

# Young Adults with Disabilities and their Transitions to Adult Life and Services: A Sociocultural Analysis of Parents' Perspectives on their Involvement



## RESEARCH

LINN JULIE SKAGESTAD 

SIGRID ØSTENSJØ 

ODDBJØRG SKJÆR ULVIK 

\*Author affiliations can be found in the back matter of this article



## ABSTRACT

This paper explores parents' perspectives on their involvement in their children's transitions to adult life and services in the context of young adults with disabilities in Norway. Based on semi-structured interviews, the accounts of seven parents were analyzed by applying a sociocultural framework. Informed by reflexive thematic analysis and considering personal, interpersonal, and cultural-institutional aspects of the parents' accounts, six themes of parental involvement were generated. It was shown how these parents operate within current cultural norms and practices of prolonged, intensive and autonomy-supportive parenting, and how these practices can come into conflict with norms of increased youth independence practiced in demanding institutional transitions. The findings also illustrate how sociocultural practices of stigmatization and marginalization can pose a particular challenge for youth with disabilities and their parents. Finally, we argue that a contextualized conception of parental involvement could widen the space for collaboration between youth with disabilities, parents, and professionals.

## CORRESPONDING AUTHOR:

**Linn Julie Skagestad**

OsloMet – Oslo Metropolitan  
University, NO

[linnjs@oslomet.no](mailto:linnjs@oslomet.no)

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## INTRODUCTION: CULTURAL AND INSTITUTIONAL CONDITIONS FOR TRANSITIONING AND PARENTAL INVOLVEMENT

In the Global North, the transition to adult life is bound up with cultural norms, such as increased self-reliance, independence from parents, and social roles such as taking post-secondary education, employment, and establishing one's own household and family (Cepa & Furstenberg 2021; Hamdani, Mistry & Gibson 2015; Valentine 2003). Examining how 'the individual' has been constituted within the history and philosophy of psychology, Goodley (2017:92) challenges the notion of the 'developing individual' who gradually attains independence, self-sufficiency, and mastery towards the endpoint of 'adulthood.' He questions the attainability and advantage of this notion, arguing that it is a simulacrum that few, if any, live up to. Other scholars contend that the line between 'dependent childhood' and 'independent adulthood' is difficult to define, as the transition to adult life often involves back-and-forth processes and ambiguities with respect to the balancing of responsibility and duties between young people and their families (Halvorsen & Hvinden 2018; Valentine 2003:40–41). Coining the term 'prolonged parenthood', the Canadian researcher Daly (2013) describes the phenomenon of young people living with and having closer ties to their parents for prolonged periods of time as the new normal. Likewise, The term 'intensive parenting' is also widely used to describe the prolonged and intensified parental support offered by Western middle-class parents (Faircloth 2014).

Institutionally, impending adult life involves a transition from child to adult healthcare and welfare services. These transitions occur abruptly once a child reaches the age of majority. However, equivalent services are not necessarily available within adult services, creating service gaps that can be challenging for young adults and their families (Aldiss et al. 2016). These gaps may be particularly demanding for young adults who require a wide range of services, such as persons with disabilities (Aldiss et al. 2016). Furthermore, research reveals that the care system often falls short in assisting young adults with disabilities in their transitions to adult life while also safeguarding their rights and interests. Such shortcomings have been linked to inadequately planned and/or coordinated service transitions, limited involvement of the young adults themselves (Bekken 2020; Wright, Robb & Shearer 2016), and unfitting normative models of 'ideal' or 'typical' transitions (Hamdani, Mistry & Gibson 2015).

In Norwegian law, the term 'parent' is used for all primary caregivers with parental responsibilities. The Norwegian Children Act (2021) (Barne- og familiedepartementet 2021) specifies that parental responsibility shall be exercised based on the child's interests and needs, and that parents shall ensure that the child receives an education according to her/his ability and aptitude. Moreover, the child's right to co-determination is emphasized, with parents urged gradually to extend the child's right to make their own decisions as they get older. It is also specified that from the age of 15, children have the right to choose their own educational path. The Norwegian Patients and User Rights Act (2022) (Helse- og omsorgsdepartementet 2022) states that children are of legal age to decide on healthcare services themselves when they turn 16. These laws are essential as they both reflect and influence contemporary cultural norms relating to proper parenting and young people's coming of age.

In recent decades, disability policy in Norway has undergone a shift, with principles of segregation giving way to those of normalization and inclusion. Since it has had a profound impact on education (for example, closure of all special schools that were run as long-stay, total institutions), as well as work and family life (see for example Norwegian Official Report NOU 22:2001), this shift constitutes an important part of the institutional context of this paper.

While considerable research has explored how parents of younger children with disabilities are involved in collaborations with service providers (see for example Almasri, An & Palisano 2018; Ryan & Quinlan 2018), knowledge about parental involvement with respect to the young adult age group is limited. The present study focuses on parental involvement in these children's transitions to adult life and services from the perspectives of their parents. Considering the limited knowledge, such research seems pertinent.

## THEORETICAL FRAMEWORKS

Resonating with the Convention on the Rights on Persons with Disabilities (CRPD) (UN 2006), the current paper draws on the Nordic relational understanding of disability (Ytterhus et al. 2015),

as well as a human rights perspective. According to the Nordic relational approach, disability results from complex interactions between the individual and their societal surroundings (socio-cultural, physical, political, and institutional) that hinder full and effective participation in society on an equal basis with others. Recognizing that these surroundings can be oppressive and disabling, disability is regarded as a relational and contextual phenomenon where specific impairments may or may not become disabling depending on the context (Ytterhus et al. 2015). Human rights perspectives, as reflected in the CRPD, recognize the diversity of persons with disabilities and the respect for difference as part of human diversity and humanity. Impairment is considered an aspect of human diversity that should never be the basis for the denial or diminishment of human rights. Human rights of persons with disabilities encompass civic, participatory, and political rights, as well as economic, social, and cultural rights (such as the right to health, education, work, preserved identity, and cultural life). Thus, persons with disabilities should be ensured access to the support and services required to exercise their rights.

