Professionals' naming of intellectual disability, past and present practice and rationales

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The study illuminates four research questions: What terms for the diagnosis ICD10: F70-79 do Norwegian professionals utilize in their work? Which changes of terminology have professionals experienced? How do professionals explain such changes? Is there a substantive explanation? A semi-structured qualitative interview guide was used on a sample of 41 informants. The main findings are: (1) Different terms are in use; (2) two major changes in naming are observed by the informants: (a) during the 1970s from 'feeble-minded' to 'mental developmental disability', and (b) after year 2000 from 'mental developmental disability' to 'developmental disability'; (3) professionals are in doubt as to which term to use; (4) they offer different explanations as to why terms change; and (5) five thematic discourses are identified, among which it is argued that the impact of ethical training of professionals is stronger than the others. Underlying these five causes it is hypothesized that they all may be induced by deeper scientific and structural changes in society.

Keywords: naming; mental; developmental disability; changes of terminology; explanations; discourse analysis and perspectives; Norway

Introduction

Within educational, social, and health sectors there have been changes in the labelling of diagnoses as well as a replacement of overall concepts like 'clients' with other assignations. This shift of terms is not only observed in Scandinavia (Bachke 2006b). It is an international wave, affecting UN-institutions (Neufeldt 1999), English speaking countries (Enns and Neufeldt 2003), and the German language area (Humer 2005). To have or not to have a correctly termed condition makes a difference. A study of sentences in court cases concerning whether certain pupils had received special needs' education according to their legal rights disclosed that the ascription of a diagnostic term was essential in deciding who received economical compensation (Lundeberg 2008). Moreover, the name used also signalizes positive or negative connotations which might lead to status or stigma, respectively. Subsequently, a label has a power in itself, and sometimes has a 'career', or time of success, and then disappears and even dies (Luckasson and Reeve 2001; Johannisson 2007). Diagnostic terms sometimes also refer to and are much influenced by ideological trends and modes within research and welfare society (Hallandvik 2005), as well as

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different basic perspectives and positions in debate on the phenomenon of definition, as in the case of the concept of *disability* (Grönvik 2007).

This article narrows the focus to the diagnosis labelled as mental retardation or developmental or intellectual disability (USA); intellectual/cognitive impairment or learning difficulty (UK); Menschen mit Behinderung and Menschen mit Beeinträchtigung (Germany/Austria); and mental developmental disability/developmental disability[1] (Norway), and coded as F70-79 in ICD10[2]. The article is a part of cumulative research on naming the diagnosis. My previous understanding was based on a literature review of how diagnostic labels were used in articles and textbooks (Bachke 2006b). Here it is the aim is to illuminate whether those findings are valid among practitioners and their discourses on labelling. The underlying goal is to describe which terms are utilized by the professional practitioners of today. Do they observe the changes of terminology? If so, why do they think terms alter? A deeper and more persistent purpose is referred to by Tidemand-Andersen (2008, 171):

> Designations are possibly stigmatising. There is a need for developing a type of terminology that to an increasing degree promotes a person's positive characteristics..., which expands room for positive and creative thinking of this group of pupils.

Literature review and research questions

In the comprehensive literature dealing with the diagnosis of mental retardation few articles or books focus on which terms are in use, and how terminology changes over time (Luckasson and Reeve 2001). The literature uncovers, however, that the diagnosis has had, and still has, many names. In the USA, one observes a move from 'feeble-minded', 'mental defective', or 'mental deficiency' via 'mentally challenged'/'mental retardation' and to more recent 'intellectual and/or developmental disability' (Luckasson and Reeve 2001) The name of the supportive organization, known almost for a century as American Association on Mental Retardation (AAMR) changed its name in 2007 to American Association on Intellectual and Developmental Disabilities (AAIDD). A Norwegian counterpart acted similarly in the late 1990s, when the concept 'psychic/mental' was removed from its name. In the UK, similar alterations of terminology have appeared, e.g. 'intellectual disabilities'/'learning disabilities', 'intellectual or cognitive impairment', or 'learning difficulties'. The picture is much the same in Scandinavia as substantiated by a literature review (Bachke 2006b). It was found that an abundance of designations has been and are used, both professionally and demotically. The most commonly used professional terms were 'mental developmental disability', 'developmental disability' and 'mental retardation' (as best translated into English). After the millennium, a significant tendency to skip the concept 'mental' and use the term 'developmental disability' alone was disclosed.

