

ARTICLE

'In the Next Moment I Answer, it is Not Possible.' Professionals' Experiences from Transition Planning for Young People

Wenche Bekken¹, Borgunn Ytterhus² and Sylvia Söderström²

¹ Oslo Metropolitan University, NO

² NTNU-Norwegian University of Science and Technology, NO

Corresponding author: Wenche Bekken (webe@oslomet.no)

In this article, we explore dilemmas professionals experience in the planning for the transition to adulthood for young people with disabilities. Five group interviews with a total of 16 professionals working in the habilitation services were conducted. They experienced structural shortcomings and a lack of resources to support the aspirations of the young people with disabilities. Much effort was directed towards giving young people a 'realistic' understanding of what they can expect from the public services within the limits of their abilities. We argue that this leaves little room for addressing the hopes and aspirations of young people with disabilities for the future. This is crucial for planning for a life as an active citizen. These shortcomings may restrict young people with disabilities opportunities in developing a strong self and question if they really matter as a worthy citizen.

Keywords: young people; disability; practice; professionals; rehabilitation; transition

Introduction

The transition to adulthood is a non-linear and complex process that takes place over time. For young people with disabilities (YPD) challenges are compounded by the need to move between healthcare, social care, and education, and from child-centred services to adult-oriented services. The complexities of the transition to adulthood seem, however, to be similar for youth with different types of disabilities (Stewart et al. 2014). The move between child-centred and adult-oriented health care services is intended to be a purposeful, planned movement of a young person with chronic physical and medical conditions (Medforth & Huntingdon 2018: 128). In Norway, children with disabilities are enrolled into the habilitation service from an early age. At legal age the system of support changes, implying that collaboration between services and institutions changes and must be re-/established. After finishing school these young people may be faced with a vacuum that can result in problems with upholding meaningful activities (Bekken 2020). It is important to critically discuss what opportunities young people are given in this planning process. We discuss this transition period in the lives of YPDs from the perspectives of professionals working in the habilitation services.

The Norwegian public authorities aim of the habilitation and rehabilitation services is to support people with disabilities so they can use their skills and participate in society in line with their own ambitions and capacities (Whitepaper on habilitation and rehabilitation, individual plan and coordinator 2018) (Helsedepartementet 2018). The habilitation and rehabilitation services are authorized regulated by the Health Directorate's Service on Habilitation and Rehabilitation, Individual Plan and Coordinator, § 2 (Helse- og omsorgsdepartementet 2011a), and run by the Specialized Health Services Act (2018) (Helsedepartementet 2018) and the Health and Care Services Act in the municipalities (2011) (Helse- og omsorgsdepartementet 2011b). Consequently, the service provision is organized by two different service levels, the primary health care service at the municipality level and the specialist health care service at the regional level. This requires extensive collaboration between professionals (horizontal relations), but also across service levels (vertical relations) throughout a person's life course. For YPDs a smooth horizontal and vertical collaboration and coordination of services and support are crucial. (Re)habilitation practices are guided by national normative guidelines (2018) and the collaboration between professionals across services and levels in the organisations and, with the YPD, is supposed to give person-centred support and effective service deliverances and user satisfaction. When the person reaches legal age new contacts and collaborations are established with less regular follow up. However, professionals in the habilitation services have a common responsibility to do their very best to prevent YPDs becoming not in education, employment, or training' (NEETs).

Halvorsen and Hvinden (2018a; 2018b) demonstrate that YPDs are at greater risk of becoming NEETs than young people without disabilities. They argue that the former must be provided real opportunities for exercising influence over the services provided – in other words, for practicing co-production of services. For the voices of YPDs to count, they must be recognized in ways that make them experience that their voice is taken seriously. Bekken (2020) suggest that this is about truly listening to and to act upon their experiences. The tension between the hope of living an ordinary life and dependence on support can be difficult to navigate, and the professionals' advice influence the hopes the young adults are given. Providing information about rights and discussing housing arrangements as young adult is for example standard procedure. Norway ratified the convention in 2013. Article 26 underlines that countries are to enable persons to attain maximum independence and ability and that countries are to provide comprehensive habilitation in the areas of health, employment, and education. A crucial goal is to include the person in decisions from an early age and to ask the YPD what they aspire for and not assume what they aspire for, regardless of disability or low expectations from professionals about the chances they have for participating in work life.

Purpose of the article

The aim of this article is to examine how the professionals manage the dilemmas they are faced with in their work with YPD. We critically discuss how the professional practices support the young adults' unique preferences and individual aspirations.

The Difficult Transition to Adulthood

Challenges related to the transition from services for children to services for adults include limited access to health care, limited information about rights and duties, and uncertainty regarding the transition process (White & McManus 2018; Young et al. 2009). It is reported that young people with disabilities experience psychosocial, cognitive, and physical challenges in the transition to becoming young adult (Ridosh et al. 2011; Holmbeck et al. 2010; Sawyer & Macnee 2010; Roebroek et al. 2009). It is documented that persons in need of life-long services run the risk of developing a weaker sense of self than those who do not need any services (Von Tetzchner 2005: 274; Halvorsen & Hvinden 2018a). Parents of children with disabilities are reported to struggle for their children's right to services and support (Lundeby 2008; Egilson & Traustadottir 2015). And, moreover, the experience of stigma remains an issue for many people with disabilities, especially when applying for and receiving services. We know less about how professionals take these challenges into account in their work with YPDs.