As we read it, the CRPD presents a contextualized conception of disability where the interaction between the individual and her/his environment is the unit of analysis. This conception corresponds well with sociocultural theory, which informs the analysis presented in this paper. Our analytical ambition is to transcend individualizing conceptions of parents' involvement and practices by not focusing on individual properties. Instead, parents' involvement in their children's transitions to adult life and services is analyzed as sociocultural activity.

Sociocultural perspectives are concerned with the mutually constitutive relationship between how people actively take part in and contribute to the social, cultural, and institutional practices in their communities, and how, in turn, these practices mediate the ways in which people participate and their opportunities to do so (Rogoff 1995/2003). Transposed to this paper, these theoretical premises mean that parents' involvement in, and understandings of their responsibilities relating to, their children's transition to adult life and services are seen as interconnected with available cultural understandings of parenting and disability, as well as the cultural meanings and institutional organization of becoming an adult. Moreover, the parents, their emerging adult children and the service providers are regarded as social participants who actively take part in (constructing) the young persons' transition to adult life, influencing their own and (each) other's involvement and opportunities for participation and impact.

Although Barbara Rogoff (1995) proposes analytical concepts for children's development, we regard her conceptualization of sociocultural activity in three corresponding planes—personal, interpersonal, and cultural-institutional—as relevant to the purposes of this paper. The three planes can variously become the focus of analysis as long as their interdependence is taken into account. Observing sociocultural activity on a personal plane of analysis involves paying attention to how individuals endeavor to understand and contribute to sociocultural activity and as such, transform and become prepared for subsequent, similar activities. This does not imply making the individual the unit of analysis. Rather, the focus is on how the individual parent interprets and deals with social, cultural, and institutional resources and constraints. The interpersonal plane of analysis concentrates on how individuals communicate and coordinate efforts and share purpose when participating in socio-culturally organized activities. In our analysis, this plane represents the interaction between the parents, young people, and service providers. On a cultural-institutional plane, attention is focused 'on the specific nature of the activity involved, and on its relation to practices and institutions of the community in which it occurs—economic, political, spiritual, and material' (1995:142–143; 2003). Conventions and laws are considered part of these cultural-institutional practices. When analyzing the parents' accounts of their involvement, our aim is to demonstrate how these planes are interconnected.

Against this background, the present paper aims to explore how parents of young adults with disabilities describe and understand their involvement in relation to their children and the service system. This includes paying attention to how parents navigate current and recognized (and potentially conflicting) cultural norms/understandings, and institutional ways of organizing support and services.

## **METHODOLOGY**

This article forms part of a doctoral study that explores collaborations between young adults with disabilities, their parents, and service providers through a sociocultural lens. The research

team consists of two psychologists and a physiotherapist with qualitative research expertise and clinical experience within the rehabilitation, healthcare, and welfare services. The overall study employs four sources of data; 13 interviews with young adults, nine participant observations in multi-professional team meetings, six parent interviews, and six individual and two focus group interviews with service providers. Such a multi-method approach makes visible different angles and nuances of the issues explored.

Seven young adults with disabilities constituted the primary sample of the study (see [Skagestad, Østensjø & Ulvik 2021](#) for further detail on the recruitment process), while their parents were recruited as a separate sample. The criteria for the young adults' participation were the requirement of multiple and long-term healthcare and welfare services. The young adult participants signed an informed consent statement, which clarified that the doctoral study would take an interest in and draw on the perspectives of the young adult participants themselves (as given in their interviews), as well as those of their parents and key service providers. In order to give the young adult participants a greater measure of authority and influence on the research, they were given the choice to decide whether they wanted their team meetings to be observed, and whether their parents and service providers should be interviewed.

Five of the participating young adults consented to the recruitment of their parents, who then received written and oral invitations. Two participants who for various reasons decided not to include their parents made it clear to us that, despite this, they were on good terms with their parents and appreciated their support. Nevertheless, the recruitment methods could represent a potential source of bias in terms of primarily including the parents of children who are satisfied with their (ways of) involvement. The parents signed an informed consent statement based on written and oral information, and were, for the sake of confidentiality, given pseudonyms. They all lived in South-East or Mid-Norway, either in or nearby large cities. All parents except one were living in a relationship, and all had two or more children. Two of the mothers were homemakers, while the other parents had full-time jobs. The relatively small sample size (elaborated below), together with the parents' homogenous sociodemographic backgrounds (ethnic, middle-class Norwegians), limit the range of experiences and perspectives captured in this study. However, middle-class parenting is widely seen as norm-producing in Western societies and the sample may be appropriate for analytical purposes.

The data material consists of six semi-structured interviews (1–1½ hours) with seven parents (five mothers and two fathers). The interviews were conducted during a one-year period (autumn 2017–autumn 2018). Except for one parent who was interviewed twice, parents were interviewed once, either individually or as a couple. Based on their preferences, two parents were interviewed by telephone; one was interviewed once by telephone and once at her child's school; and the remaining parents were interviewed at home.

All interviews were conducted by the first author. The parents were invited to reflect on the following three themes: 1) the types of services and support their children had been provided with over recent years; 2) their own and their children's involvement in collaborating with the services provided; and 3) their concerns and expectations regarding their children's coming of age. Throughout the interviews, parents were encouraged to elaborate on—and exemplify—their experiences. Follow-up questions might include particular topics from the young adults' interviews, given their consent. All interviews were recorded and transcribed verbatim, focusing on aspects relating to meaning. Details that did not add further meaning to the accounts (such as repeated words, verbal pauses/fillers, and unfinished sentences) were thus omitted.

