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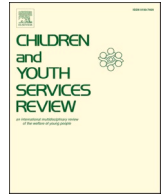
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# 'My disability was my own responsibility': An institutional ethnography of the transitional experiences of disabled young people leaving care

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## ABSTRACT

Across child welfare and disability policy, the intersectionality of being a young person with experiences with both child welfare and disability services is not well addressed. In line with this, a growing body of international evidence shows a gap in the level of transitional and post-care support provided to meet the needs of this group of young people leaving care. The present article draws on data from a qualitative interview study with eight disabled young people leaving care in Norway. However, rather than giving an account of their individual experiences of aftercare, it uses these experiences as a starting point to a broader investigation of how the institutional setting of aftercare shapes these experiences. The study is inspired by institutional ethnography (IE), a method of inquiry developed by Canadian sociologist Dorothy E. Smith, which attempts to describe the interface between individual experiences and institutional relations. Our findings showed that the study participants experienced insufficient support from child welfare services related to their disability during the transition to adulthood. The institutional forces behind these findings are explored and discussed.

## 1. Introduction

Disabled<sup>1</sup> young people leaving care have a dual experience of aging out of child welfare services<sup>2</sup> and transitioning from child to adult health or disability services. Studies examining the prevalence of disability within the population of young people leaving care report numbers ranging from around 11% to 50% depending on inclusion criteria and national context (Cheatham et al., 2020; Gundersen et al., 2011; NSW Ombudsman, 2004; Slayter, 2016). Still, there is a clear overrepresentation of youth with disabilities in the population of young people leaving care when compared with the prevalence of disability in the general youth population (Kelly et al., 2016).

Despite the prevalence of disability within the child welfare system, it has been found that policy does not satisfactorily address the intersectionality of being a young person with experiences of both child welfare and disability (Bennwik & Oterholm, 2021; Mendes & Snow,

2014; Priestley et al., 2003). It is unsurprising then that a growing body of international evidence shows a gap in the level of transitional and post-care support provided to meet the needs of this group of young people (Broadley, 2015; Mendes & Snow, 2014). The impact of not accessing adequate support in the transition to adulthood can be critical, particularly for young people leaving care who are undiagnosed or whose diagnosis is contested (Kelly et al., 2016).

Research focused on support for disabled young people leaving care is an emerging field of interest globally, but available studies show that disabled youth face a wide range of barriers in their transition from foster care to independent life (Geenen & Powers, 2007; Kelly et al., 2016; Snow et al., 2014). Such barriers include unstable living conditions, insufficient employment/educational pathways, financial difficulties and a lack of informal support (Harwick et al., 2020; Kelly et al., 2016).

It has also been shown that disabled youth leaving care often

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<sup>1</sup> Across research and practice contexts, different terms are used to refer to disability. This study is informed by critical disability studies which considers disability to be a form of social oppression rather than an individual feature and, hence, uses the term 'disabled young person' rather than 'young person with disabilities' (Goodley & Runswick-Cole, 2013). This terminology also reflects the usage of language in the lives of the young people who participated in the study.

<sup>2</sup> In this article, the term 'child welfare services' refers to the public agency that is responsible for measures regulated by the Act (1992). Such services include home-based assistance, out-of-home placements and aftercare.

experience poor exit planning and have difficulties accessing post-care support due to restrictive eligibility criteria and a lack of disability awareness within the different care systems (Duncalf, 2010; Geenen & Powers, 2007; Harwick, Lindstrom, & Unruh, 2017; Hutton et al., 2019; Roberts et al., 2018; Snow et al., 2014).

Unsurprisingly, then, it has been found that disabled young people leaving care have more negative transition outcomes than other youths leaving care across a range of domains including employment, education, income, mental ill health and housing (Anctil et al., 2007; Kang-Yi et al., 2017; Lee et al., 2018; MacDonald, 2010; Slayter, 2016).

In Norway, where this study was conducted, there have been no studies on the experiences of disabled youth leaving care or on aftercare support for this group of young people (Bennwik & Oterholm, 2017; Fossum et al., 2015; Gundersen et al., 2011). The current study seeks to address this gap in the research literature by exploring support for disabled young people leaving care in the transition to adulthood in Norway. This article takes the standpoint of this group of young people, but rather than giving an account of their individual experiences of aftercare, it uses their cases as a point of entry to a broader investigation of how the institutional setting of aftercare shapes these experiences. The study is inspired by institutional ethnography (IE), a method of inquiry developed by Canadian sociologist Dorothy E. Smith, which attempts to describe the interface between individual experiences and institutional relations and takes special interest in how institutional ruling relations shape how people live and experience their everyday lives (Deveau, 2009; Smith, 2005). The core research question is, how do institutional ways of understanding aftercare and disability shape and organize support for disabled young people leaving care?

