subjective QoL of youth with severe physical disabilities. The project obtained research permits from the Ethical Committee of Joint Authority for Päijät-Häme Social and Health Care in Lahti, Finland. Päijät-Häme Central Hospital collected the survey data between 2010 and 2012 during home visits by two researcher that lasted between 1.5 and 6 hours. In each home, parents or a personal assistant familiar with their challenges and needs helped the young person to complete the questionnaires.

Participants

All SPD participants (*N* = 74) were former patients of five child neurological clinics in Finland. They were recruited through purposeful sampling by Päijät-Häme Central Hospital’s Department of Child Neurology. Ranging in age between 19 and 22 years (*M* = 20.2, *SD* = 1.16), 32 (43.2 %) were female, and 42 (56.8 %) were male. Sixty-one (82.4 %) had another disability as well as SPD. Participant’s major impairments, education, occupational status, and housing situation are set out in Table 1. In relation to inclusion criteria were, participants had to be at least 16 years old (so facing major life transitions) wheelchair users (implying severe physical disability).

______ ______ ______ ______

Insert Table 1 about here

______ ______ ______ ______

Instruments and Measures

The WHOQOL-BREF (WHO Quality of Life-Brief) instrument was translated into Finnish by the Päijät-Häme Central Hospital’s Department of Child Neurology to collect QoL survey data. This short-form version has cross-cultural validity and includes 26 items related to subjective and multidimensional QoL domains; rated on five-point Likert interval response scales, higher scores indicate better QoL [2].

Of those 26 items, the first two global QoL relate to global QoL, and overall health; the remaining 24 items are analyzed to produce a QoL score from 0–100 across 4 domains: physical (7 items), psychological (6 items), social (3 items), and environmental (8 items) [57]. Reliability for the WHOQOL-BREF instrument was .85 (Cronbach`s alpha), which aligns with previous studies, in which alpha ranged between .70 and .89 [58–60]. Alpha values for the respective domains were .57 (physical), .80 (psychological), .44 (social), and .59 (environmental). The low alpha value for the physical domain may result from the absence of item number 15, which relates to the respondent's mobility. The low alpha for the social domain may be due to the small number of items (3) in the domain.

The 104-item Severely Disabled Youths' Life Situation and Functioning of Service Systems in Finland survey instrument is used by healthcare professionals to assess six areas: health, functioning, housing, studying/occupation, service systems, and social relations. For present purposes, the intensity of pain item from the health section was assessed on a 10-point numerical Visual Analogue Scale, where 0 indicates no pain and 10 indicates unbearable pain [61].

Statistical analyses were performed using IBM's Statistical Package for the Social Sciences (SPSS) 24.0 for Windows. The Shapiro-Wilk test was used to assess normality of distributions. Effect sizes were calculated using Cohen`s *d*, where small = 0.20, medium = 0.50, and large = 0.80 [62]. One-sample *t*-tests were conducted to identify any statistically significant differences between physical, psychological, social, and environmental QoL scores for young people with SPD and without SPD. QoL mean scores for youth with SPD were compared to WHOQOL-BREF population norms, see [18]. One-sample *t*-tests were performed to detect any statistically significant differences between QoL domain scores for young males with and without SPD. Independent samples *t*-tests were used to determine whether statistically significant differences existed between QoL domain scores for young females with SPD and without SPD.

A three-stage sequential multiple linear regression was employed, consisting of three blocks, using the QoL domains as dependent variables. Significant correlations were found with outcome variables, with the exception of gender (see Table 2). In block one, age was entered as a control variable as previous research suggested that QoL may decrease with age. Block two evaluated the impact of gender (female = 0, male = 1) on the QoL domains, as earlier studies have indicated some differences in this regard. In block three, intensity of pain was used to assess the impact of pain on QoL domains. Regression diagnostics were used to test whether the model assumptions were valid. A significance level of p < .05 was adopted for all tests.