From a sociocultural perspective, knowledge is understood as being co-produced in situated interactions between people. The first author of this study is also a psychologist with experience in working with young people and their families. Her professional background and experience in working with people similar to this study's participants may be an advantage, but also raises questions regarding potential biases. For example, if our participating parents understood psychologists to be particularly concerned with individual independence as a developmental goal (c.f. [Goodley 2017](#)), they might have emphasized supporting their children's independence as 'desired' involvement, while omitting other forms of involvement from their accounts.

During the process of data collection, the researchers reflected on whether the sample size was large enough to generate data 'adequate to tell a rich, complex and multifaceted story

about patternings related to the phenomena of interest' (Braun & Clarke 2021 p. 211). The six parent interviews conducted were rich in data, with in-depth descriptions of both experiences and contexts. They were thus judged to be suitable and adequate for a sociocultural analysis seeking to provide a multifaceted, and deeper understanding of social, cultural, and institutional conditions surrounding parental involvement. The Norwegian Data Inspectorate has approved the project (54106/3/AGH).

## **A SOCIOCULTURAL ANALYSIS OF PARENTS' ACCOUNTS OF THEIR INVOLVEMENT**

In line with the aims of this study, the first analytical step involved exploring the parents' descriptions of the specific ways in which they were involved in their children's transitions to adult life and services. To this end, interview extracts where the parents described their engagement with their children and/or with service providers in these transitions were identified and selected. The subsequent analytical steps were informed by reflexive thematic analysis, as described by Braun and Clarke (2013/2019). Firstly, the selected extracts were coded, a process involving either data-derived or researcher-derived codes. According to Braun and Clarke (2013 p. 207), data-derived codes are based on participant-generated data (explicit content and participants' language and concepts), whereas researcher-derived codes are produced when the researcher(s) apply an interpretative lens to the data. For this study, Barbara Rogoff's (1995; 2003) three planes of sociocultural analyses (as elaborated above) served as such an interpretative lens. This means that the researcher-derived codes were produced by focusing variously on personal, interpersonal, and cultural-institutional aspects of parental involvement, and their interconnections. The coding was not an exclusive process, meaning that any data extract could be given both data-derived and researcher-derived codes.

Subsequently, all codes and collated data were examined and discussed by the three authors, with a view to generating initial themes. These would reflect broader patterns of shared meaning that were relevant to the aims of the study, organized around a central concept. The development of the themes was also informed by the interviews previously conducted with the parents' young adult children, as well as observations of meetings in some of these children's support teams (see Skagestad, Østensjø & Ulvik 2021). In one way or another, the initial themes generated involved parents' understandings of their children's situation, requirements, preferences, or experiences. When we at this point examined how the parents' perspectives on these issues related to the perspectives of their child, we found that in most cases the parents' views and stories mirrored those of their children. Of the six candidate themes, four were common across the sample and two were based on the accounts of the parents of two young adults. It should be noted that the final themes are not exclusive.

## **RESULTS: A SOCIOCULTURAL PERSPECTIVE ON PARENTS' ACCOUNTS OF THEIR INVOLVEMENT**

The following presentation of results is structured around the six themes of parental involvement that generated from the sociocultural analysis of the parents' accounts. In order to give a contextualized presentation that addresses sociocultural aspects of the empirical material (personal, interpersonal, and cultural-institutional), the outline of the results is based on a detailed analysis of selected empirical examples/vignettes.

### **PARENTS SUPPORTING THEIR CHILDREN'S ASPIRATIONS AND INITIATIVES**

The parents commonly described the many ways in which they supported their children's various aspirations and initiatives. We will elaborate on this theme by drawing on the accounts of Nina and Nils. Their son had recently moved into supported housing, and required daily assistance related to his motor impairments and recurrent seizures. Nina and Nils relate that he in recent years had made clear to them that he wanted to leave home at about the same age as his siblings (16 and 18, respectively). They described how the three of them thus started looking for available supported accommodation when the boy was nearing the end of lower secondary school. This collaborative process resulted in an offer of accommodation which their son took up.

Nina and Nils then described how they helped their son in the matter of employment. He had a job, but aspired to a more rewarding one:

*Just recently, he told me ‘Mom, I really want to go back to working at the nursing home’ [where he had previously had an internship and had thrived]. [...]*

The parents therefore initiated a process of supporting their son finding work that was more in line with his interests and competencies. Here, they drew on their contacts in the municipality:

*Nils and I brought it up at a meeting with the municipality ...perhaps the municipality could instead offer him a supported position at the nursing home? As of now, they couldn’t, but it was something we could work towards. (Nina)*

Nina and Nils’ account demonstrates interpersonal aspects of parental involvement. It brings to light how parents, their young adult children, and municipal service providers interact and coordinate efforts for the shared purpose of accomplishing the children’s wishes and goals.

Expectedly, the offspring’s aspirations and priorities, as described by their parents, varied considerably. However, and as Nina and Nils’ account constitutes an example of, all the parents appeared to be profoundly oriented towards—and to endeavor to support—the particular aspirations, views and initiatives of their child. Such sensitivity to, and support for, their children’s initiatives and plans seem to correspond with contemporary cultural ideals surrounding parenting, including notions of ‘intensive’ (Faircloth 2014) and autonomy-supportive parenting. The latter term has been employed by scholars to describe more recent parental practices and ideals characterized by a pronounced sensitivity to the child’s frame of reference and perspectives (van der Kaap-Deeder et al. 2015). Moreover, the parents’ accounts seem to reflect broader political principles of normalization and inclusion (as outlined in the introduction). The parents appear to take for granted that their children should create their own pathways within the ordinary education system and working life (if need be with appropriate adaptations).