Bachke (2006a) argued that there might be many ways of explaining why the term *mental* was excluded. Based on a literature review on ethics, scientific theory, and stigma in addition to an oral discourse with linguists and colleagues, five partly overlapping explanations were offered:

(1) Increased awareness of terms' stigma effects, cf. Goffman's notion.
(2) Ethical conscientisation among professionals. This means better training, both before service and in service, leading to more awareness of basic ethical

    principles, in particular the principles of non-maleficence (do not harm) and autonomy.

(3) Users' controlled social-constructivism and empowerment. This means that service users more than before influence which term is correct and beneficial for them.

(4) Language-linked circumstances simplifying the pronunciation of the term and the use of euphemism.

(5) The professionals' involvement in detecting new sub-diagnoses instead of being concerned with labelling the condition of intellectual disability in a better way.

Most likely these explanations are influenced by a deeper and more basic discourse going on both among scientists and within the broader society. During the last few years, Scandinavian academics writing on the topic of disability have asked the question: Is disability caused by individuals or by society? Kittelsaa (2008) relates two main perspectives: (a) It is a biological-derived condition which means that it gives the person an identity that cannot easily be changed because it is seen as genetically determined, both somatically and cognitively (cf. IQ is mainly an innate ability). Or (b) it is a culturally- and socially-induced condition, which means that it is the society that impairs the individual. Sonnander (2005) recognizes even three perspectives, *the epidemiological* (similar to the biological stance)*, the relativistic* (between the biological and the cultural/societal), and *the constructionist perspective* (mostly societally derived). Grönvik (2007) has created four viewpoints. He uses different labels, but the meanings overlap partly with the above notions. Three terms take an outward view i.e. are seen from a helper's perspective. These are described by key concepts like *functional*, *relative/ environmental,* and *administrative definitions* respectively. The last takes a view from within, and is called the *subjective definition*. Such subjective definitions and terms are, however, rarely seen in the literature on intellectual disability. Professional practitioners' use of labels is hardly looked into either.

    This article intends therefore to illuminate how today's professional practitioners name the diagnosis intellectual disability, and what discourses go on among them related to labelling. The following research questions are asked:

(1) What terms for the diagnosis ICD10: F70-79 have professional practitioners met previously or used in their work? Which do they use now?

(2) Have they experienced a change in use of terms throughout their time as professionals? In particular, during the last 10 years? If any changes, which?

(3) How do they then explain such changes, and to what degree do they support the above five ways of explaining changes?

(4) Which thematic discourses are found, and is there a substantive explanation?

These questions steer the collection of data, the presentation of findings and in part the discussions in such a way that one can talk of a form of objective hermeneutics (Alvesson and Sköldberg 2005).

Methodology

As a consequence of these research questions a discourse-analytic approach was employed. From the vocabulary of discourse analysis concepts like *discursive struggle* and *investigations of change* are considered applicable due to the findings of the

literature review (Bachke 2006b). It was anticipated that practitioners had an ongoing discussion also on labelling. Closely related to this is also the question of who leads the discourse, the individuals or the systems (Jørgensen and Phillips 2008)? Conducting qualitative interviews is one recommended way of collecting data within discursive analytic approach (Jørgensen and Phillips 2008; Kvale 2007). The interview guide was structured according to topic, and the main sections were followed quite strictly, covering the informants' background, their experiences with labels, and their explanations as to why terms change. Within the three sections, the guide was used in a semi-structured way. Informants answered questions in a non-linear manner, often commenting on more than one question at a time.