______ ______ ______ ______

Insert Table 2 about here

______ ______ ______ ______

Results

The mean score for overall QoL was 3. 68 for males (*SD* = 0.82) and 4.00 for females (*SD* = 0.84), and the mean score for health-related QoL was 3. 67 for males (*SD* = 1.07), and 3. 59 for females (*SD* = 1.04). Table 3 presents the independent samples *t*-tests, mean (*SD*) domain scores and confidence intervals (95 %) by gender for youth with SPD.

______ ______ ______ ______

Insert Table 3 about here

______ ______ ______ ______

As indicated by the one-sample *t*-tests results in Table 4, youth with SPD reported a significantly lower physical QoL (*M* = 65.54, *SD* = 15.46) than youth without SPD (*t*(73) = -11.05, *p* < .001, *d* = 1.41, 95 % CI [-23.44, -16.28]). Physical QoL (*M* = 65.48, *SD* = 17.54) for male youth with SPD differed significantly from that of youth without SPD (t(41) = -8.58, p < .001, d = 1.47, 95 % CI [-28.69, -17.76]). Additionally, physical QoL (*M* = 65.63, *SD* = 12.48) for female youth with SPD was found to differ significantly from that of female youth without SPD (*t*(31) = -8.15, *p* < .001, *d* = 1.51, 95 % CI [-22.47, -13.48]). The results indicated a significantly lower psychological QoL (*M* = 65.91, *SD* = 19.80) for males with SPD as compared to those without SPD (*t*(41), = -2.75, *p* = .009, *d* = 0.41, 95 % CI [-14.56, - 2.22]).

Youth with SPD exhibited significantly lower social QoL (*M* = 66.95, *SD* = 18.66) as compared to youth without SPD (*t*(73) = -2.74, *p* = .008, *d* = 0.32, 95 % CI [-10.28, -1.63]). Youth with SPD also exhibited a significantly lower environmental QoL (*M* = 66.53, *SD* = 13.68) than youth without SPD (*t*(73) = -4.89, *p* <. 001, *d* = 0.56, 95 % CI [-10.94, -4.60]). Males with SPD returned significantly lower mean scores for environmental QoL (*M* = 65.55, *SD* = 13.01) than males without SPD (*t*(41) = -5.80, *p* < . 001, *d* = 0.54, 95 % CI [-15.70, -7.59]).

______ ______ ______ ______

Insert Table 4 about here

______ ______ ______ ______

A sequential multiple regression analysis was used to assess whether age, gender, and intensity of pain could explain a significant amount of the variance for physical, psychological, social, and environmental QoL. The results for each of the outcome variables are described below and summarized in Table 5.

Predicting physical QoL. The final model in step 3 predicted 26 % of the variance in physical QoL ($F(3, 63) = 7.18$, $p = .000$), with age ($\beta = .35$, $p = .002$) as a significant positive predictor and intensity of pain ($\beta = -.39$, $p = .001$) as a significant negative predictor.

Predicting psychological QoL. The step 3 model was significant ($F(3, 63) = 4.78$, $p = .005$), explaining 19 % of the variance in psychological QoL. Adding intensity of pain, the explained variance significantly increased, $\Delta R^2 = .03$, $F(1, 63) = 5.19$, $p = .026$. There was a significant positive association with age ($\beta = .28$, $p = .018$); gender ($p = .025$) and intensity of pain ($p = .026$) made a significant and equal negative ($\beta = -.26$) contribution to psychological QoL.

Predicting social QoL. In step 3, after adding intensity of pain, the model reached significance ($\Delta R^2 = .13$, $F(3, 63) = 5.89$, $p = .002$). This model explained 22 % of the variance ($F(3, 63) = 5.89$, $p = .001$). Age was a significant positive predictor ($\beta = .23$, $p = .041$), and intensity of pain ($\beta = -.36$, $p = .002$) was the strongest negative predictor of social QoL before gender ($\beta = -.27$, $p = .019$).