The discourse of the ‘over-protective parenting’ of children with disabilities as reflected (for instance) in the work of Gill Valentine (2003) also has relevance here. Valentine (p. 44) argues that parents of young adults with disabilities may show guarding behavior that is excessive for the child’s developmental stage because they are anxious about their children’s ability to ‘make the transition to independent citizens.’ Some of our parent-participants described how they were criticized (in their opinion wrongfully) for being over-protective when asserting their children’s (service) rights and requirements in encounters with service providers. Thus, it might be that it is particularly important to these parents to make it clear that they *do* support their children’s initiatives and plans (often involving movements towards increased independence) without being overly protective. Another way to interpret the frequency of this theme across the parents’ accounts is that parental support might be more difficult to ‘camouflage’ when young adults and their families have to collaborate with a wide range of services.

To complete our elaboration on this theme, we return to Nina’s account. Nina works near her son’s new apartment and says that she ‘*out of habit, could easily have popped in every day to help out [with his day-to-day chores].*’ However, to respect her son’s request for privacy and independence, she is determined ‘*not to do so*’ and limits her visits to social ones at weekends. This corresponds with the account of another parent, Katrine, who describes how her daughter, who was born with a visual impairment, increasingly wants to get around on her own. Although this sometimes leaves Katrine a bit worried, such as when her daughter recently travelled alone to the Norwegian capital for the first time, Katrine tries to put her worries aside to fully support her daughter in this matter. Such efforts, including changing habits (limiting contact and care) and overcoming emotional inclinations, involve personal transformation. From a sociocultural perspective, it becomes evident how such personal processes of effort and change are mutually constitutive of broader cultural-institutional practices of increased autonomy as children approach their coming of age.

## **PARENTS ACTING AS MEDIATORS BETWEEN THEIR CHILDREN’S REQUIREMENTS AND THE SERVICE SYSTEM**

Most of the parents had experienced challenges associated with the transfer from what they described as an integrated and supportive childcare system to a fragmented, less coordinated

adult care system. Their experiences are reflected in the various ways in which they intervened when the service system did not match or accommodate their children's requirements. We conceptualized this form of involvement as parents acting as 'mediators' between their children's requirements and the service system.

To elaborate on this theme, we begin by drawing on Elsa's account. Elsa's daughter was born with a complex neurological condition involving visual impairment and fatigue. Elsa describes how the transfer to the adult care system involved the loss of key professionals (including a service coordinator and a medical team) who previously had taken care of most aspects of her daughter's case. This left Elsa and her daughter with greater responsibility for service coordination and follow-up.

In her encounters with the adult care system, Elsa felt she was expected to leave more of the managerial responsibilities to her daughter as the latter approached her coming of age. However, in Elsa's experience, her daughter did not have the capacity alone to handle such increased responsibility—on top of the other tasks and transitions she was confronting (such as moving out of the family home and completing her upper secondary school education). To ensure that her daughter continued to receive required healthcare and welfare services, while retaining the capacity to manage other tasks and activities she cared about, Elsa felt she had to help her daughter navigate the fragmented adult service system.

Elsa's account of how her daughter is expected to deal with a more complex service system with less parental and professional support illustrates how the culturally constituted developmental goal of increased independence is manifested in the adult healthcare system. Moreover, when Elsa argues that her daughter at present does not have the capacity to meet such expectations due to the very medical conditions (such as extreme fatigue) for which she receives care, a rather paradoxical youth-system 'mismatch' becomes evident.

We elaborate this theme further by drawing on Sarah's account of her son reaching the age of majority (18 in Norway). Given her previous experience of shortcomings in service transitions, Sarah was aware that transition planning needed to start well in advance, to ensure that no information or (educational) opportunities were lost. She described how thoroughly she prepared for her son's eighteenth birthday. At the time, he had several ongoing application processes, including admission to a vocational program. Thus, at a meeting with her son's multi-professional team prior to his birthday, Sarah needed to know whether formal correspondence, such as letters with acceptance deadlines, would be addressed to her or her son when he turned 18. This was an important issue, as her son does not always open his letters and finds such formal letters difficult to read. To be ahead of the situation, Sarah had also raised the question of who (herself, her son, or her son's current school) should inform the administration of the vocational program about her son's requirements for educational adaptations, should he be admitted.

Sarah's account shows a personal transformation, where previous experience with service transitions can translate into a more proactive form of parental involvement to safeguard her child's educational transitions and choices. Moreover, her account makes visible how her involvement as a 'mediator' is inextricably linked with institutional and legal practices, such as a bureaucratic and divided care and educational system and young people's increased self-determination rights and responsibilities when reaching the age of majority.

## **PARENTS ACTING AS HEALTHCARE, INTERVENTION, AND SYSTEM GUIDES**

This theme reflects the parents' descriptions of how they assigned themselves the responsibility of 'guiding' both their children and involved professionals in matters regarding their children's healthcare and service requirements. Some parents also commented on their efforts to acquire knowledge to handle these matters.

Elsa's story illustrates this theme. Over the years, she has read international medical journals and corresponded with international experts to learn more about her daughter's rare medical condition, as well as available interventions. She explains that she engages in this task as the medical expertise available does not always have answers to her questions:

*I wish they [the medical specialists] had more knowledge about her condition. But they'd never treated someone with her diagnosis before.*

Elsa also addresses how she has dealt with the fact that her daughter has started going online to learn more about her condition and its (discouraging) long-term prognosis:

*I put her in touch with knowledgeable people I know in Norway and abroad—people who were the right ones to talk to.*

She states that she feels confident that these persons could help her daughter get the necessary information about her condition without dwelling too much on its long-term prognosis. Moreover, drawing on her accumulated knowledge, Elsa sometimes offers involved professionals guidance on matters of importance to her daughter's health issues and education. For example, as her daughter's requirements for educational adaptations are only met to a limited extent, Elsa has on her own initiative developed material tailored to her daughter's capacities and interests, and has made this available to her daughter's teachers. She does this to enhance her daughter's motivation for schoolwork and academic achievement.

