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How to educate professionals for the professional meeting with adults with intellectual disabilities/impairments?

ABSTRACT:
My ph.d.-work in general reflects aspects from disability research, research on professions, ethics, a socio-political context and modernization. This article just reflects minor parts of the work.

How are you as an adult with intellectual disabilities recognized and seen? From a traditional point of view the professional work would be characterized by care, support and development, communication, ethics, recognition and respect. Are these values at risk in our contemporary welfare system? And how do we make these values part of a professional education which itself is under pressure from e.g. public management and modernization?

On one hand the meeting or encounter represents essential values and ethical aspects according to professional traditions and standards as part of the welfare system in Denmark.

On the other hand people with intellectual impairments in our welfare society often experience infringement, outrage and offence. Human rights are not always respected. These experiences with infringement are not equally distributed. The German philosophers, Honneth and Habermas, both find a tendency that particularly underprivileged people are met in an infringing or intrusive way where they ought to be met with recognition as deserved.

Which factors can be seen as critical in the professional meetings with these citizens with intellectual impairment? Through my empirical work with people with intellectual disability/impairment I see dilemmas for the professional due to different tendencies.

The fact that the professions related to people with intellectual disability/impairment is not always recognized and respected could be one essential factor. Often they are characterized as semi-professions, and the question could be if these meetings can be qualified by qualifying the relevant educations?

I use the terms intellectual disability and impairment. This is due to the fact that I meet different groups in my empirical work. Some are born with developmental problems, some have a brain damage later in life – and in general I see this meeting as so fundamental that these diagnostic terms seem to mean less. It could be
I or others suffering from Alzheimer’s or dementia. Intellectual disabilities are not always visible and this might emphasize some of the problems in the meeting/encounter even more.

The Meeting – an introduction

In all kinds of professional work I see the meeting as very essential. It can be observed in the classroom, in the hospital, in the shops, in the streets and of course also in the professional relation between persons with intellectual disability and professionals working in this field, and in my work the field is placed as part of the Danish Welfare system.

The meeting is essential because as a human being you exist due to this relation. The human being is not an island in spite of temporary, individualistic tendencies. Therefore I think that there are good reasons to increase the focus on this meeting or encounter. And I want to have a double perspective on this. On one hand I register problems for people with intellectual disabilities not being seen and met with respect and recognition, and on the other hand similar experiences can be observed among the professionals. This is not just a part of Danish experience, but you see similar experiences and expressions in the international literature in general.

The background for my interest is my ongoing ph.d.-work and the general tendencies in our society. We have seen some scandals and dramatic cases of neglect in Denmark, where people with intellectual disabilities have been treated in very inhuman ways. My work as a teacher, lecturer, consultant and in general has taught me, how much we all can learn from each other, and I think our attitude to others is more essential than anything else.

I have been working with different groups of adults with intellectual disability. The medical diagnosis is not part of the analysis, but I have chosen two different groups. One group is born with some intellectual problems and brain damages – often their impairments are invisible – and when telling their stories they often reflect a lack of recognition and respect during their life. Another group has experienced a brain damage in their adult lives, and now they are living in their flats integrated in a very modern institution with different professionals to take care of support. When I am asked if these groups are big enough to be relevant for the research I say: it can be me and you
tomorrow, because so many of the problems related to this meeting are also relevant for professional work with old people and e.g. people with dementia or Alzheimer’s⁴.

At least three aspects can be seen in the discussion of the importance of the professional meeting/encounter, and I will briefly present and discuss them in the following:

Firstly: I have been involved in education in this field for many years, and at the moment we have curricula in most of the professionals educations (from which staff is recruited for the field) without a demand of acquiring specific knowledge about people with disabilities and impairments. This can be seen as highly related to the question of inclusion and recognition…. We must learn to see everyone as human beings, but…. At the same time students make choices to avoid this field. And sometimes based on a lack of knowledge as far as I can see. And sometimes based on a lack of recognition? Or lack of courage to meet diversity? If choosing to have a field placement, working with disabilities the students will meet people who are different in many ways – also aesthetically. Even if curricula mention ethics as part of the education, you cannot be sure what is learned, and complaints in the field of social work, pedagogy, care and health suggest that e.g. communication could be improved ethically. You also know that you only see the top of the problem in registered complaints, and you also know that cases of infringement and lack of recognition often take place outside the limelight.