Predicting environmental QoL. The model reached significance after adding step 3 to the model ($\Delta R^2 = .13$, $F(3, 63) = 3.23$, $p = .003$), explaining 13 % of the variance in environmental QoL (R^2=13, $F(3, 63) = 3.23$, $p = .028$). The only significant predictor was intensity of pain ($\beta = -.37$, $p = .003$).

______ ______ ______ ______

Insert Table 5 about here

______ ______ ______ ______

Discussion and Implications for Policy

This study investigated subjective QoL among youth with SPD during the transition to adulthood. The study also sought to determine whether subjective QOL differed between young males and females with SPD. A third objective was to establish whether age, gender, and intensity of pain were related to subjective QoL among youth with SPD.

The results reinforce the perception that subjective QoL among youth with SPD (both males and females) is lower than among youth without SPD, at least in the physical, social, and environmental domains. Regarding differences between youth with and without SPD by gender, the results show that males and females with SPD had poorer physical QoL than males and females without SPD. Moreover, psychological and environmental QoL among male youth with SPD was lower than that of male youth without disabilities. Moreira et al. [63] found that both genders of children and adolescents (aged 8–18) with chronic health conditions reported decreased psychological QoL.

Possible explanations for these findings include the following. Differences in physical QoL may arise from the health and functional challenges experienced by youth with SPD during their transition to adulthood. These are called secondary conditions and refer to the various physical, psychological, social, and emotional problems that result from the disability itself. For example, pain, fatigue, depression, sleep problems, and obesity are secondary conditions that can be mitigated or prevented. However, unless managed or treated, secondary conditions commonly restrict participation in activities [64].

The poorer psychological QoL values for males with SPD may be a consequence of having fewer friends than females with SPD [65]. In turn, the lower social QoL of youth with SPD may be due to their restricted opportunities to participate in social activities and to form social relationships [66]. The low environmental QoL score may reflect a lack of satisfaction with options for getting around in the built environment and enjoying leisure time activities. Safety and living conditions may also be of concerns in this domain. Additionally, everyday financial issues can be a source of worry. Among youth with SPD, financial concerns may be associated with physical functional limitations, as these commonly restrict employment opportunities [67] and therefore income. Problems in accessing health and social services and the everyday availability of information may also diminish environmental QoL.

The absence of differences in QoL by gender aligns with earlier studies; nor were there differences by gender in QoL domains, although prior studies have identified some such differences. One possible explanation relates to young people's living context in Finland; while health, education, and social services are the same for both genders, there may be some regional differences. Additionally, Finnish society's fundamental commitment to gender equality and the non-existence of gender discrimination in institutions, services, and decision-making [68] may in part account for these findings.

The results of the sequential multiple regression analysis showed that age, gender, and intensity of pain explained the variability of subjective QoL among youth with SPD (26 % of physical, 19 % of psychological, 22 % of social, and 13 % of environmental). In all QoL domains, intensity of pain was the most important predictor. Rimmer et al. [64] also found that people with disabilities experienced pain that affects their physical and environmental QoL and represents a significant barrier to functioning and participation. The present findings indicate that pain contributes negatively to subjective QoL in a holistic way, as it also influences psychological and social QoL.

Age was moderately associated with physical, psychological, and social QoL but not with environmental QoL. This finding suggests that the older the youth, the higher their QoL. This conflicts with earlier studies showing that QoL decreases with age, and that youth entering adulthood report lower subjective QoL than adolescents [e.g., 23]. One possible explanation is that older youth are more adjusted than the younger ones in terms of physical, psychological, and social QoL.

However, age had no positive association with environmental QoL, which suggests that older youth may be dissatisfied with their residence, opportunities to move around in their residential area, and access to social and health services. Moreover, increasing age may not have a positive influence on young people’s financial situation. Almost half of those who participated received a disability pension (n = 35 or 47.30 %) or attended a daytime activity center (n = 29 or 39.19 %), with no income from employment. As Finland’s system allows youth SPD to apply for a disability pension [69], education and employment of youth is not incentivized. In light of the influence of age on subjective QoL among youth with SPD, an age range wider than four years (as here) may have yielded different findings.