Sarah, too, describes how she has had to inform her son's support team about available services in the municipality, such as a speech therapist. Lisa mentions how she has helped the local pharmacy understand changes made by the doctor to the specifications applicable to the administration of her son's medication.

The parents also describe how they, drawing on their own experience, advice their children on how to increase their chances of getting their perspectives and requirements acknowledged, whether by healthcare professionals or the educational system. For example, they advised their children to prepare well for meetings to be able to give a precise description of their service requirements, and to do so in a positive and solution-oriented manner.

Interpersonal processes of parental involvement are reflected in the many ways the parents communicate and coordinate efforts with their children and service providers to promote their children's interests and requirements. This interpersonal engagement seems connected to broader legal norms relating to parental responsibility (in particular young people's right to co-determination and parents' responsibility to safeguard their child's interests, needs, and education), as set out in the Children Act (2021). Finally, the presented accounts indicate that this form of involvement (parents acting as 'guides') is intertwined with specific institutional conditions, such as the availability (or lack) of professional knowledge and insufficiently adapted education provision.

## **PARENTS ADVOCATING THEIR CHILDREN'S CASE AND RIGHTS**

Going beyond 'guidance,' the fourth theme reflects parents' descriptions of how they purposefully and forcefully advocate their children's case and rights in their dealings with the service system. The parents depict how they put pressure on the involved officials and service providers by insisting on their child's educational, participatory, and other legal rights when possible and necessary (for example, when decisions about their children's care and education were about to be made).

Katrine's account of how she reacted when her daughter's application for an internship in the municipality was rejected sheds light on this theme. The grounds given for the rejection were that the municipality was not able to accommodate the training because of the young woman's visual impairment. Since doing an internship was a compulsory part of her daughter's study program, Katrine was furious:

*I was so angry! So I sent emails and made phone calls to people at the highest level [...]. The very next day, the municipality offered her an internship.*

Describing how she has promoted her son's right to participation, Nina, for her part, says that she has often had to remind professional helpers to ask for her son's views during meetings where decisions about his service provision are made.

Elsa describes being forced to intervene, given that her daughter's suggestions for educational adaptations are often overridden in meetings with the school staff:

*They [the school staff] often respond 'that's not necessary, it'll be fine,'... so I've had to really raise my voice and be pushy on her behalf over the years. But it's OK to be like that on someone else's behalf. It's not so easy to act like that on your own behalf.*

These parents' accounts illustrate how acting as their children's 'advocates' vis-à-vis the service system is connected to broader social orders and mechanisms. The parents seem to draw on their empowered social position as adults with authority, along with their sense of being a representative of their child, to be able to engage in this way. From these positions, the parents manage to be insistent and persistent when necessary to get their children's requirements and rights heard and acknowledged, including by high-ranking officials.

## PARENTS COMPENSATING FOR SOCIAL EXCLUSION

Some parents described becoming involved in their children's social lives in order to compensate for the social exclusion they had seen their children experience over the years. Katrine's account contains an example of such exclusion processes. From early primary school, her daughter has repeatedly failed to be invited to her classmates' birthday parties. The reason given to Katrine by their parents is that they find it hard to take care of a child with a visual impairment along with the other children. Katrine tells of how she initially tried to discuss this social exclusion with school staff, but *'you sort of give up when you meet that kind of parental attitude.'*

Elsa described how she observed a change in the way classmates related to her daughter mid-way through primary school, following several years of social inclusion. Her daughter's disabilities had become more visible through use of 'special' equipment and also as a result of difficulties the girl experienced with taking part in certain popular age-related activities (such as running together during break time). Now, *'they [her daughter's peers] started to find her a bit odd, a bit different,'* Elsa reported. Recognizing that her daughter had become less socially included, making it difficult for her to establish friendships, Elsa described her concern that her child was being left out of the peer support and networks available to most young adults. To compensate for this, Elsa said she is probably more socially involved in her daughter's everyday life (offering her daughter company, emotional, and practical support, and her own social network) than parents of young adults who do not experience social exclusion.

To further discuss Katrine and Elsa's accounts, we draw on Link and Phelan's (2001) perspectives on social stigma. This is understood to occur when particular socially salient differences are deemed undesirable, and when people who are recognized as bearers of these differences experience status loss, social separation, and discrimination as a result. Both Katrine and Elsa are convinced that the social stigma associated with their daughters' disabilities has weakened their social position among their peers. They believe that these negative appraisals have been a constant barrier to inclusion in peer networks, which play an important role in young people's attempts to establish careers and identities (McDowell 2002, Traustadóttir, Rice & Jokumsen 2018). Katrine and Elsa's accounts thus suggest that broader sociocultural practices of stigma must be taken into account when exploring why parents of young adults with disabilities may become particularly involved in their children's social life.

## PARENTS CHALLENGING MARGINALIZING CONCEPTIONS ABOUT DISABILITY

Parents' descriptions of encountering—and seeking to challenge—marginalizing conceptions about their children's impairments constitutes the final theme. To illustrate this theme, we also draw on Katrine and Elsa's accounts. Katrine describes how she has contested ideas about certain types of jobs (e.g., health secretary, visual teacher) being particularly suitable for persons with a visual impairment, as expressed by members of her daughter's multi-professional team. This has been the case despite her daughter clearly expressing other career interests to her team. In Katrine's opinion, except for some occupations where unimpaired vision is clearly essential, her daughter *'should be allowed to find a suitable career by trying and failing like any other youth.'* She has made her views plain to her daughter's team.

