SJDR

ORIGINAL ARTICLE

'He Is, After All, a Young Man': Claiming Ordinary Lives for Young Adults with Profound Intellectual Disabilities

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This paper discusses youth and the significance of age in the lives of persons with profound intellectual and multiple disabilities. The analysis is based on an ethnographic research project that explores what makes a good life for this group of people. The findings indicate that whilst the meaning and significance of youth and age were discussed often by care workers and family members, age had very little significance in the lives of our research participants. Youth as a phase of life gets lost in the transition from children's services to adult services: age in the lives of persons with profound intellectual disabilities means merely a move from one service system to another. For the care workers, age provides a way to evaluate and criticize the service system and whether it caters for the individual needs of persons with profound intellectual disabilities.

Keywords: age; good life; lifelong learning; profound intellectual disability; youth

Introduction

In this paper, we will analyse cultural conceptions concerning youth in relation to young adults with profound intellectual and multiple disabilities (PIMD). The starting point of the paper is a realization that took place during the fieldwork of an ethnographic research project: whilst our research participants were of different ages, it seemed that their chronological age had only a little, if any, significance in their lives. This was especially apparent in relation to the ways their support, services and everyday lives in general, had been organised. But whilst the service *system* did not appear to be sensitive to age, our data included numerous comments and thoughts related to chronological age by staff and family members. This contradiction seemed most poignant when looking at the youngest participants of our study who were in their early twenties during the fieldwork.

Research literature has repeatedly highlighted how most young people and even adults with intellectual disabilities still face barriers in the pursuit of full adult status; they have commonly been conceptualised as 'eternal children', and are often subjected to infantilizing practices (e.g. Bjarnason 2002; Baron et al. 1999; Johnson & Walmsley 2010). Additionally, research focusing on transitions of young people with severe or profound intellectual disabilities has highlighted problems arising from the lack of forms of support and services that meet the specific needs of this group of young people (e.g. Clegg et al. 2008; Gauthier-Boudreault et al. 2017).

Whilst the existing research on young people with intellectual disabilities has produced valuable observations concerning inequalities that they face, the notion of youth (like any other age category) seems to be treated as self-evident truth in this body of research. We would argue that concepts like 'adult status' or 'age-specific needs' are unintelligible in the case of young persons with PIMD unless the qualities and cultural meanings attached to different age categories are unpacked properly. Age categories need to be analysed in order to make visible the cultural ideals and norms linked to them. Thus, in order to make sense of accounts such as 'He is, after all, a young man', as the quote from our data in the title of this paper claims, we need to unpack meanings attached to 'being young', and how they relate to the young person in question.

This paper is part of a research project where our aim was to develop an understanding of what makes a good life for people with profound intellectual and multiple disabilities. Our analysis here focuses on data produced with one participant, Hugo (pseudonym), a young man in his early twenties. In Hugo's life the question of youth was especially pronounced: whilst Hugo was living quite an active life during the fieldwork due to his current status as a student, his life in general was described by people close to him as 'narrow' and lacking the qualities that Hugo 'as a young man' should be able to access. We felt that these arguments resonated with the focus of our study, the question of a good life, because these kinds of statements seem to assume that young people should be able to pursue certain things in

order to flourish. Our analytical interest was raised by this notion that our data, especially accounts of the professionals working with Hugo, was suggesting that age is an important aspect when trying to understand what a good life to a young person with profound intellectual disability may mean. We felt that this called for closer scrutiny.

In this paper, we analyse accounts of professionals working with Hugo: what kinds of meanings they attach to youth and how these meanings relate to the way Hugo's life has been organized. Whilst we concentrate on cultural meanings related to youth, our analysis extends to discuss the purpose of this 'youth talk' by asking: (1) what kinds of representations of youth, especially in relation to Hugo and young persons with PIMD in general are produced in the interviewees' accounts; and (2) what is the function and aim of these representations?

What Difference Does Age Make?