Participants

A theoretically stratified sampling procedure was followed (Ringdal 2001). The selection of informants was done in two steps. Firstly, the researcher used his background experience from public services and university work to pick out institutions/offices within the social, health and/or education sectors. The selected arenas belonged mainly to the Norwegian county Aust-Agder and counted 26 workplaces in total. Both townships and countryside municipalities were included. Three institutions were under national administration, and one served under the umbrella of the county.[3] The 22 others were connected to the municipal level. None of the selected workplaces refused to participate, but one dropped out due to heavy work load during the period of data collection.

Secondly, the researcher contacted leaders of the sampled institutions, and asked for consent to conduct the interviews. At the same time they were asked to select informants fitting the inclusion criterion, which states that they should have worked regularly for at least four years with the target group (people with intellectual disability). Their work should be related to one of the three praxis fields, education, social or health. The names of the willing informants were then shared with the researcher who prepared a timetable for conducting the interviews. Forty-three informants were sampled, but two dropped out for various reasons, leaving a total of 41. Informants were sourced from institutions dealing with people with intellectual disabilities: home services at the municipality level (15); educational services both on municipality, county and state levels (13); daycentres and sheltered workshop on municipality level (8); and the health sector (5). The researcher has no information as to whether there were prior desertions of possible informants during the leaders' questioning of staff about participation.

Data collection

The informants were contacted by telephone to confirm time and place for interviews. In all cases except one the interviews were conducted at the informants' workplace by the researcher himself. As a warm-up, the questions on the informant's background were used. Then the open-ended questions linked to experiences of naming the diagnosis were presented. The interview was closed by challenging the informant to explain why terms change, and lastly ended by inviting the informants to consent or reject the five theoretical causes described above. The interviews took on average 20 minutes and were tape-recorded. Later on they were transcribed verbatim, producing 142 pages of text. On three occasions two people were

interviewed together simultaneously. The collection of data took place between June 2006 and February 2008.

Data analysis

The transcribed interviews were analyzed by means of a discourse psychological approach which recommends reading and rereading the text several times (Jørgensen and Phillips 2008). While reading, the thematic foci of the interview guide served as categories for fragments of text. The guide led on to a content analytic approach to the data (Jørgensen and Phillips 2008). The coding was steered by the knowledge and hypotheses derived from findings of the former literature review (Bachke 2006b). But it was a deliberate approach to look for new and different answers to the questions raised.

Issues linked to validity and reliability

Morse et al. (2002) claim that both reliability and validity are useful concepts in qualitative research. Regarding discourse analysis, Jørgensen and Phillip (2008) argue that validity is linked to concepts like *coherence* and *fertility*. Coherence provides arguments that give the analytic claims a degree of internal accordance. In this study coherence is based on the notion that there ought to be a certain level of conformity between the discourses exposed by field-related scientists and professional textbook authors in their publications, and discourses held by practitioners who work closely with people 'affected by' intellectual disability. *Fertility* is seen as the extent to which the analyses provide relevant explanations to a phenomenon, and moreover even create new understanding (Jørgensen and Phillips 2008).