### 1.1. The Norwegian context of aftercare

In Norway, under the [Child Welfare Act \(1992\)](#), all young people who have been in care before the age of majority have the right to assessment for aftercare support from child welfare services. The term aftercare does not refer to a specific transition programme or short-term transition interventions, but rather describes all child welfare measures after the age of majority. These include the provision of foster care, financial support, counselling, housing services and transitional support. Aftercare can be offered until the child welfare recipient turns 25 years old and aims to support young people during the transition to adulthood (Ministry of Children, 2011). If a young person leaving care has a disability, child welfare services have a special responsibility to assist them by establishing contact with adult services and coordinating services provided by aftercare and adult services if both are in the young person's best interests (Ministry of Children, 2011). However, Norwegian studies show that when youth with complex needs are referred to adult services after the age of majority, aftercare support usually ceases (Iversen, 2008; Oterholm, 2015).

A disabled young person leaving care may need support from both child welfare services and adult services during their transition to adulthood. Navigating these different service systems, however, may be challenging as child welfare and adult services in Norway have different legal frameworks and are structured within autonomous organizations with separate budgets and staff with different professional backgrounds. During 2019, the Norwegian Board of Health Supervision audited the cooperation between child welfare services and social services for adults and their work related to aftercare. Several regulatory breaches relating to service coordination were identified in this audit. It was found that employees in child welfare services and social services had little knowledge about services and legislation in the 'other' organization and there was a lack of organizational collaboration and cooperation (Norwegian Board of Health Supervision, 2020).

Several recent initiatives have sought to improve this situation including by issuing a recommendation for a general health examination for all children placed by child welfare services (Ministry of Children and Families, 2020) and a circular on co-operation between child

welfare and mental health services (Norwegian Directorate for Children, Youth and Families, 2020). However, none of the recent initiatives mention older youths or young people leaving care and these documents generally place a stronger emphasis on mental health and behavioural disorders than on physical, sensory or intellectual impairments.

## 2. Theoretical framework

### 2.1. Understandings of disability and impairment

As this study is interested in the intersectional experience of leaving care and disability, it is necessary to clarify the assumptions behind the concept of disability. Since the 1970s, medical and pathological models of disability have largely been challenged and replaced by a new paradigm, often referred to as the social model of disability. This model posits a conceptual distinction between 'disability' as a form of social oppression and 'impairment' as an individual characteristic and bodily experience (Oliver, 2009; Shakespeare, 2006). However, the binary divide between disability and impairment has been found increasingly problematic, especially when exposing the social nature of diagnostic criteria (Goodley, 2001). Contemporary critical disability studies (CDS) challenges the rigid dichotomies between disability and impairment and disabled and non-disabled focusing instead on the rich web of connections and relationships that constitutes disability (Goodley, 2001). In this way, CDS adopts a more complex and fluid understanding of disability that still seeks to counter disabled people's experience of oppression but also allows for self-definition and intersectional analysis based on a broader critique of normativity (Goodley et al., 2018; Mee-kosha & Shuttleworth, 2009).

A broader conceptual understanding of disability is highly relevant to the concerns of disabled young people leaving care who are navigating complex service structures and relationships as they transition from care where the identities of care leaver and disabled young person intersect. The focus in CDS on disrupting these binary positions, challenging normative ideas on embodiment and highlighting disabling and dehumanizing discourses regulated by language and practices can also inform the IE analysis adopted in this study which is similarly concerned with the interface between individual experiences and institutional ruling relations (Deveau, 2009; Smith, 2005).

In the present study, we acknowledge the rich complexity of the concept of disability and reject dualistic categorization of the body and the social as many of the experiences described in this study do not 'fit' within a singular concept of disability or impairment. Whilst most participants recounted experiences of oppression, only one young person used the term 'disability'. All participants described their bodily experiences of impairment, clinical diagnoses or pain/fatigue which could change over time and between contexts.

In alignment with critical disability studies, our findings indicate a need for more fluid understandings of disability and impairment and further acknowledgement of individual experiences within the context of the powerful impact of disabling, normative discourses and structures. Young people's preference to not use the term 'disability' could be a result of how language, text and discourse at an institutional level have created dominant forms of understandings where needs are individualized and oppression or stigma on the grounds of disability is ignored.

### 2.2. Institutional ethnography

This study is informed by several assumptions of institutional ethnography (IE). 'IE is designed to discover, unpack and challenge the social organisation of everyday life and involves commitment to doing research with and for people, rather than about them' (Lund & Nilsen, 2020, p. 3). The main questions in IE are about how things are socially organized, or how they come to happen as they do. Analytically, there are two sites of interest: the local setting, where life is lived and experienced by people, and the translocal, which is outside the boundaries of

everyday life (Campbell & Gregor, 2004, p. 29). While IE sees people as experts in how they live their lives and relies on people's experience as the point of entry into inquiry, its goal to explicate local accounts by looking for data that can help uncover organizational details of how the local setting works (Campbell & Gregor, 2004, p. 59-60; Smith, 2005).

IE takes special interest in 'ruling relations' that shape how people live and experience their lives in their local setting. Ruling relations are often vested in texts and shape how a problem is understood and experienced by the people in the local setting (Campbell, 1998; Deveau, 2009). The concept of text in IE both refers to 'active texts' and 'higher order texts'. Active texts are provided, read, completed or agreed to and could be individual care plans or information sheets that are signed (Prodinge & Turner, 2013). Higher order texts are often not visible in local settings but coordinate locally activated texts. Higher order texts might be guidelines, policy or laws (Prodinge & Turner, 2013).