What caused us to pay attention to how age was addressed in our data and to wonder the (in)significance of age in this context was most likely the tradition of normalization that we as Nordic academics have absorbed since student days. Normalization in its different forms has had a profound impact on intellectual disability service systems around the world, especially in the Nordic countries (e.g. Culham & Nind 2003; Simpson 2018). It is based upon the notion that persons with intellectual disabilities should have access to 'patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society' (Nirje 1970: 62), and that they should be able to, as much as possible, establish and/or maintain personal behaviours and characteristics that are typical in the culture they happen to live (Wolfensberger 1972: 28). One crucial demand that normalization makes is respect for age-appropriateness in all areas of life that affect one's status and identity in a given culture. In short, people with intellectual disabilities should have the opportunity 'to undergo normal developmental experiences of the life cycle' (Nirje 1969: 182) and do what the peer group of the same age is doing; adults with intellectual disabilities should be recognised as adults with the same expectations, demands, liberties, and responsibilities as other adults (Wolfensberger 1972: 180–181).

Whilst age-appropriateness has achieved an established position in the services as an important instrument for achieving equality for the service users with intellectual disability, it has also been criticised for resulting in the kinds of practices that restrict people's agency when their preferences and behaviour have been interpreted as being inappropriate in relation to their chronological age (e.g. Forster 2010). It has also been argued that the normalization principle has lost relevance in the services during the past decades whilst other concepts such as inclusion, empowerment and citizenship have taken a firm position as guiding principles in disability services (Vesala 2010).

Our discussion here returns to the arguments concerning age-appropriateness raised by the normalization principle. As mentioned above, our data suggest that age still has relevance for the professionals when making sense of the quality of services, and ultimately, of the lives of the service users. We focus in particular on possibilities and restrictions that the application of the principle of age-appropriateness might produce to the lives of people with PIMD (Forster 2010). Additionally, our aim here is to contribute to the academic discussion concerning complexities and tensions faced in the implementation of policy recommendations in relation to people with PIMD (e.g. Bigby et al. 2009; Parry Hughes et al. 2011).

Data and Analysis

Data analysed in this article has been produced in the research project 'Profound Intellectual and Multiple Disabilities and a Good Life' (SA 275988). This ethnographic project studies the everyday lives of adults with profound intellectual and multiple disabilities and asks what makes a good life for them. Research data was produced through ethnographic fieldwork with altogether six adults with PIMD in all contexts of their everyday living. Additionally, family members and close care workers of the research participants were interviewed. The full dataset of the project consists of field notes, interviews, and documents concerning the care and services of the research participants. The project has been reviewed by the University of Helsinki ethical review board and necessary research permits were acquired according to organisational requirements. The participating care workers and family members were informed of the project at the early stage of the process where access to research contexts was negotiated, and all of them gave verbal consent to participate in the research. Additionally, written consent was sought from those care workers and family members who were interviewed. Interviewed care workers were identified during the fieldwork as we wanted to talk to those care workers who had established close relationships with our research participants.

In the case of the participants with PIMD, a proxy consent was sought from a care worker or family member of the research participant, after we had mapped their close relationships in order to identify the person most suited to act as the proxy. For example, in Hugo's case, proxy consent was sought from his mother, who was informed about the project's focus and research practices in a meeting where Hugo was also present. In addition to proxy consent, we paid continuous attention during the fieldwork to the well-being of our research participants to see whether they were comfortable with having us in their lives (see Mietola, Miettinen & Vehmas 2017).

Hugo is a young man in his early twenties. He lives in a group home, where he has his own room with a bathroom. The group home has four other men living with Hugo, all older (some considerably older) than Hugo. The group home is part of a larger housing unit that consists of altogether four group homes. Hugo moved to his current home a few years

ago from an intellectual disability hospital, where he had lived since he was 11 years old. Moving to the group home and getting his own private room presented a major transition in Hugo's life. He was also studying in a vocational special education school at the time of the fieldwork, which provided Hugo with lots of new activities and social contacts.