In this study the focus is on terming the diagnosis ICD10 F70-79. Subsequently coherence and fertility are linked to a discussion on construct validity. Hallerfors (2000) emphasizes that the diagnosis of *developmental disability* is a constructed concept. He thus makes a stand for the *constructionist perspective* of Sonnander (2005), and appears to touch on the view of *users' social constructivism* (Bachke 2006a). In this way one can notice a certain degree of coherence among researchers. The question is whether this coherence is valid, not only between academics, but also between them and the practitioners in the field. Any sort of disagreement between the two groups may yield new directions for the study and make the findings of the study more valuable. It is a fact that it is hard to describe this diagnosis precisely by means of its medical criteria (its *epidemiological or biological perspective*). There is an ongoing debate on which hallmarks of the criteria are valid (Greenspan 1999; American Association on Mental Retardation 2002; Opdal and Rognhaug 2004; Tidemand-Andersen 2008); a stand that yields power to the *relativistic and environmental perspective*. This debate offers the possibility of new research to attain more concept validity, or at least disclose more in detail what the disagreements consist of. According to Rognhaug and Gomnæs (2008), there is a need to dive deeper into this. They question whether the diagnosis of intellectual disability, due to its inclusion of a vast variety of people, is scientific in its essence at all? Gjærum and Ellertsen (2002) contend that intellectual disability, at its core, is not an illness, but the developmental consequence of a heterogeneous group of factors, and thus challenge the validity of this diagnosis.

The interview session showed that construct validity was influenced by this diversity of perceptions. Some informants automatically talked of the diagnosis' name while others spontaneously spoke more of other assignations, like the change from *patient/client* to *user/customer/citizen,* or *service receiver.* To reduce such conceptual confusion the interviewer orally clarified the criteria of ICD10 F70-79. In this way construct validity was strengthened. On the other hand, this clarification might have underlined the interviewer's authority and thereby increased the researcher's effect on the statements of the informants. In a replicatory study, it might be wise to improve the construct validity by introducing the criteria of the diagnosis at the beginning of the interview. Most likely this would make it easier to use more than one interviewer. More interviewers, and, even better more researchers, would probably have increased both the construct validity and the findings' generalizability. Another way of increasing construct validity is to pilot the interview guide, which was not done in this research. All in all, however, the construct validity is judged to be high due to clarification of the key concept during the interviews, the interviewer's knowledge of the field, and generally a good interview climate.

Coming to *reliability* in discourse analysis, it is contended that this approach takes different contradictory statements for granted and counts them as a sign of the various interesting discourses going on within the subject area. In contrast to survey questionnaires, this does not reduce the reliability; it rather strengthens it because it increases the validity (Jørgensen and Phillips 2008).

Using a qualitative interview means one readily departs from the rigid structure of the interview guide. This happened also during this data collection, i.e. the sequence of the sub-sectional questions was not strictly followed. Instead, another lodestar of interview technique was adhered to: the creation of a comfortable environment for conversation. Most likely this made it easier for informants to talk and to be recorded. It might even have reduced the informants' fears of the researcher's authority, and allowed them to speak more freely and honestly, thereby strengthening the reliability of their answers. Breaking the structure of the interview guide might also influence when informants voiced their points of views, sometimes causing them to answer a similarly stated question twice, or even avoid being confronted with particular questions, and thereby affecting informants' reasoning during the conversation. This might have an impact on reliability and validity. For instance, throughout the interview the informant becomes more and more aware of what he/she really thinks is his/her opinion. It implies that the most reliable answer on an early question is stated at the end of the conversation. To 'catch' such final and more thoroughly reflected responses, the informants were, at the end of the interview, given an opportunity to state missing points or revise former replies. However, most of the informants had little to restate or add.

The context of the interviews varied. In some places there was no noise, and the informant had enough time and no stress. In other localities there were disturbances and disruptions which affected the informant's concentration and might thus have influenced the reliability of their answers. In some institutions more than one employee was interviewed. They might have talked together before the interview and influenced each other's sharing of opinions.

Studies using a questionnaire reveal that re-interviews, even within a short period of time, can produce quite different answers from the same informants on the same question (Ringdal 2001). It is difficult to say how stable the utterances of the informants of this study are. On one side it was observed that one of them said at

the end of the interview: 'This was interesting. I have not thought so much about the impact naming a term may have. Now I will be more alert'. Such re-focusing and reflections might in turn lead to a new or slightly different stance. On the other hand the informants were given a second chance to correct themselves, and did not use it. Moreover, the empirical results of the interviews are to a large extent similar to knowledge disclosed in the earlier literature review (Bachke 2006b). Subsequently, in this light it is logical to conclude that this study's reliability and validity are reasonably good.