In many cases, institutional ruling relations can be invisible or not recognized by the people who participate in the ruling relations. The disclosure of ruling relations has emancipatory potential because it permits people who live these experiences to move and act more freely on the basis of their knowledge of how their experience came to happen as it did (Campbell, 1998, p. 56). Hence, IE is not a sociology *about* people but a sociology *for* people (Smith, 2005). This commitment of IE shares the emancipatory aims and ethical values of social work practice and research (Kuronen, 2020).

### 3. Methodology and analysis

The study involved qualitative, semi-structured interviews with eight disabled young people leaving care. Inclusion criteria were young people aged 18–24 years who had experiences of child welfare support and disability, and who had left care at least six months before the interview took place.

We sought to recruit study participants by contacting a total of 83 different professionals at different levels of the child welfare services in Norway. Most of these social workers claimed they did not know any young people who met the study criteria, while others indicated they either did not have time to help with recruitment or they were worried that the young people were too 'fragile' to participate. We engaged in several discussions with gatekeepers to help them identify disabled young people in their caseloads and were often asked to stipulate which 'medical conditions' were included in the study. This use of medical language evoked theoretical and methodological challenges that required ongoing, sensitive reflection within our group of researchers and in our dialogue with study participants and gatekeepers. While this dialogue resulted in interesting new insights regarding disability and aftercare, the effort only resulted in three study participants. An alternative recruitment strategy using social media was therefore employed. We posted information about the study in Facebook groups for child welfare professionals. This only resulted in one more participant, but the information spread to other forums related to child welfare, and young people with relevant backgrounds contacted us directly. This resulted in a further five interviews. After conducting the interviews, we discovered that one person recruited via child welfare services did not have any experience of disability or impairment and therefore decided to exclude this individual from the study. One of the participants did not satisfy the age criteria, but we decided to include this young person because of their relevant experiences to improve data saturation.

The final sample consisted of eight young people aged 19–27 years living in four different regions in Norway. Two young people identified as male and six identified as female. All of them had more than one out-of-home care placement during their childhood, ranging from two to nine different placements. Five participants had experiences from both residential care and foster care, two had experiences from foster care only and one had only been placed in residential care. Six participants did not self-identify with disability-related terminology at first and rather identified themselves by diagnosis or descriptions of impairment.

All eight participants self-defined as having experience of a very wide range of impairments, and many of them had more than one diagnosis. These experiences of impairment included mental ill health (e.g. PTSD, depression, anxiety, bipolar disorder, suicidal behaviour), learning difficulties, intellectual disability, autism spectrum disorder (ASD), physical impairment (e.g. paralysis, rheumatic diseases) and behavioural disorders. We recognize that this language might suggest a medical model perspective, but we employ these terms to reflect their usage in the lives of the young people who participated in the study (Goodley & Runswick-Cole, 2013). Such language is also used in several Norwegian high-order texts, like legislation, circulars and guidelines. However, we would like to underline that this language demands critical reflection in order to avoid reproducing normative and oppressive assumptions about disability.

To maintain confidentiality, we do not specify diagnoses for individual young people when we present our results and we have excluded other identifiable information. We have given the young people fictional names: Anna, Bea, Clara, Eric, Frida, Greg, Hedda and Ida. Although this is a small-scale qualitative study, we have achieved adequate data saturation, both through the presence of some strong repeating themes in the interview accounts and by a rich variety of experiences in the young people's interview accounts.

The interview guide was shared with two young people with care backgrounds representing the organization for care-experienced youth (Landsforeningen for barnevernsbarn - LFB) in Norway. Their feedback was incorporated in the final version of the guide. The young people from LFB also advised throughout the study and helped make the information sheet, consent form and interview guide more understandable. Interestingly, reflecting the earlier discussion of critical disability studies, they challenged the initial use of the term 'disability' in the information sheet, which they considered to be alienating due to the associated stigma.

Participation was based on voluntary informed consent, and the study was approved by the Norwegian Centre for Research Data (NSD). Confidentiality was maintained in accordance with the NSD's ethical requirements. The interviews were conducted by the first author who is a PhD student and a trained social worker (female). In advance of the interviews, the first author communicated with all participants either by phone or via e-mail. In addition, all of them received an easy-to-read description of the research project containing information about the goals of the study, its role as part of a PhD project, the university responsible for the research, the researchers' affiliations, and data protection procedures. They also received information about the main themes in the interview guide in advance of the interviews: background information, preparation for the transition out of child welfare services, experiences of leaving care and life post-care. The youths could choose if they wanted to receive the interview guide in advance of the interview, but nobody took this opportunity. The participants were allowed to choose the location of the interview; locations included homes, cafes and offices. They were also allowed to choose if they wanted to do the interview during one meeting or over a couple of days. All chose one meeting, but in most interviews, we facilitated a break. The interviews lasted 1–2.5 h. Due to COVID-19, the final interviews were conducted via phone/zoom. We could find no differences in terms of length, content or depth between the interviews conducted in person and those conducted remotely. All participants chose to attend the interview alone.