Hugo does not speak or use any alternative (formal) communication method. Interaction with him is based on gestures, facial expressions, and touch. Those that work with Hugo think that it is quite easy to interpret him: Hugo clearly expresses when he is content and when he is not. The interviewed care workers also described Hugo as a determined person who indicates (e.g. by shouting) when he is in need of attention or help. In addition to his limited cognitive capacities, Hugo also has physical and visual impairments. He has cerebral palsy, which restricts his physical capacity. He uses a wheelchair and requires help in all everyday tasks (e.g. feeding, dressing, personal hygiene). He is unable to move his wheelchair on his own, but he can lift his hands and point at things. When sitting up, Hugo is able to hold his head up and turn his head. Controlling his body does, however, require lots of effort, and he gets easily exhausted. Hugo's physical well-being was a repeated topic during the fieldwork and the professionals working with him felt that it had been neglected ever since his transition from school to adult services. Hugo did, however, begin in physiotherapy at the time of the fieldwork.

Reetta conducted a three-month period fieldwork with Hugo in 2016 by participating two days a week in his life. The fieldwork took place both at Hugo's home (group home) and at school. These were at the time also the only contexts of Hugo's everyday life: since Hugo had no additional support (e.g. personal assistance) or hobbies, he had practically no opportunity to engage in activities outside these contexts. Whilst major changes had taken place in Hugo's life recently in terms of housing and education, his life was generally characterised as 'narrow'; he had a very limited social network and only occasionally had the chance for leisure time outside the housing unit. At home, Hugo was spending lots of time alone. Due to Hugo's extensive impairments, he needs help and support to initiate and maintain social interaction. Other residents in his group home also had extensive support needs and multiple impairments that affected their capacities to communicate. Staff resources in the group home were very limited, and available resources were primarily allocated to basic care tasks. As a result, whilst Hugo was repeatedly described as being sociable, in practice he had very limited opportunities to socialise. Hugo's leisure time was filled with activities that he could do on his own: he enjoyed listening to music and audiobooks lying in his bed and was engaged with this activity for hours, every day.

The data analysed in this paper consists of four interviews discussing Hugo and his life: interviews with Hugo's mother, two care workers working in his group home and his teacher in the vocational school. The interviewed care workers, as well as the teacher, were the persons in charge of Hugo's individual care and educational plans, as well as being involved in the everyday care work. The interviewed professionals had worked with Hugo for 1–3 years at the time of the interview. The professionals' interviews took place in the research contexts, during their working hours. Hugo's mother was interviewed in Hugo's private room in the group home, with Hugo participating in the interview situation by making noises and laughing. All of the interviews were recorded and typed afterwards.

Whilst the interviews work as the primary data, our analysis has been guided and supported by the ethnographic fieldwork. Our main interest in the topic of youth and age emerged during the ethnographic fieldwork when author A noticed how the professionals working with Hugo repeatedly referred to his age. These remarks, as well as wider notions about Hugo's everyday living, institutional practices of the contexts and changing structures and practices of the intellectual disability service system, have influenced our interpretation of the primary data. We acknowledge that professionals' and family members' perspectives do not represent or replace Hugo's own perspective. Thus, we treat the analysed accounts as representing interviewees' personal or organisational views about Hugo's interests, or the interests of young adults with profound intellectual disabilities in general. All these accounts are analysed in relation to Reetta's observations concerning Hugo, his everyday life, and the surrounding institutional practices. And whilst we focus here on Hugo, and our interpretations are based on fieldwork done with him, practices and forms of reasoning similar to those discussed here were present in the lives of our other research participants, regardless of their age.