The sample of this study consists of 41 informants with long experience in the field (on average, 17 years). These figures suggest that the informants should have been able to take note of changes in naming over time, and therefore also to describe them in a reliable way. The sample is inter-disciplinarily composed, and it is drawn from different 'arenas' dealing with people with intellectual disability. One might ask, does the sample contain enough informants with a higher level education (a master's degree or more)? There might be a belief that such people should be more trained in analytic thinking, and thereby be more tuned to observing changes in naming diagnosis, and possibly also better at explaining the rationales behind such changes. This study cannot properly answer such a hypothesis because the number of informants belonging to each 'demographical' subgroup is too small for statistical analysis. A general impression is that the level of alertness to current terminology seems to depend more upon personal interest, and on working context of the informants' service or institution, i.e. people employed by the county or the state were more concerned than those working for the municipalities. As already stated, for detection of correlations between background factors of informants, such as level of education, gender, working arena, and alertness to changes in naming, more informants would be needed and a questionnaire would be a better tool.

Findings

This section presents findings in five paragraphs. Section one deals with informants' background. Sections two to five are related to the four research questions: (1) which terms were in use; (2) what changes of terms have been observed; (3) how changes in naming can be explained; and (4) is there a substantive explanation? Along with the presentation of findings some discursive reflections are presented.

Demographics of the informants

All the informants worked in the Agder region of southern Norway, but many of them are born, raised, and educated elsewhere in the country. Therefore it seems reasonable to think that this sample is not regionally biased. The sample's distribution on gender showed 12 male and 29 female informants. The mean age was 49.5 years (males 53 years, females 48 years). Informants' experience in the field had a mean of 17 years, women having longer time in relevant service (almost 18 years) than men (ca. 15 years). Their educational background varied from college level (n = 6), Bachelor degree from universities/university colleges only (n = 11), further education of one year or more, but not Master's degree (n = 16), Master's degree (n = 4), to any level of education above a Master's degree (n = 4). Regarding educational profile, it was found that 6 had health related education, 15 were trained educators/special needs' educators, and 20 were trained within the social sector. Their

positions in the praxis field were, at the time of the interviews: 21 worked directly with target clients as teachers or therapists, 12 held more of an administrative role, and 8 acted mainly as counsellors/advisors. Thirty-three were linked to municipal services, one to the county level, and seven served at the governmental level (state employed). Their institutional affiliations were: homes/home services, 12; work places/sheltered workshops or day centres, 7; schools (direct teaching), 5; school system (educational psychological counselling), 5; resource/competence centres (cross municipal and/or governmental level), 6; hospitals, 4; other arenas, 2. As stated before, the number of informants is too low for reliable statistical analyses. This applies in particular to sub-groups. The reason why the demographic details are presented in such detail is to underscore the reliability of the data. The sample is quite broadly and randomly selected across relevant arenas.

Which terms were in use (research question 1)?

The informants' stated experiences with terminology are counted and presented in Table 1. It shows which names they had mostly heard of and/or used previously and presently. Only the eight most frequently used terms are included. Throughout the interviews, 23 different terms in total were mentioned, including professional and demotic expressions. This indicates that the flora of assignations seems to increase rather than diminish during recent years (cf. Bachke 2006b who found less than 20).

Table 1 shows that each informant had experienced several terms throughout their career – even more than the totals in the table show. Since the informants were of different ages, what is meant by 'previously in use' varies. The oldest informants in the sample started their working career in the early 1960s, and in their lifetime had even encountered the terms in use before 1950. The younger informants were educated around 1990, and were more or less unacquainted with terms utilized before that time.