The interviews were recorded on an encrypted audio recorder, transcribed in Norwegian and read by the first author. In addition, one co-author read a couple of the transcripts in full length and contributed to discussions about coding. The analysis was done in three steps. We first approached the interviews through thematic analysis, as described by Braun and Clarke (2006). We used NVivo to manage the data in this step of the analysis. A main finding was that all participants described lack of support from child welfare services related to disability despite the impact of disability-related issues on challenges during their

transition to adulthood as they navigated complex welfare systems. They also expressed an expectation that child welfare should provide them with more care and support.

This disjuncture between how things were ‘supposed’ to be and how they actually manifested in the lives of the young people made us want to understand more about the ‘coordinating forces’ behind this finding. We realized that we had to turn our gaze toward the institutional context of aftercare and child welfare services. In this process, we used institutional ethnography (IE) to re-analyse the transcripts and ‘trace’ institutional influence (Rankin, 2017). By searching for terms like ‘rule’, ‘document’, ‘meeting’ and ‘system’ and by looking for narratives about the youths’ encounters with welfare services, we were guided towards the translocal organization of aftercare. In order to access this part of the social organization, we investigated national legislation, governmental guidelines, circulars and other governmental white papers published between 1998 and the present date. The reason for limiting our search to 1998 is that aftercare legislation in Norway went through vital revisions that year.

There is no single way of doing IE, but we were inspired by the four steps outlined by Lund (Lund, 2015, p. 70):

1. Identify a standpoint from where you wish to investigate institutional processes. This includes identifying disjunctures and formulating the research problematic.<sup>3</sup>
2. Based on indications given by the research participants, identify some of the immediate institutional processes shaping that experience. In our study, these processes primarily were identified through conversation with the youths who participated in the study and by identifying texts they either indirectly activated or specifically referred to.
3. Move beyond immediately and locally occurring processes to explore how these are related to processes that take place elsewhere/elsewhen.
4. Describe how the translocal processes operate as grounds of the local experience – return to the standpoint.

It is important to underline that IE is an iterative process and that we move between these four steps continuously throughout the analysis. Still, in this article, we have chosen to describe steps 1 and 2 as the results of the study, step 3 as the discussion and step 4 as the conclusion.

#### 4. Findings

We start by outlining the standpoint in the study and some of the immediate, local institutional processes that could have shaped the young peoples’ experience of not accessing support from child welfare. We have categorized these processes as ignoring disability, placing responsibility on the youth, exclusionary practice, and abrupt transitions to adult services. In presenting the findings we display the first two steps of the IE process.

##### 4.1. Ignoring disability

One of the institutional processes most often described in our interviews was ‘ignoring disability’. In their interviews, participants often reported that addressing impairments and disability was not part of the child welfare services’ agenda’. Even participants who were satisfied with the general support they received during the transition from care

<sup>3</sup> The research problematic should not be understood as research questions, but rather a strategy for discovery that ‘is generated from the data, and (...) often rests on stories (accounts) that reveal troubles arising in (or conflicts between) authorized and experiential knowledge; whereby the tensions that standpoint informants know about and experience are either invisible or misrepresented within the authorized accounts’ (Rankin, 2017, p. 3).

indicated that disability was not addressed when planning the transition to adulthood. Some of their stories indicated that matters related to disability went totally under the radar in their interactions with child welfare services. Others suggested that child welfare services were well aware of their impairments but that they somehow did not take responsibility to explore their disability-related needs. None of the study participants had received any disability-related support from child welfare services during the transition to adulthood, and they describe their ‘disability work’ as a very lonely enterprise.

Clara was one of the young people who described such an experience. She received assistance with education and housing from aftercare services but no support related to her mental ill health. Clara questioned this and felt it was strange that child welfare services did not ‘care about’ this important dimension of her life, especially since her mental ill health had affected so many parts of her daily life. She also wondered about the mandate of child welfare and did not know what she could expect from them.

Clara: They absolutely do know that I struggle with (mental health diagnosis). And now, well I was treated at (hospital) five months ago. And they knew that I was there... So they are well aware of my challenges. But they never ask how I am doing or... No.

I: And they have not asked you what kind of support you need?

Clara: No, they have not (...) But they did not really get to know me. Because suddenly, when I was going to a meeting with them, I had a new case worker. It was very strange. I probably had seven different case workers. I am not sure. And you do not really meet them that often (...).

I: So your mental health problems weren’t really an issue?

Clara: No... not really. They were not. I do not really know why. But I think that I just assumed that since they did not ask, it was not their responsibility. That it was my own responsibility.

Clara had stopped talking to child welfare services about her mental health and figured that she had to manage all related work independently. Because she did not address the matter of mental health, it disappeared from her interactions with child welfare services. Clara was sure that they knew about her challenges, but she perceived that child welfare services did not see her as a person who needed support related to mental health. Thus, her mental health needs became invisible in Clara’s interaction with child welfare services.

Bea is another young woman who felt that her disability was not recognized by child welfare services. Bea was placed in out-of-home care from an early age and lived in several foster homes and in residential care during childhood. When she entered her teens, she started feeling bodily pain and fatigue, but nobody had really kept track of her health records during all her moves. When Bea turned 17, child welfare agreed to support her to attend a high school in another town; however, Bea’s health situation soon deteriorated, and she was no longer able to manage full school days:

Bea: I struggled so much, and I tried to tell them that I could not manage full days at school. Because they started complaining over the truancy. And I told them, that I just cannot do it. It hurts. But they never really took it seriously.