Factors promoting a successful transition has been found to be professional expertise in transition practices and interdisciplinary teams that support individual YPD and their unique preferences and aspirations. Moreover, professionals need to plan and co-ordinate the transition process, share their expertise, and collaborate with each other (Medforth & Huntingdon 2018). Facilitators that help young people with disabilities develop their capacity include self-advocacy, pursuing post-secondary education, family support, and social networks (Hanes et al. 2019). Transition planning needs to start early, with one key worker managing the transition; the YPD needs to feel acknowledged and secure, their parents must be kept informed; and open interdisciplinary communication is necessary, as is a documented transition plan (Medforth & Huntingdon 2018). There is a gap in the literature about the dilemmas that the professionals may be faced with in supporting YPD's preferences and aspirations.

Hamdani, Mistry, and Gibson (2015) found that transition practices reproduce normative notions and dominant social values of independence, adulthood, and life trajectories. Such aims may not be appropriate for all YPDs, and Hamdani, Mistry, and Gibson (2015) recommend that an alternative understanding of the life course and approaches to transition need to be considered alongside the dominant practices. They argue that professionals should be aware of both positive and negative consequences of transition practices that emphasize normal trajectories and milestones and that discussions with YPDs should offer multiple possibilities for living a good life. Stewart et al. (2014) recommend that rehabilitation providers address the complexities of transition in a holistic, strengths-based, and collaborative manner and acknowledge the significance of the interactions between person and environment. Those who provide (re)habilitation services are encouraged to find sensitive ways to balance thinking about the present and the future to match individual circumstances and priorities (Hamdani, Mistry & Gibson 2015). This article seeks to contribute with new knowledge to this research literature by presenting dilemmas professionals may be faced with in their work with YPDs in transition. By critically examining the professionals' handling of these dilemmas, the article contributes with knowledge about how structural shortcomings in the welfare services interfere with the professional work.

Professionals Influencing Identities (Possibilities)

Several factors influence the encounter between professionals and YPDs. The professionals must balance between to accommodate the needs of the YPD and the efficiency of the system. This may put the professionals in dilemmas of what to prioritize: the demands of the organisation or the needs of the YPD. The rehabilitation and habilitation services are organized under the sector of health in Norway, with a division of responsibility between the municipalities and regional state enterprises. In the community services, the follow-up and outreach health care services, the governance of the client-centred work is assessed by quantitative objectives (Dall 2020). This administration is also the case in the specialist healthcare services; however, expert-led decision-making processes are expected in addition to interprofessional work. The emphasis on quantitative objectives as governing strategy affects the amount of time

used for collaborative work across services and with the young people. User-centred and holistic planning are placed within the collaborative network of parties from different arenas (habilitation services, school, work, etc.), which have different professional backgrounds. In practice, there are several concepts at play. The rehabilitation services are influenced by medical reasons, market (consumer and efficiency), and psychology (individual, user involvement) (Mik-Meyer 2017). The professionalization of the rehabilitation services is a combination of professionalism in the direction of medical specialisation/expertise in the treatment of patients and collaboration between professionals with different professional backgrounds.

Theory on encounters between clients and professionals underscores the influence professionals have on how clients' capabilities are defined (Villadsen 2003). How professionals perceive clients' identities directs attention to how clients are understood, objectified, and seen in terms of generalized understandings (Goffman 1967; Järvinen & Mik-Meyer 2003; Smith 2006). A central question is how subjectivity of YPD in habilitation and rehabilitation services is given attention in collaboration and professionals' work.

According to Mead (1967), a precondition for a person to develop a good sense of self is opportunity for subjectivity in relationship to others. The self is a social construction and not an inherent characteristic. Consequently, we can 'lose parts of the body without any serious invasion of the self' (Mead 1967: 136), but how other people respond to our bodily appearance will affect one's self-perception even more. One may ask to what extent professionals use critical reflection in how they take care of YPDs' sense of self. The relationship between the professionals and the YPD is often filled with an asymmetrical power relation. The influence exerted by professionals over the YPD leaves room for the YPD's subjectivity and sense of self and is practiced along a continuum. The ongoing interaction and communication with YPD in everyday professional work determines how individuals are treated and what options are given (Järvinen & Mik-Meyer 2003; Schirmer & Michailakis 2015). The more a client is dependent on services, the stronger the impact that professionals (and the system) may have on that person's self-conceptualization (Villadsen 2003). Seen from a critical perspective, professional work may risk disregarding subjective experiences because of an a priori normative understanding of the client and what is expected of the professional work.

Giving subjectivity priority in the encounters and planning for the future directs the focus to young people's knowledge (Bekken 2020). A YPD's aspirations may be difficult to act upon because listening to the young peoples' voices take time and there are not time and resources available in the (rehabilitation) system (Bekken 2020; Järvinen & Mik-Meyer 2003; Fitzgerald 2010).

In the transition to adulthood, the hopes and aspirations for the future of the YPDs are about finding out who you are. The 'treatment' of hope is not just about the YPD's hopes and aspirations, but about how the professional understands, acts towards, and thinks about the hope of the person they work with. It is also about how hope (and aspirations) as a theme is emphasized in institutions (Arvanitidis & Olsen 2017). Structural frameworks, such as restrictions on time spent with clients and little interaction between employees at different levels of the organizational structure, affect the time available to work with aspirations and hopes (Arvanitidis & Olsen 2017: 13). Arvanitidis and Olsen (2017: 10) argue that 'by being aware of the client's understanding of his/her situation, what he/she understands as meaningful goals, and the means to achieve these goals, the professional treats the client with respect and recognizes that the client has knowledge and resources to find solutions. This may lead to engagement in the process and strengthen the client's confidence.' Professionals have the power to underscore a YPD's capabilities through their work.