Table 1 shows that some terms are no longer used in practical professional settings: 'feeble-minded', 'mentally handicapped/deficient' and 'Mongolian/mongolism'. Furthermore, it shows the same trends indicated by the previous literature review (Bachke 2006b): (a) three assignations are currently and rather permanently used by

Table 1. An overview of terms in use previously or now utilised by professionals – research question 1

Diagnostic term	Previously in use	Presently used
Feeble-minded (Åndssvak)	21	0
Mentally handicapped/deficient (Evneveik)	16	0
Mongolian/mongolism (Mongoloid)	10	0
Mental developmental disability (Psykisk utviklingshemming/-hemmet)	35	32
Person with mental developmental disability (Person med psykisk utviklingshemming)	7	16
Developmental disability (Utviklingshemming)	15	30
Mental retardation (Mental retardasjon)	22	20
General or comprehensive learning difficulties (Generelle/sammensatte lærevansker)	3	10
Total terms referred to in this table	129	108

practitioners: 'mental developmental disability', 'developmental disability', and 'mental retardation'; (b) the term 'developmental disability' is evidently increasingly used; and (c) for the two other names there are only insignificant changes.

It will be noticed that the long and more complete construction 'person with mental developmental disability' is more in use now than previously, but there seems to be a reluctance to utilize it widely. Only 16 out of 41 reported it to be in regular use. The informants stated that the dislike is mostly caused by the length of the term, which makes it inconvenient to express. Preferred abbreviations are 'developmental disability' or 'mental developmental disability' – the latter sometimes shortened to 'PUH' (from the Norwegian construct '*psykisk utviklingshemmming*'). This practice goes on despite a degree of professional and ethical anguish. They excuse the use of 'PUH' by arguing it is quick and easy to pronounce, and at the same time conveys full meaning when professionals speak to each other.

Table 1 reveals also that the term 'complex or comprehensive learning difficulties' is increasingly used. In particular, this practice is found among informants working at hospitals and within services offered by school psychologists and educational competence centres. A reason for this might be that these employees are better educated, act as experts, and subsequently more regularly read English-language professional books and research journals so that they are more influenced by English terminology. Moreover, learning difficulties are interpreted to be a more temporary diagnostic term, a bit rougher and at the same time less pervasive: As one informant told: 'We use the term "general learning difficulties" till we after some years can be more certain of the exact diagnosis'. Another informant stated: '. . . we have used this term "complex learning difficulties" as a borderline term to ICD10's F-80-level'. These utterances express the fact that in some cases intellectual disability can be hard to diagnose, probably due to unclear criteria. In other cases, one might be reluctant to make use of the diagnosis because of uncertainty as to which term is at present 'politically' correct. The abundance and variety of terms in use might encourage doubt among professionals on which term to select. One informant expressed this outspokenly: 'One becomes very uncertain as to whether one utilizes the correct term or not'.

Changes of terms (research question 2)

A careful reading of Table 1 discloses changes in terms; cf. the disappearance of some of the old designations like 'feeble minded'. However, not all informants had *experienced* this change. When informants were asked whether he/she had observed a change in the labelling of the diagnosis, either during their life time or during the last decade, some of them (9 informants or 22% of the sample) were unsure as to whether there had been any such change. How do we interpret this? Some of these informants explained that they had been using the same term throughout their practice, 'mental developmental disability'. They had, moreover, not noticed that the Norwegian support union, NFU, had simplified its name by removing the concept 'psychic' (mental). Nor had they met members of the NFU that had acted aggressively or reproachfully towards them because they utilized wrong labels. Overall, these informants have had their focus on something else than labelling F70-79 correctly. The other 32 informants had, however, noted the changes of naming. On the question of changes during previous periods, the informants made 37 statements implying changes during the period 1970–95. Most of these statements, 26 of 37, refer to the decline of outdated terms like 'feeble minded', 'mentally deficient', or