I: Did you feel that they did not believe you?

Bea: Yes, definitely. I felt that they didn’t believe that I was in such pain. They only got mad because of my school absence, you know, because they had been kind to me and agreed to let me move to (the town) and helped me settle there and....

I: They gave you an opportunity?

Bea: Yes. And... then I did not perform well at school. And in one way my health situation was bad enough. To me it felt like a punishment that I could not attend school fully. And then, in addition, I felt like they wanted to punish me because they did not believe me. So

finally, I think I stopped telling them about it (health). Because they did not take it seriously.

Due to what child welfare services defined as ‘truancy’ from school, Bea felt more or less forced to quit school when she reached the age of majority. Child welfare told her that since she did not attend school as agreed, they would no longer cover her rent and living costs in the town where her school was located. Bea felt that she was seen as ‘disobedient’ rather than ‘disabled’, and this silenced her. She stopped talking about her impairment and started to feel like a burden on the system:

Bea: If I needed to go to the doctor (...) I had to apply to them (for funding). But they always complained so much about not having enough money to support me (...) So for me, it became very difficult to send applications... And to go to the doctor, because I knew it would cost something. And I could not pay that myself, because I did not have that money (...) And I was worried about bothering them.

#### 4.2. Placing responsibility on the youth

Another matter frequently discussed in the interviews was the division of responsibility between the young person and child welfare services when organizing support after the age of majority. This matter was seen in part as a mere organizational issue, as shown in the interview with Anna.

Anna: (...) We did have meetings with the representative from (child mental health services), where we talked about what we agreed about, and stuff like that. The only thing was that child welfare services didn't have anything to do with the psychologist. That I kind of... should keep my mental health to myself (...).

I: But when you were transitioning over to adult services...

Anna: Yes, then I didn't get any support related to mental health. Then I only had (child welfare worker).

I: And to get necessary mental health services after 18... you had to do that by yourself?

Anna: Yes. I arranged that by myself, with some help from NAV (social services for adults). Or, actually it was my GP (who helped).

Anna had experienced mental ill health for many years and accessed therapy and medical treatment during her time in care. Mental ill health still affected her life extensively after she reached the age of majority making it difficult for Anna to use public transport, go shopping or work or study full time. However, when child welfare started planning her transition to adulthood, very little attention was given to these challenges. In Anna's own interpretation, mental health was her own responsibility. Anna herself did not problematize this, and she was very satisfied with the support she got from child welfare services in general. She felt very close to her case worker and saw the staff at the residential care facility as family. She quite simply did not believe that support related to her mental ill health fell within the mandate of child welfare services after she had reached the age of majority.

In other interviews participants problematized the way they were left to organize and coordinate support on their own. On the one hand, they were uncertain whether or not child welfare services were responsible for this kind of support; on the other hand, they questioned how their experience of disability could be ignored when it was an integral part of their support needs during their transition from care. It was common for them to feel that having to secure and coordinate support for disability-related needs placed a heavy responsibility on them, but they often felt they had no other choice. For example, Greg who had acquired a physical disability after a serious accident, described being his own ‘case worker’. Greg's disability gave him an undisputable right to services, but he had to navigate a very complex service system and become a self-advocate in order to access these services:

Greg: Nobody tells you anything... about what your rights are, how you should do things... And I do not understand why you are not given a counsellor or a guide who could tell you. You have to do everything by yourself. Apply for this, apply for that. And I cannot even write, you know... just for me to have something written – it would take a whole day. Travel somewhere, find somebody... Just to deliver an application... To spell it out – it is hell. It is too unwieldy (...) I have applied for most of the services myself. I have been on my own, writing those applications. Read different laws. Learnt a lot about the system myself. Seen it as a challenge. Because I am extremely stubborn, you know. I do not give up. When I know something is not right, then I try figuring things out by myself. And I call him (a lawyer), and I tell him what I have found out and ask if I am entitled to different kinds of benefits or support measures. And actually, I have often been right. And this way, I have also learnt a lot...

Greg and many of the others expressed advanced knowledge of the welfare system. This knowledge did not come easily, and many reported being exhausted by the workload connected to manoeuvring between different welfare services. Still, such knowledge also created room for individual agency and opportunity for the young people to reach their self-directed goals and access the support they were entitled to.

#### 4.3. Exclusionary practice

Not only did the participants experience being left alone to organize their access to support, but they also described different forms of ‘demands’ from child welfare services in order to access aftercare support. In many of the interviews, impairments were described as a barrier to meeting such demands. For example, Hedda developed mental ill health in combination with a substance dependence in her teens. When she was about to reach the age of majority, child welfare services offered her aftercare, but only on the condition that she would not use any drugs after moving out of residential care:

Hedda: Child welfare services were very concerned about making a contract. And they wrote that one of the conditions, or one of the demands, was that if I did any drugs, I would no longer have a right to aftercare. And the thing is... all my papers tell that I had severe drug problems from age 13. So, of course you will turn to drugs when you leave child welfare. I think I even was affected when I signed that contract, you know. So after only three months, there was a breach of contract.