Method and Analytical Considerations

In-depth interviews (group and individual) are used to gather information about professionals' practices and understandings about what affect their work with clients in transition to adulthood. This qualitative research design emphasizes the experiences from everyday practices (Gulbrandsen 2014). The aim of the interview was to get in-depth information about how professionals in the habilitation services work with YPDs and to explore factors that affect the work and how this connects to planning for transition from being a child to becoming an adult.

The criteria for participating in the study was being a professional working in the primary and in the specialist health care services and having experience from preparing the transition from children services to adult services. Together the two services are the unit of professionals working with the child and parents during childhood.

Eight professionals from three specialist health care services (special pedagogues, psychologist, physiotherapist, occupational therapists, and social worker) and eight professionals from two community services (physiotherapist, occupational therapists, nurse, and social worker) in the region of eastern Norway accepted the invitation to participate.

The professionals were recruited through leaders at children's rehabilitation units. The units were approved to participate in the study by the health trusts' privacy ombudsmen in the specialist services.

Each participant was given an option between individual or group interview, where the latter were favoured by the participants to limit use of time and because they found it interesting to listen to each other's experiences. Conducting group interviews gave the researcher much information in a relatively short time. The professionals' affiliations organized the participants into five groups. There were two to four participants in each group. One participant could not attend the scheduled date and was therefore interviewed individually. One of the participants was male; the rest were females. In all groups there were participants with more than ten years of experience who had worked in both services.

There are several ways of conducting interviews in groups (Barbour 2017; Morgan & Kruger 1993; Morgan 2017; Morgan & Bottorf 2010). In this study the group interview follows an everyday life anchored strategy (Gulbrandsen 2014; Haavind 2009), meaning that the topic in the interview is discussed with reference to what the professionals do in their everyday practical work, 'an ordinary day at work', with attention to work and planning for transition to adulthood. Together the participants and the interviewer explored the practices, the regularities (how they usually do it), the irregularities, and what they think about the practices (if things could have been done differently). The interviews lasted between one and two hours. The interviews were transcribed verbatim.

Analytical Considerations

In line with the method, a systematic analysis was conducted to identify themes and the meaning of the everyday practices (Gubrium & Holstein 2009; Gulbrandsen 2014; Gullestad 1989; Gullestad 1991). The first strategy was to systematize what they do in their everyday work with YPDs and planning for ending services for children and becoming a young adult. This resulted in themes related to challenges. The themes were compared within and across all interviews and rechecked by going back to the data. Four main themes were identified: (1) structural shortcomings, (2) lack of resources to support the young adults' aspirations, (3) work with YPDs who are often vulnerable and dependent on their parents and (4) professional work directed towards giving YPDs a 'realistic' understanding. The second strategy was to ask the following analytical questions to our themes: How do the professionals talk about the YPDs? And how do they talk about their work? This strategy is helpful when re-checking and giving a thicker description of the themes identified (Gubrium & Holstein 2009). This strategy was helpful in the process of conceptualizing the findings. From this, three dilemmas were identified. In this article, we present the dilemmas and discuss them using theory. This is the final step of the analysis.

The study was approved by the Norwegian Social Science Data Service (NSD). All the participants gave written and oral consent to participation. The names of persons and places have been anonymized in line with personal protection regulations.

Presenting the Dilemmas

The professionals describe their work with YPDs as helping them understand what is realistic to expect and practice becoming independent. This work involves information giving and repetitive practice of tasks (self-medication and handling the services by themselves). They describe young people who need extensive guidance and support because they are lonely and dependent on their parents. In the professionals' descriptions and narratives three main ethical dilemmas were identified: 'the resource dilemma', 'the responsibility-liability dilemma', and third, 'the preference formation dilemma'.

The resource dilemma

The resource dilemma is about how the amount of time and resources available affects the number of young people and the variety of disability problems professionals work with. Many YPDs do not have regular follow-up due to long waiting lists. Two occupational therapists (OT) highlighted such situations where the professionals must prioritize:

OT1: My experience is that things are put into the system when the need for care is great. But for the rest of the children who also need follow-up but are functioning ok ...

OT2 interrupts: or that they manage fairly well and kind of fall between two chairs. [OT1 confirms OT2]. OT2 continues: We have many [children] with cerebral palsy degree 1 and 2 that we hardly ever see because things function well enough for them, but who may have a great potential for rehabilitation. What we do, is 'putting out fires' of primary needs, yes, don't you agree? It's also a bit random.

The baseline is that they should provide the same service to everyone they work with, but they must prioritize because they are measured on time per client, and they cannot offer person-centred services to all of them. They also describe that the number of tasks can be so extensive that they cannot even decide which ones are the most important and instead end up simply 'putting out fires'. Time constraints caused by having a large number of patients and a time standard for how much time they should use per patient results in there being 'no time for more than just the primary or the physical'; 'without time to have conversations with the person, it becomes difficult to "really" base the work on the YPD's wishes and needs.' Basic support/treatment includes things such as wheelchair adaptation, wound care, or medication.

The professionals explain that they do not have time to sit down for conversations. There is seldom time to talk about aspirations for the future, opportunities and/or challenges that may arise, friendships, and hopes for education or work. In the interviews it was pointed out that it takes time for YPDs to build trust and to have conversations about the things that matter to them in this period of life, such as hopes for the future, family, romantic relationships, friends, or work opportunities.