'mongolism'. Instead the new term 'mental developmental disability' was retained. The second most observed change was from 'mentally deficient' to 'general learning difficulties' (stated by four informants). Other changes of terms during this period, mentioned by one or two informants only, were from:

● Brain injured	to mental developmental disability
● Handicapped	to mental developmental disability
● Mental retardation	to mental developmental disability
● Mental developmental disability	to person with mental developmental disability
● Slow learner/dysfunctional	to multiple dysfunctions

Concerning changes during the decade 1996–2006, one change was reported by many informants. Twenty-five (58%) out of a total of 43 statements relate to the change from 'mental developmental disability' to 'developmental disability'. Other changes mentioned by just a few informants are:

● Mental developmental disability	to person with mental developmental disability
● Mental developmental disability	to person with aid requirements
● Mental developmental disability	to general learning disabilities
● Mental developmental disability	to a person's proper name
● Mental developmental disability	to user, resident, aid recipient
● Dysfunctionalities	to developmental disturbances

The professional practitioners experienced two kinds of feelings in connection with the steadily ongoing changes of terms. On one hand, the *feeling of uncertainty* as to which term is valid, when they communicated with users and their relatives, and when they talked to colleagues. Secondly, the professionals faced *the pressure of expectation* that they were using the correct term. This is clearly formulated in statements like: 'There has been an emphasis on and an expectation towards using the correct assignation'; and 'Most people miss a safe professional term. They are afraid of saying something wrong'.

How to explain changes in naming (research question 3)?

During the interviews, spontaneous explanations were initially asked for. Among these, 16 out of 36 (44.4%) are covered by Bachke's theoretical explanations No. 1 and No. 2 (*stigma* and *ethical training*) (Bachke 2006a). Examples are:

- They have observed that it is stigmatizing or not so well functioning
- The word mental (psychic) is stigmatizing
- To avoid hurting somebody
- Then it becomes more a strain than a term
- People are better trained and informed

To a lesser extent the informants touched upon other explanatory categories of Bachke (2006a): e.g. No. 4 (*language related conditions*) mentioned by 4; No. 3 (*users' empowerment*) stated by 3; and No. 5 (*experts' focus on sub-diagnoses*) related to by 3.

More surprisingly, several new categories of explanations were revealed, as seen in the example statements below:

(a) There might be something else hidden in this phenomenon… the general development of the society, the process of democratization, freedom, the perspective of normalization. Today we have a quite different concept of normalization than we had previously. It is related to the total development of society in the perspective of liberation… and human values.

(b) International trends influence the way we name the diagnosis.

(c) It might have something to do with the reform [of 1991].

(d) The impact of reforms and changes of laws in the sector is evident [Helsevernet for Psykisk Utviklingshemmede-reform of 1991 and law of use of constraints of 1999].

(e) We are more instructed to give more precise diagnosis than earlier.

(f) Changes are inevitable in all sectors of society. Therefore they are unavoidable in this diagnostic field too.

(g) Professional language as well as jargon changes over time – within all sectors actually.

(h) General research and scientific ideology produces input: Changes in naming is a natural fruit of the development within science more broadly.

(i) Different professions work with the same type of pupils/clients/patients/users. This leads to a mutual influence and discussions that result in changes, diversity and sometimes conflicts and confusion.

(j) Media and public debate in the field affect which terms are valid and 'in'.

In general these statements disclose and underline how professional terms and language are under the influence of outside forces, such as: the general development of society (statement a and f); international professional trends (b); in a wider sense, general scientific development (g and h); the influence of reforms and new laws (c and d); the way health and social sectors in the community are led by means of laws and economical systems (e); and the public debate (j). Some of these factors interrelate to each other and may create what researchers of social and political sciences call *trends* or *modes* (Hallandvik 2005).