After Hedda ‘broke’ the contract, her aftercare was terminated. Hedda explained that this was her own mistake: she was the one who used illegal drugs despite having signed the contract. At the same time, she questioned how child welfare services could identify her main problem as the main reason for not giving her support.

Another participant, Frida, told a story that differed somewhat from many of the others. Frida's mental ill health became ‘visible’ in the form of self-injurious behaviour in her teens. Contrary to Hedda, Frida still felt that the transition to adulthood had gone well because she was able to ‘behave’ according to the expectations of child welfare, which provided aftercare support that compensated for the lack of mental health services. She went on to achieve excellent grades at school, engage with cultural organizations and hold positions in a political party. In Frida's own understanding, this was a result of who she is and her compliance with expectations from child welfare:

I: What led to this good outcome?

Frida: (...) I think it has a lot to do with me. Who I am. Because I could have been difficult, but I am very easy to work with. (...).

I: Does one have to be ‘easy’ for things to work out well?

Frida: Maybe. Because, well, somebody I know... is extremely challenging. And the support he gets is so bad. The problems are not necessarily challenging; they could have been solved easily, but nobody takes the time. Because he is so demanding and difficult.

I: You have to be easy to get help?

Frida: Yes.

Frida's story corresponds with the experiences of Ida, another young woman in this study. Like Frida, Ida also had tried to 'behave' according to the demands of child welfare services.

Ida: Child welfare services have several demands. And I know that this is not in accordance with the law. People have a right to aftercare. But I have experienced – and I have talked to others about it, who experienced the same – that there were several ultimatums if you wanted aftercare, if you wanted to get further support. You had to follow certain rules, and if not, your support was terminated. And when you are in that situation, and things are that difficult, and you have to relate to this very restrictive framework for how to behave. And if you are not like that, well 'then we do not bother to help you'. It is very difficult (...) And I did not dare to tell them what I needed because I was worried that it was too much and that I would get no help at all.

Several other participants also used terms like 'being easy/difficult' or 'obedient/disobedient' when they were asked to reflect on ways to successfully navigate the child welfare system. Even if some of them, like Hedda, questioned the demands of the system, they still seemed to accept this framework of regulation. In some cases, the conditions of success could coexist with their diagnosis. For example, in Frida's situation, it was possible to self-injure and still be an 'easy' youth. In other cases, the framework of regulation clashed with the young person's situation and aftercare was either terminated or the youth had to 'hide' his/her needs.

#### 4.4. Abrupt transitions to adulthood

Since many of the youths in this study needed support from adult services after aging out of child welfare services, it is important to understand their experience of the coordination between child welfare and adult services. Eric is an example of a young person who clearly qualified for support after aging out of child welfare services. In his early teens, he was diagnosed with ASD and he was placed in different institutions with a high level of support. Eric found it hard to understand what his diagnosis meant, but he recognized that he would continue to need different forms of support from adult services after aging out of child welfare and understood that he was perceived as 'challenging' by child welfare services. The transition to adult services had been raised as an issue by child welfare services, but it still came as a big surprise to him:

Eric: Nobody gave me any notice in advance (about moving from residential care). On the day of the move, they just told me... well, now you have to move. I did not understand what happened. I just... OK. Because I was told that I at least should get six months' notice before I had to move. You see? And this is actually what their own rules say. And I... OK, they do have a policy, but they do not intend to follow it themselves? (...).

I: But did child welfare services offer any support where you live now (adult services)?

Eric: No. Well... how I perceive it... they have tried to renounce their responsibility... and kind of pushed it over to adult services. (...).

I: Did child welfare services ever talk about the possibility of giving you special support related to your diagnoses in the transition to adulthood?

Eric: No, they only said 'you have autism, you are stupid'. That's it. That is what they told me.

Eric found that child welfare services ceased their involvement when he moved over to adult services categorizing him as 'stupid'. He felt that his "stupidity" almost became a green-card for child welfare to give him up and "push" him over to adult social services.

Eric's story is in line with how other young people with a clear medical diagnosis experienced being 'pushed' over to adult services and how they were often described as being 'too difficult' for child welfare services. Although these young people clearly qualified for support from adult services, they did not describe being 'pushed over' as a positive transition to person-centred support but rather as being removed from the child welfare service. None of them described an easy transition to adult services; rather, their stories reflected an overwhelming struggle to get the support they needed to live their lives fully.

## 5. Discussion – Institutional traces

The third step in IE is to trace how immediate, local, institutional processes might be connected to translocal ruling relations. A vital experience of the study participants was that child welfare services did not recognize their experiences of impairment or disability when planning for their transition to adulthood. The young people also participated in this 'ruling' by becoming silent and by doing their 'disability work' either completely on their own or as individual users of adult services. This knowledge and practice took place in an institutional context shaped by several high order texts that affect how aftercare and disability are understood and how support for disabled youth leaving care is structured and delivered.