Other limitations, such as the division of responsibilities and tasks between the services, can contribute to less talk about the future, which the occupational therapist describes below:

I think that we should have been more involved in evaluations (work capacity) because I believe that we could have time available for that, if the system had facilitated for it, than we would have focused on the social just as much as the physical and the psychological, because it is completely natural that this is the base. If we were given time to reflect more openly. I must admit that I'm sucked into the system, you know, and then you put on our 'blinkers' because we have too much to do. If we had been given the opportunity, we could have carried out evaluations.

The professionals interviewed recognize the potential in the YPDs they work with, but there are structural limitations making it difficult to work with this potential. Another of the occupational therapists in the study articulated this dilemma:

It's a bit of an ethical dilemma, because if I address [the question] 'what do you want?' then I must say in the next sentence that it can't be done ... It'll be a bit like that [laughs a little] ... We must bring it up, but the system gives us some limitations. For example, I can work with a boy with severe disabilities who wants to work part-time, but it's not possible to get a job where you can only work 30 per cent. There is a limit of 50 per cent, and then the social welfare system comes in. Then you can get a job through them, but if it is less than 50 per cent, then it is the local community's responsibility, and then what opportunities there are all depends on the economy of the local community ... and what [work placements] the local community has established. It is not the case that we can create an availability for a place to work. Therefore, I feel I must disappoint many. The more I know about the system, the more I must disappoint them. I have few colleagues who manage to inform [the service users] about that there are no jobs the community for them.

Listening to a person's wishes commits you to action, or as a nurse put it, 'Then you must also be willing to follow up [on] what is important to the person'. This poses a dilemma for the professional when it comes to taking responsibility and acting upon the person's wishes because they know that there are no resources in the system to accommodate those wishes.

The responsibility dilemma

This dilemma is about how much responsibility is right to expect from the YPD. The professionals describe that they use much of their time addressing independence issues. The ending of child services at legal age and preparation for adulthood are part of the work they do. They described their job as establishing a system for young adults after child rehabilitation is completed. Training for independence is important and involves repeating the same information over and over again and respecting parents' opinions as well. It is important for parents to be well-informed about housing arrangements and financial security. Training that includes learning how to do things that are expected of an adult person is important for succeeding as an adult. One occupational therapist shared a typical situation:

I can tell a little about one person I have worked with, which I have followed before the age of eighteen and through the transition with school and high school. I try to get him to reflect: 'you can use me as a supervisor, I can guide you on some of the choices you make ...', together with the school, we often have contact with the school. 'But now when you have turned 18, you are supposed to be independent and you must contact me, not your mom or dad or anyone else, it's you and I who keep in contact. It is you who must arrange it, you must think.' We start a bit before they are 18 and prepare them for the role they are supposed to have [...] 'Yes, now you have to contact the hospital, you have to contact the doctor'. [...] Give them tasks to practice [...] It's quite a big job, but still, this is how I can make them independent.

To repeatedly show the YPDs how to perform practical tasks that are expected of them to manage as adults also comes with a dilemma, an occupational therapist explains:

... but I try to get youths to participate in the 'responsibility group meetings' as early as possible, not too young, but from 15 at least. In middle school, in the middle of high school, then I start like, 'have you thought about that...?' Actually, I tell them in advance that there will be a meeting and what the meeting will be about. I explain to them a bit... I want them to take responsibility, but they already have a lot of responsibility; they must do a lot of training and they have a lot of 'otherness', to put it that way. So, I don't want to put too much pressure on them at too young an age. But I do inform them about what will be organized, and I try to start when they are approaching 15 ... to start to participate. At least they need to know which issues will be discussed. If they don't want to talk, they can participate and just listen to what is being said. At least I try...and I think that this will gradually ... (a colleague interrupts by saying 'internalize'). More and more responsibility step by step.

Another description from the occupational therapist can be mentioned:

So, everything we do from the time they are in school is with independence in mind. So, if [we are] practicing catheterization, 'do it yourself with someone at school', [...]. All the time we keep on saying 'you will not stay at home forever'. There will come a time where it is not cool to receive help... 'That's life, you have to start doing things yourself, and you must practice.' It can take two years before they do a task themselves. Yes, so everything we practice on is really about what you can do yourself. Eh, both what you can do and what you must do yourself.

Independence training involves learning about practical things, like how to contact the services without help from parents, taking the responsibility of having an opinion, and being able to handle medical care on their own.

There is a lot the YDPs must learn to take responsibility for. The interviewees underscored that having a disability and being different is a responsibility. Taking responsibility must be learnt gradually. They explained that children and youths' participation in so-called responsibility groups varies depending on the degree of disability and willingness to participate. Some will not participate while others will, but these groups are an arena for practicing expressing opinions about one's life. Schools and health care professionals try to involve children in such groups as early as possible, from 10 or 15 years old.

The preference formation dilemma

The preference formation dilemma is about how the professionals shape the YDPs' choices: how much weight professionals should put on their own expertise, judgement, and objective understanding of the YDPs' abilities, characteristics, and expectations related to work capacity and social life, and the YDP's aspirations and hopes for the future.