Our analytic approach is discursive in the sense that we see the views expressed and narration produced by our interviewees as situated in a specific historical and cultural context, formed within particular cultural and discursive practices (see e.g. Tamboukou 2008; Niemi & Mietola 2017). We treat the interviewees' accounts as social action, as talk specifically produced in and for research (e.g. Silverman 2001). Additionally, we acknowledge the specificity of interview talk produced as part of ethnography: the interviews have started from a point where the interviewer already has built shared experiences with the interviewees during the fieldwork and has 'insider knowledge' of the local practices discussed (e.g. Atkinson & Coffey 2002).

In our analysis, we draw from analytical perspectives developed in the field of sociology of age. Our analysis has been particularly inspired by notions concerning naturalization of age: at the same time as age is something that is all the time accomplished (by us acting according to our age), it also is something that becomes invisible when it is 'done' appropriately – when we 'act our age' (Laz 1998). Similarly, we only become conscious about age when someone 'fails' to act according to normative expectations related to, say, adulthood. In these moments, age suddenly requires explanation. Our analysis was motivated by the notion of accountability of age (Nikander 2000; Laz 1998); we wondered why our interviewees needed to account for age, and what is done with these accounts – what kind of arguments are built around the notion of 'youth'.

Due to the focus of our research project, 'a good life', our analytical interest is especially directed towards the moral implications of our interviewees' accounts. Our initial notion of how age was discussed in our data was that the accounts concerning Hugo's age seemed to say something of what his life is like, and what it ought to be like in order to be 'a good life'. There seemed to be a 'moral tinge' (Bergmann 1998) in this type of talk. In order to get a grasp of this dimension of the interview talk, we approach the interview as a site, where our interviewees construct themselves (and others) as moral agents (Atkinson & Coffey 2002; Bergmann 1998; Nikander 2000). Our paper argues that the 'youth talk' works for the interviewees as a key source for achieving morality: it provides them a way to relate themselves to the established practices in the field of intellectual disability services in Finland, and in particular to the common practices of the unit where the interviewed professionals were working in. We thus suggest that the 'youth talk' can be approached as an 'indirect mode of moralising' (Bergmann 1998), as a mean for raising controversial views and topics, and at the same time as a way of managing self-presentation in the interview situation (Widdicombe 1998).

The following sections thus concentrate to discuss two aspects of our analysis: the *meanings* our interviewees attach to youth in their narration, and the *purpose* of the 'youth talk' in a specific historical and cultural context. Our findings will be presented in the following three sections. The first one will focus on the representations of youth produced by the 'youth talk'. In the second section, the discussion will focus on the purpose of 'youth talk', how these accounts turn the focus from Hugo to the wider context of the intellectual disability service system. The third section will continue to discuss the process where youth gets lost in the service system.

Findings

The Meaning of Youth

[I ask from the care worker what school has brought into Hugo's life] 'Well, now he's got a normal everyday life. Like leaving for school or work. Young person. He used to go to the day centre, as a half-day [client], but that did not meet Hugo's needs at all. There [at school] they have lots of activities, since Hugo comes home tired. And it's good when you are tired after work or school day. And I feel that there are a lot less of those yelling attacks. Which he had at one point. It could have been that the young person was bored, here in the middle of the 'fossils'. Since it is quiet, the upstairs gang is quite old, the downstairs group is younger. So it [school] has really brought lots of substance into Hugo's life.'

The conception of youth appears culturally very particular in our interviewees' talk. In the extract above, for example, being a young person is directly associated with 'normal everyday life'; a life in line with western societal conventions of an individual who is active, who goes to school or to work. This kind of image of 'normal youth' also resonates with current youth policies, where young people not going to school or work (so-called NEET-youth) are immediately problematised. In our data, the notion of being active, however, includes any activity that takes place outside one's home. Thus, leisure activities taking place outside one's home would be considered as a sign of a normal, active life. The interviewees also conceptualise the ideal of 'being active' in relation to passivity and lack of activities; a state of being that very much characterised Hugo's life before he started his current studies.