Gender was the weakest predictor of QoL, predicting lower psychological and social QoL for males. These results suggest that psychological and social QoL do not increase as males grow older. On the whole, it is possble that gender may have reached statistical significance in other QoL domains if more background information about the participants had been included in the analysis; here, the association of gender with QoL became stronger when included along with age.

These results provide an insight into the QoL of youth with SPD confirming that these young people may experience pain, social participation problems, and loneliness, impacting on their QoL later in adulthood [70,59,71]. However, the results must be interpreted with caution for a number of reasons. Among these, there was no assessment of objective QoL or personality traits [72], both of which might have influenced the results. In particular, as age, gender, and intensity of pain explained only part of subjective QoL among youth with SPD, an assessment of objective QoL would increase understanding of overall QoL. Objective QoL indicators include the individual's living circumstances, as well as health, education, income, and employment, complementing the subjective indicators [73]. In addition, a larger sample size and random sampling would produce more reliable and generalizable results.

The results of this study have a number of practical implications for service providers, given that the transition to adulthood for youth with SPD includes changes in health, health services, education, and social services. As these young people reported lower subjective QoL than those without SPD, the relevant policy makers should cooperate with youth to develop services that are accessible and holistic to better meet the needs of young people and to improve QoL among transition-age youth [74]. Additionally, the pain of youth with SPD should be recognized in the transition from child to adult health services, as pain has an impact on subjective QoL [75]. In addition, male youth with SPD need preventive support to promote psychological and social well-being in adulthood [76], as the regression analysis shows that males experienced lower psychological and social QoL than females. For example, male youth may benefit from leisure-time activities that prevent social isolation, which may indicate a lack of social support and close relationships [77]. Finally, the lower environmental QoL of both genders reflects their poor financial situation, which may prevent them from enjoying social or leisure-time activities [78]. Social services should respond to this need to improve young people's financial situation.

The findings also reveal that 28 (37,84 %) of these young people did not attend secondary school following basic and preparatory education. As youth with SPD also have the right to employment [79], further research should aim to identify and remove any barriers to their participation in secondary education and employment.

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Declaration of interest

The authors report no conflicts of interest.

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Table 1

Description of Participants (*N*=74)

Variable	*n*	%
Impairment		
Physical disablity	74	100.00
Cerebral palsy	47	63.51
Intellectual disability	39	52.70
Speech disability	31	41.89
Visual disability	24	32.43
Other (e.g. visual processing disorder, learning disability)	21	28.35
Education		
Mainstream education completely individualized	52	70.27
Mainstream education partly individualized	7	27.03 22.97
Mainstream education at comprehensive school	13	17.57
Preparatory education	17	10.80
Special vocational school	20	9.46
Vocational school	8	
Other (e.g. folk high school, special folk high school, upper secondary school)	18	24.32
Occupational status		
Disability pension	35	47.30
Daytime activity center	29	39.19
Other	10	13.50
Housing situation		
Home with parents	36	48.65
Nursing home	13	17.57
Residential care	12	16.22
Home with parents and respite care	7	9.46
Other	6	8.11

Note. Impairment: 61 youth (82.43 %) exhibited comorbidity of impairments. Education: completed or currently undergoing.