The YDPs are described as lonely: they do not have many friends; they lose a social community when they leave school, and often they are not included in work life and other social communities. Disability and related fatigue are factors that may increase their risk of becoming socially isolated as adults. The professionals consider loneliness a major challenge, both in adolescence and after finishing school. A physiotherapist explains:

I am aware that many of those with CP, for example, the most difficult [thing] for them as adults is not the wheelchair but solitude. We keep that in mind and try to stimulate or encourage them to join in activities so that they can get a social network. All the way from when they are very young, really.

Or as this special pedagogue underlined,

I still think that solitude, considering moving away from home, not having friends and not having a social network, is perhaps the biggest challenge.

When the professionals talked about loneliness, they underlined the importance of 'realism', meaning being realistic about the capacities of the YPD and the challenges they might face as adults. It was underscored in the interviews that it is difficult to talk about loneliness, especially the conditions that can create loneliness. These conditions include the effects of impairment and the fact that society does not facilitate the inclusion of people with disabilities. Fatigue, and how to live with it, is often a crucial topic of conversation. They described how many young people are already exhausted in their early twenties, and a physiotherapist said:

Focusing on what you are able to do, how much you can cope with during a day, is an important topic, as they get older.

Or,

To put it this way, we talk a lot about energy economization, and that it is important to focus on energy in social situations, and how that can 'save' energy for some situations that are not considered as important. That they also use the wheelchair or take a taxi instead of walking to school and... yes... or not needing to do homework from time to time.

We saw from the surveys that many of the patients spent a lot of energy on, for example, school and then stayed at home and rested the rest of the afternoon and were too exhausted to spend time with friends. Then they became very isolated.

One of the special pedagogues explained that it takes time to work with 'reality orientation':

It takes time to talk about these issues, and it must be done over several years. A fifteen-year-old person is not as oriented towards the future as a nineteen-year-old person is.

And 'reality orientation' was underscored:

It's all about reality orientation. When they realize that the impairment causes more difficulties than they thought when it comes to studying, living... Meaning that, living for themselves, getting a job, coping with work if they get a job, and that they may need more help than they have been aware of... After all, they have had parents who have done a lot for them. A colleague (physiotherapist) continues: Reality kind of hits them in the face when they're like 19 and begin life as a student.

Testing and mapping of cognitive functions and capacities are regarded as relevant for guiding career choices that are 'realistic'. For example, a neuropsychological test can help guide educational choices. A short report that summarizes the medical status of the individual is presented to the YPD, their parents, their general practitioner, and other collaborative professionals at the ending/transition meeting when ending children services. At legal age, or the year they end upper secondary school, the collaboration with the services for children stops. The professionals describe this as unfortunate because they seldom hear from these young people again.

In their efforts to help YPDs to be realistic, the professionals face a dilemma: do they offer false hope or tell the users that they cannot do certain things because they lack the capacity, thereby taking away hope and belief for their own life? Both options are embedded with uncertainty because they do not know for sure the outcome. Testing and mapping help solve the dilemma.

Much of the professional work in preparing for adulthood is about ensuring a good system of services and arrangements supporting the YPDs and providing information about rights and responsibilities to parents and to the YPD. They are expected to be experts. The specialist services are expected to give advice based on medical assessment of the user's function and capacities.

Discussion

Structural frameworks such as time and resources affect the performance of work tasks and how professionals interact and communicate with adolescents. Professionals often encounter dilemmas due to a lack of resources. The professionals also encountered dilemmas related to how much responsibility they should impose on the young people, and preference formation is limited to questions of cognitive and physical capacity. The three dilemmas show how considerations related to sensitive subjective issues of care and vulnerability are difficult to handle and are thus put on the back burner or even neglected entirely in the provision of services.

The findings reveal established practices that resemble a successful transition (Lindsay et al. 2019; Medforth and Huntingdon 2018; White & McManus 2018); however, they report on several challenges in supporting the adolescents in pursuing their true aspirations. The dilemmas professionals face in their daily work have implications for the identity the YPDs are given and the opportunities they face in the transition to adulthood. While professionals often recognize their aspirations and needs, they lack the possibility to make them come true. They find it hard to be explicit about this dilemma and often avoid talking with the YPD and their parents about it. The governing practice is that YPDs in transition must adjust to the services offered. Using dialog as a measure to promote YPDs' subjective experiences and wishes for the future becomes secondary. Balancing the amount of responsibility for independence given to the YPD is described as difficult because they know that it will not be easy for them to be included in education or work. The professionals try to establish a system for them but are not responsible for following this up after services ends at legal age.

Identity as excluded

The professionals describe dilemmas and practices in which they try to lower the YPD's expectations of becoming the active citizens they aspire to be. In terms of their status, the YPDs that our participants talk about are considered as being partly or fully excluded from ordinary activities. Our findings recall Schirmer and Michailakis's (2015) thought-provoking concept 'exclusion administration'. This refers to working with people in cases where there is no prospect of regular inclusion. According to Schirmer and Michailakis (2015: 59), the management will affect how the professionals emphasize inclusion and exclusion and what sort of activities the YPDs will be included in. The YPD's status as '*excluded* from ordinary life' is not explicitly stated in the transition work. However, it can be traced to the practices of the professionals, who describe that YPDs are included in arrangement and support systems that reinforce their identity as disabled and dependent on others and thus incapable of participating in ordinary work life or activities as they aspire to do.

When assessing the benefits and drawbacks of imposing responsibility on the YPDs, professionals constantly face a trade-off. On the one hand, demanding too much responsibility can lead young people to feel helpless. On the other hand, not requiring young people to take responsibility themselves does not provide them with the skills needed to become independent. Nevertheless, empowering YPDs with independence is a task the professional must assume. Services must be tailor-made in collaboration with the individual. Most of the communication between the professionals and the YPDs is about practical tasks; talking about practical matters is less challenging than having conversations about personal matters with which young people may need some extra support, for example reflections about the future, romantic relationships, experiences of love, interests, aspirations for education and work, and so forth.