[I ask about a good life, whether Hugo is living a good life] 'Well the good thing is that he is currently studying, that he got into this school. And at home, like a good life. Um. Well, what I would like to happen, I'm not sure, it might be a struggle, but that Hugo would have some more, like hobbies, or like, activities. And some, like friends. That Hugo's life at home is like quite stereotypic, like same all over again. Like the good thing probably is that the basic needs are met every day, of course, not talking about that. (…) But, well. Like those social skills and the psychological ones. That Hugo's life is pretty basic, quite narrow like, nothing really happens.'

When analysing these representations of 'youth' and 'good life', our thinking was immediately drawn to questions concerning age-appropriateness and its usage in the services for people with intellectual disabilities. While age-appropriateness has worked in the services as an important tool for enhancing equality of the service users, it has also been noted that the services have adopted a very particular interpretation of age-appropriateness – one that emphasises cultural normativity of action (e.g. Forster 2010; Vesala 2010). This notion seems to be relevant also in relation to our data. The care workers' accounts draw on a culturally specific, normative conception of youth. Additionally, these accounts can be interpreted to suggest that this conception can and should be applied to Hugo in an unfiltered fashion. Firstly, according to these arguments a young person should live an active life, go to school or work, have friends and hobbies, and since Hugo is a young person, his life should be measured against these normative expectations regarding youth. Secondly, in the care workers' accounts, certain needs are connected to 'being young'. It is not just an active life that Hugo needs – he has also specific psychological and social needs that are part of 'being young' (see Gauthier-Boudreault et al. 2017).

Should we think that people of Hugo's age ought to live an active life, according to the prevalent normative conception of youth in all areas of life in the spirit of normalization (Wolfensberger 1972: 180–181), the principle of

age-appropriateness faces problems. As Forster (2010: 129) has argued, age-appropriateness 'could be used to deprive an individual of activities others consider inconsistent with the person's chronological age'. This would be particularly harmful in case of people with PIMD because the vast majority of their practical needs do not have age-equivalent corollaries because their 'comprehension of the social world, and in turn the person's social interaction needs, are quite distinct from that of age-equivalent peers' (Forster 2010: 130). Thus, if strict age-appropriateness were applied, we would have to prevent Hugo from listening to his favourite fairy tales or watching his favourite cartoons. That would be a way to suppress the little self-determination he has the chance to practice in his life.

Perhaps, then, limited use of age-appropriateness would be feasible, meaning, it would be used 'as a principle for opening up opportunit[ies] in a person's life' (Forster 2010: 131). This kind of policy would, in fact, be in line with the care workers' way of thinking as well. In our interpretation, they use age-appropriateness to highlight the inequality Hugo experiences, to stress his *right* to lead a more active life, and to have better access to the kinds of experiences that young people of his age usually have. In addition, when the interviewees talked about youth and active life, they were calling for more activities, friends and hobbies without taking a stance what they should look like (e.g. what counts as friendship). This is the kind of mentality that takes into account both objective ideals (e.g. active life) and Hugo's subjective preferences.

When we continued to analyse the above extracts in more detail and focussed specifically on what kinds of qualities were attached to Hugo and PIMD in general, and how the differences between Hugo's life and 'the active life' are explained, we noticed that the accounts were critical towards the service system. In the second extract, the care worker explicitly associates the 'stereotypic' nature of Hugo's life to the way his life has been organised, not to Hugo himself; stereotypic life is not the result of profound intellectual disability as such, it is the result of insufficient and inappropriate services (lack of activities, hobbies and friends). Consequently, accounts that emphasise activeness also challenge dominant understandings of PIMD as a passive state, characterised by deficiencies and limitations. 'Being active' is represented as congruent with Hugo's needs, as beneficial to him, and most importantly, as something a person with PIMD can also be. By suggesting that there are some age-specific needs, attention is turned away from Hugo's impairments. With the youth talk, the care workers thus point out how Hugo is not just a person with profound intellectual and multiple disabilities, but also, and perhaps more importantly, a young person.