Secondly the discourse and the way of talking about the professions reflect values as recognition, respect, and humanity. Professional standards and ethics are stressed in different ways: A Danish philosopher Jørgen Husted formulates: *Ethical consciousness is a fundamental part of the professional practice for a social worker* (social work in a broad sense)². Husted develops decision-making models useful on ethical issues, but even if you have such models you need to judge ethically and how to learn using these models as part of an education. In my opinion you have to get answers to such questions working with education of professionals. Also the Montevideo Declaration represent some values³: “We reaffirm that ethics must be a permanent reference, collectively conceived and carried out with the critical participation of the subject”.

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1 Carlson and Kittay (2009) mention a number of 2.5% of a general population, but the problem could also be seen in relation to people with Alzheimers’ and other forms of dementia, and then we might see around 20% of the population. And the same point was presented by prof. Jerome Bickenbach at a conference in DK 07.02.2012

2 Husted (2009): *Etik og værdier i socialt arbejde*

At the same time different philosophical traditions can be seen in the field of education. One end of the scale can be close to a very idealistic and religious thinking and have associations of a vocation. In another end you could mention the bio-ethic dimensions. Are we developing a society of the perfect human being or where do we see the limit?

Thirdly the professional work, meeting and education for this work take places in a society representing different tendencies. People with intellectual disability are seen as expensive – they are not useful as workforce, and they do not represent modern competencies e.g.: flexibility, ability to be project manager for your own life and work, reflectivity.

The increasing economic problems in our so-called welfare system make this group a target for reductions (money = time) and it is increasingly difficult to implement the UN -Disability Convention. On one hand professionals tell a story of autonomy and self-determination, and often these values are emphasized in literature and in texts of legislation. On the other hand the professional work is often governed, regulated and controlled into the very details, so autonomy and self-determination could at the same time be seen as neglect and violation. Autonomy for the adult with intellectual disability might result in exclusion and loneliness, if you do not get the right and necessary support.

This brief introduction gives an impression that the professional meeting is under pressure due to different reasons. The question is, if education can be part of strengthening and qualifying this meeting and how?

**The Meeting - from different Points of View**

As mentioned I see valuable values and terms reflected in the professional meeting or encounter. Some of these can easily be named while others are more difficult to define. In general I see a need for a profound discussion on several terms if we will strengthen and qualify the meeting – in order to support both people with intellectual disabilities and the professionals in the field. I shall here concentrate on three terms: normality and diversity, autonomy and humanity.
Some of the terms and values are mentioned in the UN Disability Convention, e.g.: General Assembly, A/61/611, 6.12.06, Article 3 - General principles: The principles of the present Convention shall be:

a. Respect for inherent dignity, individual autonomy —including the freedom to make one’s own choices, and independence of persons;

b. Non-discrimination;

c. Full and effective participation and inclusion in society;

d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e. Equality of opportunity;

g. Equality between men and women;

Reading these values and just trying to give a small impression of the situation in the professional field in Denmark, I see a need for a discussion on diversity and normality in general. Following discourses in media and in the ongoing debates we on one hand seem to be very tolerant and open and trying to establish different possibilities for people with intellectual disabilities e.g. for having a job. On the other hand it seems - according to statistics, numbers and experiences - increasingly difficult due to general crisis and a general situation in the labor market to realize such ideas. And the tone of voice telling about people not being able to follow the speed and the flexibility in the job market perhaps because of e.g. intellectual disability is not gentle. Actually it seems as if the borders for normality have narrowed.

Autonomy and independence seems to be part of our modern society. We develop individualistic life styles, we are working in different project organizations in our individual way, and we are planning our lives stressing that we can decide ourselves. This seems to be the yardstick and the reference used in many places, and for a lot of people this is the achievements you expect from yourself. But can this yardstick work for all of us? Of course the human dignity must be protected. But is it fruitful to contradict autonomy and self-determination with negative terms only? I see the human being – able, not-able or disabled – as dependent on others as essential to being human at all.

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4 http://www.un.org/disabilities/default.asp?id=259, my omissions and underscore
Humanity is a very essential term in the different Conventions from UN, and this is the very basic idea to bring into the professional meeting. This is related to a readiness and an attitude seeing the other in his or her Otherness. To be ready for or to be able to embody this attitude as a professional, when meeting the human being with intellectual disabilities, might be a part of your personality, and it might be part of an education.

The American philosopher Licia Carlsson shows that philosophy in general has expressed very little interest in the group of people with intellectual disabilities. She advocates for reflection on this and suggests that we must remember, that we all experience being “not-able”\(^5\). Garland-Thomson says, that disability is a very profound human experience that in time will affect most of us.

My short introductory comments on some of the essential values and terms in the professional meeting make me suggest that a discussion including these values are raised along this line, following these comments and including a nuanced philosophical inspiration.