Prospects of being defined as ordinary – The role of exploring hopes

The three dilemmas professionals must deal with raise ethical questions about care, respect, and facilitation of individual development. The interviews reveal an ambivalence among professionals about their role in preparing YPDs for adulthood because they as professionals do not have the resources to do what they think is best for the YPDs, and they experience a society that does not accept, recognize, or include people with impairments. The planning for the future is consolidated in the services and not in the YPD. It is difficult to talk about aspirations because they are afraid that they will give YPDs false hopes for the future. All together there are many barriers reducing the options the YPDs are given for the future as adults.

Weingarten (2010) underscores that encouraging realistic hopes requires paying attention to what means are available and providing support in line with those means. This means to explore interests, how being a social person is acted out in everyday life, parents' role in caregiving, and how care and support can be given by others in addition to the parents. Realism, understood as a process, involves recognizing subjective experience as meaningful, with the practical consequence to bracket the normative judgement of the young persons' aspirations as unrealistic, and explore 'the unrealistic' together with the YPD and the parents. Assessment of cognitive and physical capacity guides the advice the professionals give the YPDs about education and work. The assessment is objective and sets a standard for 'what is realistic' to achieve. However, in a regime where realistic options are determined by objective evaluations, there are few possibilities for emancipation for adolescents, as emancipation requires taking subjectivity seriously into account.

Negotiating realistic hopes takes time (Weingarten 2010). There must be acceptance for failure and openness to the possibility that the hope can completely change. Considering hopes and aspirations needs to start from an early age. Without addressing subjectivity (hope and aspirations), it is difficult to explore what loneliness is and how it can be reduced, and the different pathways (in)dependency can take. It can be difficult to establish a system of support which safeguards inclusion in activities that are meaningful activities to the young people. A cursory treatment of subjectivity of the adolescents upholds an identity as not only dependent and lonely but also vulnerable because of the impairment. Unexplored ideas of individuals' vulnerability deprive the vulnerable of recognition as people worth listening to.

It can be argued that the absence of a clear follow-up plan after legal age should be emphasized in the national guidelines for habilitation and rehabilitation (2018) (Helsedepartementet 2018). For example, in the section about the 'transition to adulthood' in the guidelines (2018), it is underscored that individual follow-up plans and having a coordinator responsible for collaboration, early intervention and user involvement is mentioned, but no further specifications are given regarding transitions. The guidelines do not address the relationship between aspirations and transition to adulthood. The discretionary decisions the professionals describe exemplify loyalty to specialized knowledge and the quantitative objectives expected from the organization. In addition, they use widespread social norms about disabled people as discretion. The preference formation reduced to a discussion of cognitive and physical capacity is strongly legitimated. Biomedical considerations are important, even though it should be balanced according to the aim of rehabilitation (Shakespeare, Watson and Alghaib 2018; Solvang, Hanisch & Reinhardt 2017). Individual tailor-made services have to be negotiated with the YPD, and these services must not depend on the local municipality's economy but has to be raised to the state level to make sure YPDs' transitions to adulthood become equalized and fair.

Concluding Remarks

The dilemmas of resources, responsibility, and preference formation warrant a discussion of the relationship between structural conditions, practical work, and the identity YPDs are given during planning for the transition to young adulthood. The professionals describe practices where the YPDs must adapt to the services and their shortcomings. This leaves little room for aspirations and hopes for the future or for processes essential to positive self-development. The professionals are aware that this is not ideal, but they nevertheless focus on the standards by which they themselves are evaluated, documenting that their tasks are performed according to administrative routines. The implication is that individual characteristics are not sufficiently considered. The experiences, aspirations and hopes of the YPD should be given more attention in professional work and in the guidelines for rehabilitation service provision. Subjective experience is a key element to understand and accept different ways of living an ordinary life and to develop a strong sense of self. More attention should be given to how professional practices and professionals' own emotional work influences YPD's self-perception and opportunities in life.

Acknowledgements

We would like to thank the Sophies Minde Foundation for providing funding for the project. We would also like to give a special thanks to the informants for giving of their time and experiences, and to our research group, GULF, for inspiring discussion on the topic.

Competing Interests

The authors have no competing interests to declare.