Youth talk and the post-institutional service system

Hugo's age was mentioned already during the first days of the fieldwork when Author A talked about Hugo's interests and preferences with the group home's personnel. They told that Hugo loves to listen to audiobooks, especially a particular CD of fairy tales, which was almost worn out due to its repeated use. Similar discussions occurred when the care workers looked for television programmes that would interest Hugo. Usually, Hugo watched children's programmes. According to care workers, this was because there was only a limited number of programmes directed to grown-ups that were accessible (e.g. plain language). It seemed that the care workers felt they had to explain and justify these choices, and openly stated their awareness that these programmes were not age-appropriate. At the same time, the care workers emphasised how these programmes, books and music were the ones Hugo enjoyed and the ones that were accessible to him.

Age thus was a concern for the care workers – an issue they were aware of and sensitive to. We made similar observations with our other research participants: the professionals working with them repeatedly discussed our participants' preferences in terms of music, clothing and activities, and how these related to their chronological age. Whilst we immediately interpreted these accounts as making visible how age-appropriateness is still used by the care workers as a central way to make sense of the values and targets of their work, we were, however, somewhat confused why this topic had to be repeatedly raised with us. It seemed that age had to be accounted for in these moments where the practices did not follow the (unwritten) rule of age-appropriate behaviour.

The concept of age is ultimately normative: 'When we say "act your age" we press for behaviour that conforms to norms' (Laz 1998: 86). And when we fail to act our age, we need to account for our action (Laz 1998; Nikander 2000). In the intellectual disability service system, however, this accountability is placed on the care workers: it is not Hugo who 'fails' to 'act his age', but instead it is the care system – and ultimately the care workers – that fail to provide him a life that parallels his chronological age. This is why age needs to be addressed. And indeed, in the interviews Hugo's age was mainly discussed in relation to the wider question of how the care system is able to respond to needs of care users, of different ages:

> [I ask the care worker how does good life materialise in Hugo's life] 'We listen to Hugo when he's got something to say. And we try to find means of expression so that Hugo can express what is [the matter]. And of course, if we had better resources, going outside the house more during weekends. He is anyhow, well, he's not like middle-aged yet. And well, the middle-aged do go [out] too (laughs).'

The Finnish intellectual disability system is still going through deinstitutionalisation of services: whilst transition to and development of community care has been the primary policy emphasis since 1970s, some individuals with intellectual

disabilities are still living in intellectual disability hospitals. Deinstitutionalisation is also strongly present in our data; four out of six of our research participants have moved out of these hospitals, three only recently, and many of the care workers participating in our study had also at some point worked in these institutions. Whilst our research participants' homes are located in ordinary neighbourhoods, they live in large housing units, with little or no influence on where and how they live. The aim of these services is to provide service users opportunities to live ordinary lives in ordinary surroundings. However, the limited availability of support and staff often means that the service users, who have extensive needs for support, actually have very limited possibilities to participate in activities outside their living units.

Bearing in mind the history of the disability service system, the care workers' comments concerning age can be conceptualised as moral accounts. With references to Hugo's age, the interviewees make visible their critical stance in relation to the current state of the services. These accounts form a counter-narrative that challenges the dominant policy discourse and exposes the institutional qualities of care still present in intellectual disability services. Thus, when the interviewees point out the narrowness of Hugo's life, or the limited opportunities of the care users to take part in activities outside one's home, as in the extract above, the interviewees produce concrete and critical examples of how the services do not live up to the values and targets of the current policy.

The above extract makes visible also how the 'youth talk' can be used in the services, and why there is a need for these types of arguments. Hugo's age can be used as an argument in negotiations concerning the use of limited (staff) resources in the unit. Whilst on a general level Hugo's right to self-determination ('to be heard') and social inclusion ('get out of the house') is recognised by the care workers, in everyday care work the use of resources is considered from the viewpoint of all the residents in group homes. When time and support are distributed from a shared 'pot' of limited resources, care users' interests might collide. Thus, references to age and related needs can be used to emphasise the special importance of Hugo having opportunities to live an 'active life'. Since the principle of age-appropriateness is still acknowledged, age also makes a powerful argument within the service system.