Elsa describes her concern about how her daughter's visual impairment has, in the school context, been associated with assumptions regarding her ability to learn. She has had to explain that her daughter does not have learning disabilities:

*Once, the school counselor suggested a specific English textbook because it "wasn't too advanced." [...]. So you have to deal with prejudice like that.*

She has also come across educational professionals questioning whether the assistance provided at school could prevent her daughter from learning to be independent. Her response has been as follows:

*Our daughter has been super-independent from an early age. We try to explain to the teachers that she sometimes needs assistance because of her fatigue and not because she's not independent.*

These accounts illustrate how disability is tied to cultural meanings such as otherness (for example, a particular impairment being linked to distinct, atypical career paths), dependence and (academic) incapacity. Other researchers have also documented how such meanings underpin conceptions of disability in contemporary Western society (Gray 2009; Shakespeare 1994). Thus, when the parents challenge marginalizing conceptions about their children's impairments, this form of involvement appears closely intertwined and in negotiation with broader cultural ideas.

## **DISCUSSION: SOCIOCULTURAL CONDITIONS FOR PARENTAL INVOLVEMENT**

During our analysis of the accounts of parents of young adults with disabilities in their transitions to adult life and services, it became evident that the parents' various forms of involvement were tied to specific social, cultural, and institutional contexts. In line with the aims of this study, we now further discuss current ideals relating to coming of age and parental practices, as well as conditions that appear more specific to young adults with disabilities and their parents, all of which constituting these contexts. We also discuss how the parents appear to deal with the available resources and the constraints encountered within the different contexts, and how their collaborations with their children and the service system may reflect conflictual sociocultural practices. Here, we draw on the work of the Danish psychologist Charlotte Højholt (2020), who emphasizes the interconnectedness of people's everyday challenges and broader conflictual social practices.

The six themes generated by our sociocultural analysis of the parents' accounts reflect the many ways in which the parents were involved in relation to their children and their service providers. The forms and comprehensiveness of their involvement indicate that these parents operate within contemporary practices and norms of parenthood, such as those of intensive and autonomy-supportive parenting (Faircloth 2014; van der Kaap-Deeder et al. 2015) and prolonged parenthood (Daly 2013).

For the most part, and as outlined in the methodology section, there seemed to be little tension between parents' perspectives and those of their children. Such lack of conflict in youth-parent perspectives could be related to the recruitment of a particular group of young adults, namely those with open and problem-free communication with their parents. However, it could also reflect broader societal tendencies of closer and more trusting youth-parent relationships (Ungdata 2022). Importantly, in families characterized by a greater degree of conflict between parents and their young adult children parental involvement may play out differently than it does in the present study (e.g., as less autonomy-supporting), with parents perhaps positioning themselves in ways where they interfere with or limit their children's opportunities for self-determination. Finally, the comprehensiveness and forms of parents' involvement may also reflect a parent sample that is competent and willing to engage in this way. This raises questions about the situations of young adults with disabilities who do not receive such comprehensive parental support.

We continue the discussion by dwelling on the third theme: 'parents acting as mediators between their children's requirements and the service system.' This theme highlights some key contradictions within the sociocultural conditions for parental involvement. Our analysis tied this form of parental involvement to mismatches between the requirements and preferences of young adults with disabilities and the service system. It showed that these mismatches were often related to the organization of adult services (more fragmented and with less professional follow-up) and to institutional and age-related expectations of increased youth independence. From parents' perspectives, such expectations may become troublesome when they experience that their children wish to prioritize tasks or activities other than the managerial ones highlighted

by the service system and/or when their children lack the capacity to manage such a complex service system without parental support. The parents' accounts indicate that when increased youth independence serves as an institutional and age-related ideal in collaborations with the service system, the views of young people themselves and specific requirements that may not coincide with this ideal may be overlooked or dismissed. From a human rights perspective, this finding implies that to safeguard the civic and participatory rights of young adults with disabilities (such as the right to health, choice, and preserved identities), a more reflexive approach to the ideal of youth independence is warranted in collaborations with the service system. This finding also suggests a need to rethink the organization of transitions to adult services to better match contemporary understandings of becoming an adult (as a prolonged, supported process).

Although youth-system mismatches may create challenges for many young adults and their families, our results suggest that such mismatches are particularly demanding when a wide range of services are involved to meet the requirements of the young adults. This finding resonates with a previous Norwegian study on young people with disabilities and their contacts with healthcare services (Ramstad, Jahnsen & Diseth 2015). This research shows how the transition from child to adult services is particularly challenging, given that adult services often are difficult to access, insufficiently coordinated, and therefore hard to navigate. Along with our findings, this earlier study further suggests that the various (service) transitions these young adults face must be seen in relation to each other, both regarding the total demands they create and the ways in which parents become involved.

Overall, our parents' accounts illustrate how ideals of increased youth independence practiced by the service system in demanding institutional transitions may come into conflict with contemporary cultural practices of prolonged parenthood and intensive and autonomy-supportive parenting. This may occur when parents are sensitive to their children's wishes to prioritize other (transitional) activities over service coordination and follow-up—and therefore offer them managerial support.

Some of the parents in our study described being more involved in their children's social life than other parents of children of the same age. They linked this greater involvement to the social exclusion their children had experienced due to their disabilities. Their stories indicate that broad, politically endorsed principles of an inclusive society do not necessarily govern the social practices of schools or local communities. The same parents also challenged marginalizing understandings of disability (such as 'otherness' and incapability), arguing that such beliefs can push young adults with disabilities to the periphery of society. Altogether, the parents' accounts display how social and cultural practices of stigmatization and marginalization can pose a particular challenge to young adults with disabilities and their parents. Corresponding with the Nordic relational understanding of disability (Ytterhus et al. 2015), these accounts demonstrate how oppressive sociocultural surroundings may hinder equal participatory opportunities for young adults with disabilities. Moreover, when parents challenge such marginalizing practices, this can be seen as an effort to make the sociocultural surroundings less oppressive, thereby promoting more equal opportunities for young adults with disabilities.