### 5.1. Ruling understandings of aftercare

An example of a high order text is the [Child Welfare Act \(1992\)](#), which states that the overall mandate for child welfare is to ensure that children and youth who live in conditions that may be detrimental to their health and development receive the necessary assistance and care at the right time. In 2018, the term love was even added to the Child Welfare Act to underline the expectations of how child welfare should meet the needs of children and youth in care ([Økland & Sørsdal, 2020](#)). Given this legal duty, it is hard to understand how child welfare services could possibly ignore the disability-related needs of the young people who participated in this study. However, in subsequent governmental white papers addressing aftercare, and adult life more specifically, the concepts of care and support seem to disappear when young people move from childhood to adult status ([Bennwik & Oterholm, 2021](#)). By constructing adult life as a time of autonomy and independence and describing aftercare as part of the process of transitioning to this stage of adult independence, concepts of support and care are excluded ([Bennwik & Oterholm, 2021](#)). A recent Norwegian study on aftercare similarly found that while aftercare support was prioritized for young people with additional challenges, it was primarily intended to assist them to manage independently as adults ([Paulsen et al., 2020](#)). Thus, child welfare workers might not have 'scripts' to guide the facilitation of transition to other forms of interdependent adulthood where young people can rely on various levels of support as needed.

Study participants' accounts of how their experiences of disability were not recognized by child welfare services can also be understood in light of how welfare services in Norway are organized. The national guidelines for cooperation between child welfare and disability services is another high order text that states that the municipality of origin is responsible for aftercare measures, and the municipality of residence is responsible for disability services ([Norwegian Directorate for Children, Youth and Families, 2018](#)). This division of roles provides an opportunity for each service to negate its duty to support a disabled young person leaving care by defining their needs as being the responsibility of

the other service. The complex inter-relationship of mental ill health, disability, childhood trauma and post-care challenges is artificially separated by a structural division of funding and service provision that can be used to determine and justify the discontinuation of child welfare services.

Additionally, the right to aftercare services is not absolute but depends on what is in a child's best interest. If child welfare services consider that it is in a young person's best interest to be transferred to adult services, where there is more specialist expertise in disability and health and special education support, this can legitimate a decision to terminate aftercare. The transition to adult services, however, is poorly regulated and scarcely described in child welfare policy as it is formulated in high order texts such as governmental circulars, national guidelines and legislation. In the 2011 government circular on aftercare, it is stated that child welfare services have special responsibility for establishing contact and coordinating cooperation with other relevant services during aftercare (Ministry of Children, 2011). It is also stated that child welfare should inform the 'other' services about the needs of young people leaving care and assist them to find relevant services to meet their identified needs. However, the circular does not mention disability, and what is meant by 'other services' is unclear (Ministry of Children, 2011). The national guidelines for cooperation between child welfare services and adult social services contain only one mention of disabled care leavers as a group of young people who will need special support in aftercare (NAV, 2016). The guidelines state that the division of responsibility and cooperation between child welfare and adult services must be decided in each individual case based on the needs of each youth (NAV, 2016). Such broadly stated guidance allows services to consider young people leaving care with 'special' support needs as exceptions who could potentially be outside of the remit of aftercare and should be transferred to adult social services instead (Iversen, 2008; Oterholm, 2015). This 'othering' of disabled young people leaving care in policy and practice could explain why the young people in this study felt 'pushed' out of child welfare services.

The understandings of aftercare that are described in these high order texts offer a wide range of negotiations when disabled young people with experience in care reach the age of majority and decisions about which services are needed to serve their best interests. The experiences of study participants suggest that these negotiations did not take place, or that the young people were not included in discussions and plans for their transition to adult services. This lack of clear planning, participation and coordination may also reflect a lack of knowledge among child welfare professionals in the municipality of origin about how well young people's needs will be met by adult services in the municipality of residence when aftercare provision is withdrawn.

When the regulatory frames of law, policy and organizational procedures that govern service provision ignore young people's experiences and concerns, youth are expected to fit into institutional categories governed by regulatory texts that authorize the institution's existence rather than provide person-centred services to meet the young people's needs. The narratives of the youths who participated in the study indicate that child welfare services imposed young people's care identity as a master status because child welfare is their institutional, regulatory frame. When young people leaving care have a disability, they do not fit easily into this frame despite efforts to impose conditions on their behaviour, and the focus shifts to a disability regulatory frame that justifies a referral to adult services where 'specialist' disability support can be accessed and a discontinuance of child welfare services. However, our findings indicate that adult services are often unavailable or inadequate to meet the support needs of disabled young people leaving care in transition to adult life. These efforts to slot these young people into a service category indicates a disjuncture with the reality of their intersectional experiences and their dual identities as both care leavers and disabled.

## 5.2. Ruling understandings of disability

Norwegian welfare policy is said to be based upon the social model of disability (Ministry of Children and Equality, 2018). At the same time, access to most disability services and disability benefits are based upon medical diagnoses. As an example, the National Insurance Act (1997, § 8–4), states that only diagnosed health conditions qualify for disability benefits. Findings from this study raise concerns that the understanding of disability in aftercare services is based on a medical model and, hence, addressing the disability is seen as the responsibility of adult health or disability services rather than child welfare services. For example, young people who had a clear medical diagnosis were rapidly transferred to adult services but did not receive any further aftercare support. This decision might have been based on the assumption that health care and treatment should help address impairment-related needs. However, little attention was paid to childhood trauma or how to best to support a young person transitioning from care with very limited informal or formal support in place. In addition, decisions about access to child welfare or adult services seemed to be made without discussing with the young people about their needs and preferences for support.