Youth lost in the service system

Earlier research has highlighted how there is a general lack of specific services targeted to youth and young adults with profound intellectual disabilities; in the transition from children's services to adult services activities and support tend to decrease (e.g. Gauthier-Boudreault et al. 2017; Hudson 2006; Morris 1999). Similarly, the availability of different types of rehabilitative services, such as physiotherapy or speech therapy, tends to decrease after paediatric services, and the criteria for entitlement for these services become more stringent. Usually, young people and their families have only limited post-school options to choose from. In Finland, the typical option offered is a placement in a day activity centre. These units, however, cater for service users of very different needs and ages and have a high user-to-staff ratio.

In Hugo's life this lack of suitable support and service had actualised in all the major transitions: in his move from childhood home to intellectual disability hospital (which was at the time offered as the only available option), and also in the transition from comprehensive school to day activity centre (Mietola 2018). Whilst the interviewees felt that major positive changes had taken place in Hugo's life recently since he moved to the group home and started school, general worry and criticism towards the service system is still present in the data:

> Teacher: Well, I've understood that there is a background of multiple years, that Hugo had transferred to the day activity centre, kind of directly from the comprehensive school. So like, multiple years have gone kind of down a pit. That has been a young man's active time, like many years have gone in a way that there might not have been active support there so that Hugo could bring out his own expression and such.

In the above extract, the teacher describes how after comprehensive school Hugo's path has ended up in 'a pit'. With this metaphor, the teacher refers to the void between children's and adult services (Morris 1999). Whilst the metaphor points out the lack of specific services targeted to youth, the teacher's account also underlines how this fall into the pit has materialised as a break in Hugo's life course and development. The lack of active support in the critical years of young person's life has not only deprived Hugo of learning but also questioned the efforts of maintaining the already acquired skills (Gauthier-Boudreault et al. 2017). The teacher's account does not merely emphasise the specificity of young people's needs, but also highlights how the service system ignores youth as a specific phase of life, as a time of change, development and learning (see Priestley 2003). This builds a harsh contrast between the ways young people are approached in Western societies in general, as a future resource, and youth as a state of becoming (see Honkatukia 2017).

During the interview, Hugo's teacher also verbalised the key differences between school and day activity services; it is not only a matter of resources but the target of the services. In schools, all activities are planned and evaluated with learning and development in mind (as required by the national curriculum), whereas the social services lack a similar binding goal. Thus, the transition from school to day activity services also means a significant change in terms of expectations and goals – what is expected from an individual and what kinds of future plans are made for him or her. Instead of making future plans by supporting and making use of existing skills (and setting new goals for learning and development on top of them), the services might not even recognise these skills – or even approach the young person as an individual with potential for learning and development in the first place.

Teacher: Like here [at school] we are now using loads of resources on that one student, for one to three years, and do lots of work, and have quite intensive time. But does that carry, if there are no services later on? Or that it [resources] falls into a total minimum. And then, there are no resources, like there in the group home, or else-where. So like, where does it lead to.

[I ask Hugo's mother what her thoughts and hopes are concerning Hugo's future, after school] Well they don't have anything similar then, like where Hugo could continue, there isn't. Where they would still [train] the com-munication skills and such, like would in a similar manner train, but other than that, I don't really know. (…) The danger is of course that those skills acquired when you don't keep them up, then they will decline. And there will not be available any learning [of] new [skills], you need to support learning. So it's like really sad, I think.

In the above accounts, the teacher and mother express their worries regarding Hugo's future. Whilst lifelong learning has an established position in education and disability policy internationally, our data suggest that the right to lifelong learning is not recognised in the case of persons with profound intellectual disabilities. Rather, the lives of our research participants were characterised by stagnation. Even with the youngest research participants in their twenties, there was a notable lack of discussion among the care workers about their future plans or personal life objectives. It seems that there is no need for such planning or visioning when the service user is placed into appropriate housing and day activity services. Whilst there might be a discussion concerning different types of rehabilitative services or possibilities of getting support person for leisure activities, the 'bigger picture' remains unchallenged.