I shall only present some aspects of this discussion related to education of the professionals in the field. As professionals in the field in a Danish context I see social educators (Social pedagogues), teachers, nurses, social workers, physiotherapist, occupational therapist, and they are all educated with a degree as professional bachelors. And they are all educated in an interaction between theory and practice. During the education all students can make a lot of choices, and actually they can graduate without knowing anything about disability, and even if the curricula contain demands on ethics it is hard to estimate what and how, and even harder to assess ethical attitudes\(^6\). It is not my aim just to improve students’ ability to talk about ethics, but awareness and sensibility and ethical reflections do not develop out of the blue.

**Philosophical inspiration and values in the meeting**

If one is looking for inspiration to grasp, understand and perhaps develop the meeting between the professionals and people with intellectual disability you find different philosophers and often from a tradition closely related to phenomenology.

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\(^6\) 2012 a ph.d. was defended by Bjørn Ribers at Roskilde University Center in Denmark: ”Den etiske udfordring” (eng: the ethical challenge) as a play on words similar to the very famous philosopher K.E. Løgstrups book: “The Ethical Demand”. The problem was according to this research that it is hard to give words to ethical reflections even if you have an education as e.g. social educator behind you.
You will find a philosopher as Emmanuel Lévinas (1906 – 1995) analyzing the meeting and stressing the different roles in the interaction in a way that seems quite idealistic when we are talking professional work. He says that you will be “forced” to react, answer and take responsibility from the “Other” in a way where you as professional turns into an object and the Other is subject. This relation is so strong that you as professional will be like a hostage, according to Lévinas. This is due to the face of the Other (not literally). The most important of these two parts is the Other, Lévinas says, and yet you will never be able to see the Other as he or she really is.

This idealistic way of seeing the meeting we also see by the Danish philosopher K.E.Løgstrup, i.a in his “Ethical Demand”. The meeting will call for certain reactions outside your intentions, conscious control, and will, he will argue, and he also says that there always will be parts of the Other Person you must leave untouched. Trying to understand or trying too hard to interfere can be part of violation and humiliation. There is a limit even if this limit is invisible, but it is important regarding humanity and dignity.

I see these two approaches as very valuable when trying to keep and support humanistic values in our interaction with others. At the same time I think it is necessary to supplement these approaches with other ethical dimensions in order to make it more concrete in the professional work. Otherwise I see a risk of basing the professional work on something vocation-like and almost mysterious.

I will turn to another philosopher – contemporary and bringing into the discussions some very relevant points. Axel Honneth works with the term of recognition, and even if this term is difficult to translate, it is essential and important. In recognition Honneth stresses our moral attitude towards the other, and he tells that marginalized and disadvantaged (socially or in other ways) people more often than others experience humiliation, infringement and lack of recognition. And in spite of giving more rights to i.e. people with disabilities according to e.g. the Disability Convention, people will experience contempt and violation and have their self-esteem hurt.

Honneth fears that our society develops a tendency to undermine the positive values mentioned so far. Working procedures, bureaucracy, a demand of evidence and documentation, our individualistic life-style, a superficial way of observing etc – all could support a development of NOT recognizing.

8 Løgstrup, K.E. (1997): The Ethical Demand with an introduction by A. MacIntyre and H. Fink, Notre Dame, Danish orginal 1956
In his attempt to identify elements in the expression of recognition he points at our body language, including facial expressions and gestures, our ability to listen and observe – not merely with ears and eyes, but using your whole body. In this work Honneth is inspired by Lévinas, but he also thinks Lévinas is very idealistic.

In this place I cannot take the argumentation very far, but if these inspirations should be taken a step further to a “pragmatic turn”, I would apply some of the ideas from Jürgen Habermas and his ideas about ethics in communication. As a supplement I would add ideas from philosophers integrating the body in a more profound way than it can be seen with Habermas and Honneth. In this way different approaches might be useful in the daily professional work, and I see the responsiveness resulting from this as qualifying the professional meeting without sacrificing the idea of humanity and human dignity.

Empirical findings in the meeting

Asking people with intellectual disabilities about their lives and how they experience the meeting with different professionals leaves me with an impression that a lot of professionals are doing a very good job trying to apply these important values in the meeting. At the same time you also hear and see that this meeting is under pressure from many sides. Lack of time and lack of resources in general tend to let the meeting suffer.

If a diaper is placed in a way that a woman in the wheel chair and with a brain damage can feel a fold and the professional – perhaps because she is busy – says, that the diaper is perfectly placed, the woman experience a humiliation and lack of recognition. She is totally dependent on the professional, and her own experience is now overruled.