References

- Arvanitidis, Marianne M. and Benedicte C. R. Olsen. 2017. "Håp og sosialt arbeid". *Fontene forskning: et tidsskrift fra Fellesorganisasjonen (FO)* 1: 4–15. <https://fonteneforskning.no/forskningsartikler/hap-og-sosialt-arbeid-6.19.507400.b9536b5bcd>.
- Barbour, Rosaline. 2017. "Setting the scene for a new era of focus group research." In *New Era in Focus Group Research: Challenges, Innovation and Practice*, edited by Rosaline S. Barbour and David L. Morgan, 1–13. Palgrave Macmillan UK: Imprint: London, Palgrave Macmillan. DOI: https://doi.org/10.1057/978-1-137-58614-8_1
- Bekken, Wenche. 2020. "Negotiating embodied knowledge in the transition to adulthood: A social model of human rights." *Disability & Society*. DOI: <https://doi.org/10.1080/09687599.2020.1816902>. Published online: 17 Sep 2020.
- Dall, Tanja. 2020. "Distribution of responsibility in inter-professional teams in welfare-to-work." *Nordic Social Work Research* 10(1): 80–93. DOI: <https://doi.org/10.1080/2156857X.2018.1518818>
- Egilson, Snefridur T., and Ranveig Traustadottir. 2015. "Familier med funksjonshemmede barn: Dagligliv i en sosial kontekst." In *Utviklingshemming. Hverdagsliv, levkår og politikk*, edited by Patrick Kermit, Anders Gustavsson, Anna Kittelsaa and Borgunn Ytterhus, chapter 6. Oslo: Universitetsforlaget.
- Fitzgerald, Robyn, Anne Graham, Anne Smith, and Nicola Taylor. 2010. "Children's participation as a struggle over recognition: Exploring the promises of dialog." In *A Handbook of Children and Young People's Participation: Perspectives from theory to practice*, edited by Berry Percy-Smith and Nigel Thomas. Chapter 27. London: Routledge.
- Goffman, Erving. 1967. *Interaction ritual: Essays in face-to-face behavior*. Chicago: Aldine.
- Gubrium, Jaber F., and James A. Holstein. 2009. *Analyzing narrative reality*. Los Angeles: Sage. DOI: <https://doi.org/10.4135/9781452234854>
- Gulbrandsen, Liv Mette. 2014. *Barns deltakelse i hverdagsliv og profesjonell praksis: en utforskende tilnærming*. Oslo: Universitetsforlaget.
- Gullestad, Marianne. 1989. Kultur og hverdagsliv: På sporet av det moderne Norge. (Culture and everyday life: The trajectory of modern Norway). Oslo: Universitetsforlaget.
- Gullestad, Marianne. 1991. "The transformation of the Norwegian notion of everyday life." *American Ethnologist* 18(3): 480–499. <https://www.jstor.org/stable/645590>. DOI: <https://doi.org/10.1525/ae.1991.18.3.02a00040>
- Halvorsen, Rune and Bjørn Hvinden. 2018a. "Youth, diversity and employment in times of crisis and economic restructuring – An introduction." In *Youth, Diversity and Employment: Comparative perspectives on labour market policies*, edited by Rune Halvorsen and Bjørn Hvinden, 1–32. Cheltenham, UK: Edward Elgar Publishing.
- Halvorsen, Rune and Bjørn Hvinden. 2018b. "Integrated discussion: Managing diversity among youth in Nordic social protection policies." In *Youth, Diversity and Employment: Comparative perspectives on labour market policies*, edited by Rune Halvorsen and Bjørn Hvinden, 199–229. Cheltenham, UK: Edward Elgar Publishing. DOI: <https://doi.org/10.4337/9781783476008.00014>
- Hamdani, Yani, Bhavnita Mistry, and Barbara E. Gibson. 2015. "Transition to adulthood with a progressive condition: Best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy." *Disability and Rehabilitation* 37(13): 1144–1151. DOI: <https://doi.org/10.3109/09638288.2014.956187>
- Hanes, Julia E., Oksana Hlyva, Peter Rosenbaum, Matthew Freeman, Tram Nguyen, Robert J. Palisano and Jan Willem Gorter. 2019. "Beyond stereotypes of cerebral palsy: Exploring the lived experiences of young Canadians." *Child: Care, Health and Development* 45: 613–622. DOI: <https://doi.org/10.1111/cch.12705>
- Helse- og omsorgsdepartementet (Ministry of Health and Caring Services). 2011a. Forskrift om habilitering og rehabilitering, individuell plan og koordinator. Last version 01.05.2018. Oslo: Lovdata; 2011. Retrieved from: Forskrift om habilitering og rehabilitering, individuell plan og koordinator – Lovdata.
- Helse- og omsorgsdepartementet (Ministry of Health and Caring Services). 2011b. Helse- og omsorgstjenesteloven (The Municipal Health and Care Services Act). Oslo: Lovdata. 2011. Retrieved from: <https://lovdata.no/dokument/NL/lov/2011-06-24-30>.
- Helsedepartementet. 2018. The Norwegian Directorate of Health. Nasjonale retningslinjer for habilitering, rehabilitering, individuell plan og koordinator [National Guidelines for habilitation, rehabilitation, individual plan and coordinator]. 2018 [cited March 13 2020]. Available from: <https://www.helsedirektoratet.no/veiledere/rehabilitering-habilitering-individuell-plan-og-koordinator>.
- Holmbeck, Greyson N., Ann I. Alriksson-Schmidt, Melissa Bellin, Cecily Betz, and Katie A. Devine. 2010. "A family perspective: How this product can inform and empower families of youth with spina fibia." *Pediatric Clinics of North America* 57: 919–934. DOI: <https://doi.org/10.1016/j.pcl.2010.07.012>
- Järvinen, Margaretha. and Nanna Mik-Meyer. 2003. *At skabe en klient: institutionelle identiteter i socialt arbejde*. Copenhagen: Hans Reitzels.
- Lindsay, Sally, Ellanie Cagliostro, Joanne Leck, and Jennifer Stineson. 2019. "Career aspirations and workplace expectations among youth with physical disabilities." *Disability and Rehabilitation*. DOI: <https://doi.org/10.1080/09638288.2019.1671505>