Table 2

Correlations, Means, and Standard Deviations for Age, Gender, Intensity of Pain and QoL

Variable	1	2	3	4	5	6	7
1. Age	–	–	–	–	–	–	–
2. Gender	.03	–	–	–	–	–	–
3. Intensity of pain	.06	-.13	–	–	–	–	–
4. Physical QoL	.35**	-.01	-.36**	–	–	–	–
5. Psychological QoL	.28*	-.20	-.21	.74**	–	–	–
6. Social QoL	.21	-.21	-.31*	.53**	.63**	–	–
7. Environmental QoL	.01	-.08	-.35**	.44**	.44**	.43**	–
M	20.19	0.57	5.12	65.54	69.11	66.95	66.53
SD	1.16	0.50	2.76	15.46	18.42	18.66	13.68

Note. N = 67–74; female = 0; male = 1
**p* < .01. ***p* < .05

Table 3

WHOQOL-BREF Domain Scores by Gender for Youth With Severe Physical Disabilities

Gender		WHOQOL-Brèf domains															
		Physical				Psychological				Social				Environment			
				95 % CI				95 % CI				95 % CI				95 % CI	
	N	*M*	*SD*	*LL*	*UL*	*M*	*SD*	*LL*	*UL*	*M*	*SD*	*LL*	*UL*	*M*	*SD*	*LL*	*UL*
Male	42	65.48	17.54	60.01	70.94	65.91	19.80	59.74	72.08	63.59	18.97	57.68	69.50	65.55	13.01	61.50	69.61
Female	32	65.63	12.48	61.13	70.12	73.31	15.76	67.62	78.99	71.35	17.57	65.02	77.69	67.82	14.62	62.54	73.09
All	74	65.54	15.46	61.96	69.12	69.11	18.42	64.84	73.38	66.95	18.66	62.62	71.27	66.53	13.68	63.36	69.70

*Note.*CI = confidence interval; *LL* = lower limit; *UL* = upper limit; *d* = Cohen`s effect size.
Statistics for gender differences: Physical: *t* (72) 0.04, *p* = .968, *d* = 0.01 ; Psychological: *t* (72) 1.73, *p* = .087, *d* = 0.41; Social: *t* (72) 1.80, *p* = .076, *d* = 0.42; Environmental: *t* (72) 0.70, *p* = .484, *d* = 0.17.

Table 4

One-sample t-tests Results Comparing Young Males and Females With and Without SPD on QoL Domains

QoL Domain	Gender	Group	*N*	*M*	*SD*	95 % CI		*t*	df	*d*
Physical						*LL*	*UL*			
	Male									
		SPD	42	65.48	17.54	-28.69	-17.76	-8.58^{***}	41	1.47
		NSPD	17	88.70	9.80	83.70	93.70			
	Female									
		SPD	32	65.63	12.48	-22.47	-13.48	-8.15^{***}	31	1.51
		NSPD	30	83.60	11.30	79.40	87.80			
	All									
		SPD	74	65.54	15.46	-23.44	-16.28	-11.05^{***}	73	1.41
		NSPD	47	85.40	10.90	82.20	88.60			
Psychological										
	Male									
		SPD	42	65.91	19.80	-14.56	-2.22	-2.75^{**}	41	0.41
		NSPD	17	74.30	16.80	65.70	82.90			
	Female									
		SPD	32	73.31	15.76	-2.08	9.29	1.29	31	-0.22
		NSPD	30	69.70	17.90	63.00	76.40			
	All									
		SPD	74	69.11	18.42	-6.56	1.98	-1.07	73	0.13
		NSPD	47	71.40	17.50	66.30	76.50			
Social										
	Male									
		SPD	42	63.59	18.97	-10.42	1.40	-1.54	41	0.22
		NSPD	17	68.10	23.40	56.10	80.10			
	Female									
		SPD	32	71.35	17.57	-10.58	2.09	-1.37	31	0.26
		NSPD	30	75.60	15.30	69.90	81.30			
	All									
		SPD	74	66.95	18.66	-10.28	-1.63	-2.74^{**}	73	0.32
		NSPD	47	72.90	18.80	67.40	78.40			
Environment										
	Male									
		SPD	42	65.55	13.01	-15.70	-7.59	-5.80^{***}	41	0.54
		NSPD	17	77.20	10.60	71.80	82.70			
	Female									
		SPD	32	67.82	14.62	-10.16	0.39	-1.89	31	0.32
		NSPD	30	72.70	15.60	66.90	78.50	-1.89	31	0.32