A man with a brain damage is quite disappointed over his new “home”. He thinks that a promise to be met on all his needs is not being fulfilled. He has an experience not to find anybody with whom he can have a more existential conversation.

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9 See e.g. Habermas, Jürgen: *The Theory of Communicative Action* (German 1981) – other sources could be relevant, and I have worked with his theories in practice: Nørgaard, Britta (2000): *Habermas i praksis – indføring i dele af teorierne*.

10 Merleau-Ponty on one hand and Bernhard Waldenfels on another.

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A young man born with intellectual disability has an experience of being misplaced during his childhood and younger years and this misplacement had the result that he did not learn much in school. Now as a thirty year old man he wants to prove that he can do something and be a part of the “proper labor market”, as he says. But discrimination means that he cannot choose an education as other citizens can. Because of his background with diagnoses he cannot just begin an education, but must go through a substantial amount of bureaucracy.

A professional tells about her work and she mentions especially one younger woman with a brain damage. This woman is living away from her children and husband because of her intellectual disability and the professional says about this: “She sits in the back of my head when I drive towards my home after work”. In this case you might say that the professional is “hostage” according to Lévinas terms.

Stating these brief examples does not tell HOW the experiences are presented to me. Interviewing these people gives a clear experience of frustration, humiliation, anger and violation. Answers are given in very emotional and expressive ways. And even if a lot of good work is done, I think that Honneth is right when he says that a lot of violation takes place outside the limelight11.

On my way to an interview with a person with a brain damage a professional asked me with skepticism, if it at all was possible to interview this person. And after a 40 minutes interview with a man trying to express himself in a very distinct way in spite of a lot of problems, I can just feel sorry for both parts – the professional misses conversations with a valuable human being, and the man with a brain damage misses to be seen and met as a valuable person.

These short examples from a big empirical material convinces me – together with many years of experiences in this field, that education must prepare students and professionals to enter this kind of work with a very open mind, awareness and sensibility.

**Educational problems and challenges**

Educating for the work with people with intellectual disabilities we often meet some problems and challenges. Some of the work done in the field can be done without a lot of theory and without a


longer education. This means that the professionals in the field are not always met with recognition of their work, and they are sometimes called semi-professions. Different characteristics belong to the term profession, and if you work in this field, some of the professional groups as well as the people with disabilities could be characterized as hybrids or leaking categories\textsuperscript{12}. This might be a disadvantage in recruiting students, and professionals might find the lack of recognition reflected in their rather low status in society.

It can be argued that the educational situation is following the same patterns as the professional work itself. More students have to graduate on a small budget, meaning fewer lessons, more students and less teaching staff. We have a situation in the educational system where we want our young people to graduate as fast as possible. I think that some of the important competences and values mentioned in this article cannot be forced and paced.

I have been advocating for values like humanity, ethics, recognition, awareness, and for communicative competencies, ability to decipher together with a profound knowledge on different areas like legislation, documentation, scientific research. But how do we teach stuff like this, and can everybody learn these things? And if so, how can we assess this in tests and be sure that we graduate qualified professionals?

In my opinion ethics and humanity cannot just be taught in the classroom or in a lecture hall. It is important to have time for reflections and be in a situation where you feel trust and feel comfortable to discuss difficult situations. At the same time I find it important that the teachers have the courage to push and induce new points of view even if you make the students a bit uncomfortable.

The study programs for this field often contain periods with practice, and I think it is very important to integrate students’ experience from real life in the teaching of these topics. I think the academic world could learn more than we until now have realized, by looking closely into practice and by asking those who really know the situation from inside.

\textit{A subjective remark:}

I have been met with many questions: is it possible to interview this group, and yes, it is possible – with patience, empathy and an open mind I have experienced wonders. I wonder why so few have been asking and have invited these people to tell their stories and their experiences. But the

\textsuperscript{12} Carlson, Licia (2010): \textit{The Faces of Intellectual Disability. Philosophical Reflections.}

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phenomenological approach is time assuming and as a research method it is also subject to critical questions. This is why I present this paper with some preliminary reflections and results.

I raise this question in a Danish context. If I had been in Germany it already had been raised by many philosophers i.e. Markus Dederich and Martin Schnell. They also raise another important question, still remaining to be raised in Denmark about guardianship, trusteeship and more generally a question of our recognition of dependency.13

**Literature**


13Ackermann und Dederich (2011)


Nørgaard, Britta (2000): *Habermas i praksis – indføring i dele af teorierne*, Skipper Clement Seminariets Forlag