- Lundeby, H. 2008. *Parents with disabled children: A study of the family patterns, employment and their interaction with the service providers*. PhD diss., The Norwegian University of Science and Technology.
- Mead, Georg H. 1967. *Mind, self and society: From the standpoint of a social behaviorist*. Chicago: The University of Chicago Press (1934). DOI: <https://doi.org/10.7208/chicago/9780226516608.001.0001>
- Medforth, Nicholas, and Elaine Huntingdon. 2018. "Still Lost in Transition?" *Comprehensive Child and Adolescent Nursing* 41(2): 128–142. DOI: <https://doi.org/10.1080/24694193.2017.1330370>
- Mik-Meyer, Nanna. 2017. *The power of citizen and professionals in welfare encounters: Then influence of bureaucracy, market and psychology*. Manchester: Manchester University Press. DOI: <https://doi.org/10.7228/manchester/9781526110282.003.0008>
- Morgan, David L. 2017. "Conclusions: A call for further innovation in focus groups". In *A new era in focus group research. Challenges, innovation and practice*, edited by Rosaline S. Barbour and David L. Morgan, 411–420. Palgrave Macmillan UK: Imprint: London, Palgrave Macmillan. DOI: https://doi.org/10.1057/978-1-137-58614-8_19
- Morgan, David, and Joan L. Bottorf. 2010. "Advancing our craft: Focus group methods and practice." *Qualitative Health Research* 20(5): 579–581. DOI: <https://doi.org/10.1177/1049732310364625>
- Morgan, David L., and Richard Kruger. 1993. "When to use focus group and why?" In *Successful focus groups: Advancing the state of the art*, edited by David L. Morgan, 3–19. Newbury Park, California: Sage. DOI: <https://doi.org/10.4135/9781483349008.n1>
- Ridosh, Monique, Patricia Braun, Gayle Roux, Melissa H. Bellin, and Kathleen J. Sawin. 2011. "Transition in young adults with spina bifida: a qualitative study." *Child: Care, Health and Development* 37(6): 866–874. DOI: <https://doi.org/10.1111/j.1365-2214.2011.01329.x>
- Roebroek, Marij E., Reidun Jahnsen, Carlos Carona, Ruth M. Kent, and Anne Chamberlain. 2009. "Adult outcomes and lifespan issues for people with childhood-onset physical disability." *Developmental Medicine & Child Neurology* 51(8): 670–678. DOI: <https://doi.org/10.1111/j.1469-8749.2009.03322.x>
- Sawyer, Susan M., and Sarah Macnee. 2010. "Transition to adult health care for adolescents with spina bifida: Research issues." *Developmental Disabilities Research Reviews* 16(1): 60–65. DOI: <https://doi.org/10.1002/ddrr.98>
- Schirmer, Wladimir, and Dimitri Michailakis. 2015. "The Luhmannian approach to exclusion/inclusion and its relevance to social work." *Journal of Social Work* 15(1): 45–64. DOI: <https://doi.org/10.1177/1468017313504607>
- Shakespeare, Tom, Nick Watson, and Ola A. Alghaib. 2018. "Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability." *Critical Social Policy* 37(1): 22–41. DOI: <https://doi.org/10.1177/0261018316649120>
- Smith, Dorothy E. 2006. *Institutional ethnography as practice*. Lanham, MD: Rowman & Littlefield.
- Solvang, Per K., Halvor Hanisch, and Jan D. Reinhardt. 2017. "Rehabilitation research matrix: Producing knowledge at micro, meso, and macro levels." *Disability and Rehabilitation* 39(19): 1983–1989. DOI: <https://doi.org/10.1080/09638288.2016.1212115>
- Stewart, Debra, Mary Law, Nancy L. Young, Mary Forhan, Helen Healy, Jan Bruk-Gaffney, and Matthew Freeman. 2014. "Complexities during transitions to adulthood for youth with disabilities: Person-environment interactions." *Disability and Rehabilitation* 36(23): 1998–2004. DOI: <https://doi.org/10.3109/09638288.2014.885994>
- von Tetzchner, Stephen. 2005. *Utviklingspsykologi: Barne- og ungdomsalderen*. 4th ed. Oslo: Gyldendal Akademisk.
- Weingarten, Kaethe. 2010. "Reasonable hope: Construct, clinical applications, and supports." *Family Process* 49(1): 5–25. DOI: <https://doi.org/10.1111/j.1545-5300.2010.01305.x>
- White, P. H., and M. A. McManus. 2018. "Introduction: Historical perspectives, current priorities, and healthcare transition processes, evidence, and measurement." In *Health Care Transition: Building a Program for Adolescents and Young Adults with Chronic Illness and Disability*, edited by Albert C. Hergenroeder and Constance M. Wiemann, 3–11. Switzerland: Springer International Publishing. DOI: https://doi.org/10.1007/978-3-319-72868-1_1
- Young, Nancy L., Wendy S. Barden, Wendy A. Mills, Tricia A. Burke, Mary Law, and Katherine Boydell. 2009. "Transition to adult-oriented health care: Perspectives of youth and adults with complex disabilities." *Physical and Occupational Therapy in Pediatrics* 29(4): 345–36. DOI: <https://doi.org/10.3109/01942630903245994>

How to cite this article: Bekken, Wenche, Borgunn Ytterhus and Sylvia Söderström. (2021). 'In the Next Moment I Answer, it is Not Possible.' Professionals' Experiences from Transition Planning for Young People. *Scandinavian Journal of Disability Research*, 23(1): 338–347. DOI: <https://doi.org/10.16993/sjdr.783>

Submitted: 06 January 2021 **Accepted:** 16 November 2021 **Published:** 10 December 2021

Copyright: © 2021 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.