(continued)

Table 4

One-sample t-tests Results Comparing Young Males and Females With and Without SPD on QoL Domains (continued)

QoL Domain	Gender	Group	*N*	*M*	*SD*	95 % CI		*t*	*df*	*d*
						LL	*UL*			
	All									
		SPD	74	66.53	13.68	-10.94	-4.60	-4.89***	73	0.56
		NSPD	47	74.30	14.00	70.20	78.40			

Note. NSPD = young males and females without SPD; CI = confidence interval; *LL* = lower limit; *UL* = upper limit; *d* = Cohen`s effect size. QOL domain scores and effect sizes of non-SPD youth are from ”Interpreting the WHOQOL-BRÉF: Preliminary population norms and effect sizes” by G. Hawthorne, H. Herrman & B. Murphy, 2006, *Social Indicators Research*, 77, p. 44.
*p < .05. **p < .01. ***p < .001.

Table 5

Summary of Sequential Multiple Regression Analysis for Variables Predicting Quality of Life Domains

Dependent variable		Independent variable	*F* (degrees of freedom)		R^2	ΔR^2	β	*t*
Physical QoL	Step 1	A	7.44*	(1, 65)	.10	.10*	.32	2.73*
	Step 2	A and G	3.67*	(2, 64)	.10	.00		
		A					.32	2.71*
		G					-.02	-.14
	Step 3	A, G, IP	7.18*	(3, 63)	.26	.15*		
		A					.35	3.18*
		G					-.07	-.60
		IP					-.39	-3.58*
Psychological QoL	Step 1	A	4.57*	(1, 65)	.07	.07*	.26	2.14*
	Step 2	A and G	4.30*	(2, 64)	.12	.05		
		A					.28	2.21*
		G					-.23	-1.96
	Step 3	A, G, IP	4.78*	(3, 63)	.19	.03*		
		A					.28	2.42*
		G					-.26	-2.29*
		IP					-.26	-2.28*
Social QoL	Step 1	A	2.91	(1, 65)	.04	.04	.21	1.71
	Step 2	A and G	3.30*	(2, 64)	.09	.05		
		A					.21	1.76
		G					-.23	-1.89
	Step 3	A, G, IP	5.89*	(3, 63)	.22	.13*		
		A					.23	2.09*
		G					-.27	-2.41*
		IP					-.36	-3.19*
Environmental QoL	Step 1	A	.03	(1, 65)	.00	.00	.02	.18
	Step 2	A and G	.06	(2, 64)	.00	.00		
		A					.02	.18
		G					-.04	-.29
	Step 3	A, G, IP	3.23*	(3, 63)	.13	.13*		
		A					.05	.40
		G					-.08	-.69
		IP					-.37	-3.09*

Note. A = age; G = gender; IP = intensity of pain; female = 0; male = 1.
*p < .05.

II

PREDICTORS OF COMPLETION OF UPPER SECONDARY EDUCATION OF YOUNG ADULTS WITH SEVERE PHYSICAL AND MULTIPLE DISABILITIES IN FINLAND

by

Heräjärvi, N. U., Leskinen, M. O., Pirttimaa, R. A., Jokinen, K. J., & Arvio, M. A. (2020).

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III

IDENTIFYING THE FACTORS ASSOCIATED WITH NEGATIVE PUBLIC HEALTH CARE EXPERIENCES OF YOUNG ADULTS WITH SEVERE PHYSICAL DISABILITIES WITH OR WITHOUT A CO-OCCURRING INTELLECTUAL DISABILITY AFTER THEIR TRANSITION FROM CHILD TO ADULT HEALTH CARE IN FINLAND

by

Heräjärvi, N., Leskinen, M., Pirttimaa, R., Virtanen, T., & Jokinen, K. (2023).

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