This type of stagnation is most poignant in the case of a young person, like Hugo. Everyone working with Hugo emphasised the positive impacts of going back to school, and some expressed concerns about his post-school options. However, there seemed to be very little consideration of how the service system could provide Hugo lifelong opportunities to develop to his fullest potential. Instead of expecting a transition which would provide him with more opportunities, the interviewees expect another fall into a pit.

Returning to our discussion about the parallels between the lives of Hugo and his non-disabled peers, the most poignant difference for us is the way youth as a stage of planning and visioning is not present in Hugo's life. The fact that his life course deviates from the normative life course seems to mean that there is a lack of '"horizon" for orientation and planning of life' (Kohli 2007: 256). There is no plan B, an established narrative for visioning and forming a dignified life plan for a young person with profound intellectual disabilities. It is not only youth that might get lost in the system, but also a vision of the future.

Conclusion

We have discussed in this paper the ways professionals in the care system talk about youth in order to highlight and promote young care users' rights. This kind of tactical use of the principle of age-appropriateness allows the care workers to discuss problematic aspects of the current services and make concrete claims for change in the service system that already recognises the worth of the principle. The youth talk also provides the interviewees a means for 'indirect mode of moralising' (Bergman 1998): by addressing Hugo's age, the interviewees draw attention to urgent problems present in the care service system, or even in the service unit they work themselves. With the youth talk they make us researchers aware of their critical views, and about their personal and professional values and targets, even if these would collide with the everyday realities of the services.

The existing body of research has shown how people with intellectual disabilities have traditionally been deprived of recognition of their adulthood. We have, however, discussed in this paper how Hugo, and other persons with PIMD, may not even be recognised as young people, with interests, needs, and rights young people tend to have. Our analysis suggests that in the case of young people with profound intellectual disabilities, youth as a phase of life gets lost in the intellectual disability service system.

Admittedly, the general policy of lifelong learning or reaching 'one's full potential' might seem abstract and difficult to put into practice in relation to people with profound intellectual disabilities (see Kauppila et al. 2018). Still, the worries raised by our interviewees concerning Hugo's future, in particular in relation to development, learning or even change, are worth noting. In our view, without future-orientated plans, the wider questions about targets and commitments of care and services, or even considerations about 'good life', are overrun by practices that merely keep the service users content and fulfil their basic needs regarding housing, food and hygiene (but nothing else). The element of warehousing, the 'narrowness' of the lives of the care users, is not accidental or merely a result of insufficient resources. We would argue that it is also the result of the lack of ethical engagement with the meaning of a good life for persons with profound intellectual disabilities. In other words, the system, in its all goodwill, has focused on meeting the basic needs for food, rest and bodily health but ignored more general engagement to think and envision what kinds of ideals, norms and values should guide its policies and practices.

The current services offer very limited opportunities to our research participants to experience anything new. It is likely that Hugo's interests and preferences will stay the same, and they continue to be met in a similar manner. In other words, Hugo will stay the same because he is not given the chance to change. Whilst Hugo appears content, it is a different matter whether he lives a good life within a service system that too often settles for warehousing and

stagnation. In his care workers' view, a good life is about genuine opportunities for new experiences ('get out of the house'), to learn new skills and maintain the ones he has. These opportunities require options and resources from the service system. Similarly, attaining these 'rights' would require the service system to approach individuals with PIMD and their needs in a new way. Not as fixed objects of care, but as changing subjects with dreams and aspirations. If we do not know what they might be, we can either give up and resort to warehousing or offer these persons impulses in order to work out what new skills and experiences would be in line with their personalities.

Acknowledgements

Competing Interests

The authors have no competing interests to declare.

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