Finally, in Western societies there is a contradiction between intergenerational hierarchies and power relations and young people's extended participatory rights (James 2009). This contradiction is also represented in our analysis, when the parents describe how they sometimes act as advocates for their children vis-à-vis the service system to ensure their legal and participatory rights. Because adults tend to occupy positions of greater power and social standing than younger persons (James 2009), this form of involvement is possible. Correspondingly, when exploring youth participatory strategies in our previous article, we found young adults actively drawing on their parents' 'adult authority' to make their voices better heard vis-à-vis service providers (Skagestad, Østensjø & Ulvik 2021).

To conclude, the results demonstrate the interconnectedness of parental involvement and specific sociocultural conditions, including contradictions between such conditions. As such, it suggests the importance of exploring sociocultural conditions for parental involvement in various contexts. It becomes evident how parents of children with disabilities operate within current cultural norms and practices of prolonged parenthood and intensive and autonomy-supportive parenting, and how these practices can come into conflict with norms of increased

youth independence practiced by the service system in demanding institutional transitions. The results further indicate how sociocultural practices of stigmatization and marginalization can pose a particular challenge to young adults with disabilities and their parents, contributing to social exclusion and the pushing of young adults with disabilities into devaluated social positions.

Our findings contribute to a contextualized conception of parental involvement, thereby opening a greater space for collaboration between young adults with disabilities, parents and service providers—collaboration that could better secure the human and participatory rights of these young adults.

## COMPETING INTERESTS

The authors have no competing interests to declare.

## AUTHOR AFFILIATIONS

**Linn Julie Skagestad**  [orcid.org/0000-0001-6513-9247](https://orcid.org/0000-0001-6513-9247)

OsloMet – Oslo Metropolitan University, NO

**Sigrid Østensjø**  [orcid.org/0000-0002-7418-2973](https://orcid.org/0000-0002-7418-2973)

OsloMet – Oslo Metropolitan University, NO

**Oddbjørg Skjær Ulvik**  [orcid.org/0000-0002-4269-0471](https://orcid.org/0000-0002-4269-0471)

OsloMet – Oslo Metropolitan University, NO

## REFERENCES

- Aldiss, Susie, Hilary Cass, Judith Ellis, and Faith Gibson.** 2016. “‘We Sometimes Hold on to Ours’—Professionals’ Views on Factors that both Delay and Facilitate Transition to Adult Care.” *Frontiers in Pediatrics*. DOI: <https://doi.org/10.3389/fped.2016.00125>
- Almasri, Nihad A., Mihee An, and Robert J. Palisano.** 2018. “Parents’ Perception of Receiving Family-Centered Care for Their Children with Physical Disabilities: A Meta-Analysis.” *Physical & Occupational Therapy in Pediatrics* 38(4): 427–443. DOI: <https://doi.org/10.1080/01942638.2017.1337664>
- Barne- og familiedepartementet (Ministry of Children and Families).** 2021. Lov om barn og foreldre (Act relating to Children and Parents). Oslo: Lovdata. 2021. Retrieved from: <https://lovdata.no/dokument/NL/lov/1981-04-08-7?q=barneloven>.
- 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>
- Braun, Virginia, and Victoria Clarke.** 2013. *Successful Qualitative Research: A Practical Guide for Beginners*. Los Angeles: Sage.
- Braun, Virginia, and Victoria Clarke.** 2019. “Reflecting on Reflexive Thematic Analysis.” *Qualitative Research in Sport, Exercise and Health* 11(4): 589–597. DOI: <https://doi.org/10.1080/2159676X.2019.1628806>
- Braun, Virginia, and Victoria Clarke.** 2021. “To Saturate or Not to Saturate? Questioning Data Saturation as a Useful Concept for Thematic Analysis and Sample-Size Rationales.” *Qualitative Research in Sport, Exercise and Health* 13(2): 201–216, DOI: <https://doi.org/10.1080/2159676X.2019.1704846>
- Cepa, Kennan, and Frank F. Furstenberg.** 2021. “Reaching Adulthood: Persistent Beliefs about the Importance and Timing of Adult Milestones.” *Journal of family issues* 42(1): 27–57. DOI: <https://doi.org/10.1177/0192513X20918612>
- Daly, Kerry.** 2013. “Prolonged Parenting: Extending the Limits of Active Parenting.” *Transition* 43(2): 5–9. Retrieved from: [https://vanierinstitute.ca/wp-content/uploads/2015/10/Transition\\_43-2\\_EN.pdf](https://vanierinstitute.ca/wp-content/uploads/2015/10/Transition_43-2_EN.pdf)
- Faircloth, Charlotte.** 2014. “Intensive Parenting and the Expansion of Parenting.” In *Parenting Culture Studies*, edited by Ellie Lee, Jennie Bristow, Charlotte Faircloth, and Jan Macvarish, 25–50. London: Palgrave Macmillan. DOI: [https://doi.org/10.1057/9781137304612\\_2](https://doi.org/10.1057/9781137304612_2)
- Goodley, Dan.** 2017. *Disability Studies. An Interdisciplinary Introduction*. London: Sage.
- Gray, Caroline.** 2009. “Narratives of Disability and the Movement from Deficiency to Difference.” *Cultural Sociology* 3(2): 317–332. DOI: <https://doi.org/10.1177/1749975509105537>
- Halvorsen, Rune, and Bjørn Hvinden.** 2018. “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: Edward Elgar Publishing. DOI: <https://doi.org/10.4337/9781783476008>