Several of the study participants also described feeling that their impairment was misunderstood by professionals in child welfare services who deemed certain behaviours or challenges to be a form of disobedience, laziness or deviance. Such assumptions mean that if a young person does not meet the criteria for adult services, their presenting needs and behaviours are then attributed to other causes, leading to further stigmatization. Interestingly, even if the young people expressed uneasiness with this service response, they largely participated in the ruling relations by submitting to the regulatory practices established to stop what was perceived to be problematic behaviour.

Another thread in the participant narratives is how this persistent individualization of impairment meant that their experience of disability as a form of social oppression in their daily lives and within service structures was not recognized. As the young people were being prepared for a transition to independent adulthood, ongoing needs and challenges became their own responsibility, a view strongly aligned with the medical model. This is also in line with how their cases were considered by adult services, where clinical diagnosis and level of impairment were used as eligibility criteria.

The ideal of autonomy and independence in adulthood stands in stark contrast to the notion of interdependence, which is gaining influence in both leaving care research and disability studies (Priestley, 2003). Interdependence is a blending of self-sufficiency and dependence, and inherent in the concept is the assumption that vulnerability is a constitutive feature of the human condition and that all adults count on support from others (Bostad & Hanisch, 2016; Propp et al., 2003). This concept is particularly relevant for disabled young people leaving care who have weakened support systems and may have diverse ongoing support needs as they transition into adult life (Kelly et al., 2016).

## 6. Conclusion – Going back to the standpoint experience

At the fourth step in the IE process, we return to the standpoint and describe how the translocal processes operate as the basis of the local experience. If the ruling knowledge about aftercare is based on an overall aim of adult independence, child welfare services are at risk of ignoring other ways of being an adult. The young people who participated in our study worked hard to meet the goal of becoming independent adults but were given little support when they encountered disabling barriers. This notion of individualization works against these young people in two ways. Firstly, it assumes young people leaving care should eventually transition into independent, self-sufficient adult lives where they manage their own care. However, many youths do not achieve such independence, and interdependence and systemic support are key for any care leaver (Propp, et al., 2003). Secondly, it individualizes the experience of impairment and fails to see the role of



society and the impact of disabling discourses, structures and relations. As such, it serves to establish narrow notions of what it means to be disabled, to leave care and to be an adult instead of embracing the complexity of the lives of disabled young people with care experiences in young adulthood.

Furthermore, the organizational and financial split between aftercare and disability services is also problematic. The funding of services by different municipalities depending on a person's master identity as either a care leaver or a disabled young adult creates a false dichotomy in support for these young people and confusion regarding responsibility for the delivery and coordination of services. What these young people actually need is integrated aftercare support and access to professionals with diverse expertise in supporting disabled young people leaving care. Of course, the understanding of which type of service is in a young person's best interests will depend upon how disability and aftercare are understood. If the ruling knowledge about disability is based on a medical model, the needs of disabled young people leaving care become individualized and the responsibility of the young person rather than child welfare services.

Study participants also described how their experience of impairment and disability was rendered invisible in the child welfare system which further oppresses disabled young people leaving care by failing to identify and respond to their holistic needs. Ignoring disability also overlooks the resilience and agency of these young people. When using traditional outcomes-based evaluation criteria such as income level, employment or education, many of these young people would be described as having poor outcomes. This stands in strong contrast to their own accounts of agency when describing the challenging work that they put into overcoming disabling barriers, establishing social networks, navigating the welfare system, engaging in education, finding a place to live and managing financially. For some, such agency was enacted with minimal support from child welfare services and many of the young people described feeling vulnerable and exhausted by the lonely work of establishing their adult life. These findings suggest the need for a new approach to child welfare services that supports the agency, resilience and inter-dependence of disabled young people leaving care as they negotiate various service systems during their transition to adult life.

The application of IE in this study has helped elucidate the complex interface between institutional ruling knowledge and practice and the transitional experiences of disabled young people leaving care. This article has shown how ruling ways of understanding aftercare, disability and adulthood shape and organize support for disabled young people leaving care, which often fails to meet their needs. Drawing on critical disability studies, the findings also indicate a need to re-examine the disabling effect of these normative discourses and to support the resistance and agency shown by these disabled young people. Further inquiry into the institution of aftercare for disabled young people is also needed to investigate the interaction between structure and individual agency at the boundary of childhood and an adulthood for disabled young people requiring ongoing support as they leave care. In addition, there is a need to explore how disability could be reconceptualised and included in aftercare policy and services to expand the notion of a 'successful transition to adulthood' and, most importantly, to provide a new understanding of how child welfare services better can support disabled young people leaving care in their transition to adulthood.

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**Inгри-Hanne Braenne Bennwik:** Methodology, Investigation, Formal analysis, Conceptualization, Writing – original draft, Writing – review & editing. **Inger Oterholm:** Methodology, Conceptualization, Writing – review & editing, Supervision. **Berni Kelly:** Methodology,

Conceptualization, Supervision, Writing – review & editing, Supervision.

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The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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