- Hamdani, Yani, Bhavnita Mistry, and Barbara E. Gibson.** 2015. "Transitioning 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>
- Helse- og omsorgsdepartementet (Ministry of Health and Caring Services).** 2022. Lov om pasient- og brukerrettigheter (The Norwegian Patients and User Rights Act). Oslo: Lovdata. 2022. Retrieved from: <https://lovdata.no/dokument/NL/lov/1999-07-02-63?q=pasient-%20og%20brukerrett>.
- Helse- og omsorgsdepartementet.** 2001. Fra Bruker til Borger: En Strategi for Nedbygging av Funksjonshemmende Barrierer [From User to Citizen: On Dismantling Disabling Barriers]. *Norwegian Official Report NOU* 2001: 22. Oslo.
- Højholt, Charlotte.** 2020. "Conflictuality and Situated Inequality in Children's School Life." *Children's Geographics* 20(3): 297–310. DOI: <https://doi.org/10.1080/14733285.2020.1817335>
- James, Allison.** 2009. "Agency." In *The Palgrave Handbook of Childhood Studies*, edited by Jens Qvortrup, William A. Corsaro, and Michael-Sebastian Honig, 34–45. London: Palgrave-Macmillan.
- Link, Bruce, and Jo Phelan.** 2001. "Conceptualizing Stigma." *Annual Review of Sociology* 27(1): 363–385. DOI: <https://doi.org/10.1146/annurev.soc.27.1.363>
- McDowell, Linda.** 2002. "Transitions to Work: Masculine Identities, Youth Inequality and Labour Market Change." *Gender, Place and Culture: A Journal of Feminist Geography* 9(1): 39–59. DOI: <https://doi.org/10.1080/09663690120115038>
- Ramstad, Kjersti, Reidun Jahnsen, and Trond H. Diseth.** 2015. "Ungdom med Cerebral Parese og Deres Kontakt med Fastlege og Habiliteringstjeneste." *Tidsskrift for den Norske Legeforening* 135(5): 429–33. DOI: <https://doi.org/10.4045/tidsskr.14.0434>
- Rogoff, Barbara.** 2003. *The Cultural Nature of Human Development*. Oxford: Oxford University Press.
- Rogoff, Barbara.** 1995. "Observing Sociocultural Activity on Three Planes: Participatory Appropriation, Guided Participation, and Apprenticeship." In *Sociocultural studies of mind*, edited by James V. Wertsch, Pablo Del Rio, and Amelia Alvarez, 139–164. Cambridge: Cambridge University Press. DOI: <https://doi.org/10.1017/CBO9781139174299.008>
- Ryan, Christian, and Elizabeth Quinlan.** 2018. "Whoever Shouts the Loudest: Listening to Parents of Children with Disabilities." *Journal of Applied Research in Intellectual Disabilities* 31(S2): 203–214. DOI: <https://doi.org/10.1111/jar.12354>
- Shakespeare, Tom.** 1994. "Cultural Representation of Disabled People: Dustbins for Disavowal?" *Disability & Society* 9(3): 283–299. DOI: <https://doi.org/10.1080/09687599466780341>
- Skagestad, Linn Julie, Sigrid Østensjø, and Oddbjørg Skjær Ulvik.** 2021. "Collaborations between Young People Living with Bodily Impairments and their Multiprofessional Teams: The Relational Dynamics of Participation and Power." *Children & Society* 35(5): 633–647. DOI: <https://doi.org/10.1111/chso.12419>
- Traustadóttir, Rannveig, James Rice, and Kristjana Jokumsen.** 2018. "Social Networks, Recruitment Strategies and the Ambiguities of Employment Activation Programmes: Perspectives of Employers and Vulnerable Youth." In *Youth, Diversity and Employment: Comparative Perspectives on Labour Market Policies*, edited by Rune Halvorsen and Bjørn Hvinden, 178–198. Cheltenham: Edward Elgar Publishing. DOI: <https://doi.org/10.4337/9781783476008.00013>
- Ungdata.** 2022. Nasjonale Resultater [National survey results]. NOVA [Norwegian Social Research] report 5/22.
- United Nations.** 2006. Convention on the Rights of Persons with Disabilities. Retrieved from: <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.
- Valentine, Gill.** 2003. "Boundary Crossings: Transitions from Childhood to Adulthood." *Children's Geographies* 1(1): 37–52. DOI: <https://doi.org/10.1080/14733280320186>
- Van der Kaap-Deeder, Jolene, Maarten Vansteenkiste, Bart Soenens, Tom Loeys, Elien Mabbe, and Rafael Gargurevich.** 2015. "Autonomy-Supportive Parenting and Autonomy-Supportive Sibling Interactions: The Role of Mothers' and Siblings' Psychological Need Satisfaction." *Personality and Social Psychology Bulletin* 41(11): 1590–1604. DOI: <https://doi.org/10.1177/0146167215602225>
- Wright, Alice E., James Robb, and Morven C. Shearer.** 2016. "Transition from Paediatric to Adult Health Services in Scotland for Young People with Cerebral Palsy." *Journal of Child Health Care* 20(2): 205–213. DOI: <https://doi.org/10.1177/1367493514564632>
- Ytterhus, Borgunn, Snæfríður Egilson, Rannveig Traustadóttir, and Berit Berg.** 2015. "Perspectives on Childhood and Disability." In *Childhood and disability in the Nordic countries: Being, Becoming, Belonging, Studies in Childhood and Youth*, edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snæfríður Egilson, and Berit Berg, 27–45. Basingstoke: Palgrave Macmillan. DOI: [https://doi.org/10.1057/9781137032645\\_2](https://doi.org/10.1057/9781137032645_2)

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