In the second place, at the end of the interviews, the informants were confronted with Bachke's five proposed explanations for changing the label (Bachke 2006a) and asked to comment on each of them, possibly accept or reject them. The results are presented in Table 2. The nine informants who had not observed any change in labelling are excluded from Table 2. Moreover, one should note that some informants did not voice opinions on all explanations, but only on some. Others supported the same explanation with phrases in different contexts linked to the same meaning, and therefore can be counted as having given double support. That is why the stigma-explanation received 35 'hits', from the 32 included informants (those observing changes in labelling). One should also notice that some informants stated clearly that some of the originally proposed hypothetical explanations resembled each other. Such comments have influenced a restating of the naming the explanations; cf. the categories of explanations in column one compared to those original 'titles' in column two in Table 2. For instance the first explicatory category, *an educational discourse,* combines Bachke's first two original hypotheses, namely awareness of the terms' stigma effects and ethical conscientization. The second category, *a users'*

Table 2.   Discursive explanations of why terms change (research question 3). Number of informants supporting the different explanations plus examples of supportive statements voiced by them

Explanations of changes in form of discourses held	Originally proposed hypotheses of changes	N	Examples of statements
Impact from an educational discourse emphasising ethics among practitioners	Negative effects of stigma	35	*The term 'mental' is stigmatizing* *The PUH-concept is the most stigmatizing. It has low status*
	Ethical conscientisation	31	*One feels like being more ethically alert than ever*
Impact from a users' discourse, emphasizing individuals' and sup-porting unions flying the empowerment-flag	Pressure from users and their supporting union	26	*The parents have applied pressure to naming.* *Parents' union (NFU) is stronger than ever. It is more influential.*
	Active users' constructivism	15	*Users' empowerment is alpha and omega. Users educate me Parents educate professionals*
Impact from a lingual discourse headed by linguists and users and their supporters	Simplifying pronunciation/length Euphemism	26	*The term is too long to say* *The terms are outworn and acquire much negative weight. Subsequently one makes new names* *The kinder the term is, the less scared people feel One looks for euphemistic paraphrases*
A tacit discourse among biologically and defectologically-oriented scientists	Researchers more interested in defining new syndromes	24	*One is left with the impression that the target group, people with mental retardation, is not so interesting* *If one as researcher can discover a new syndrome, he receives 'a feather in his hat'*
A mass media discourse	Not expressed before	11	*Media and the public debate influence of which term is valid and' in'* *I think media are very influential*

discourse, integrates column two's two expressions, 'pressure from the users' and 'active users' constructivism'. Since a good number of informants related to 'trendlike' statements, a category for such statements was added, counted, and referred to as *a mass media discourse*. The media's important role – generally and particularly – in making labels is underpinned by a study on the press' treatment of people with intellectual disabilities (Morlandstø 2005).

Table 2 presents the classifications of 168 statements, an average of four for each informant (n = 41), or more than five if n = 32. It shows that this sample of professionals to a large degree supports the hypothetical explanations for change of term. However, the support varies between 35 (*stigma*) and 15 statements (*active users' constructivism*). The new explanation, spontaneously suggested by the informants, the *trend/media* explanation, is reflected in 11 statements.

Table 2 contains a reminder of possible researcher influence on informants. By presenting five hypothetical explanations, the interviewer might have inadvertently influenced the informants. However, since these were not introduced until after the informant was offered an opportunity to give his/her spontaneous causes for change, the probability should not be high. Some informants beforehand and therefore independently supported the five original explanations. Some proposed fresh explanations, like the new media related discourse category, which emphasizes their independence too. The unevenness of support shown for the five hypothetical explanations underlines the same: The interviewer has hardly influenced the informants' opinion sharing and answers.

A substantive explanation (research question 4)

None of the informants argued strongly that there were one or two explanations that overruled the others. Neither did they strictly limit their view to making only one explanation valid for the change of labelling the diagnosis F70-79. The content of the interviews cannot directly support or reject the question whether there is a substantive explication or not. However, it is worthwhile to discuss this question by weighing the different categories of explanations: Do they overlap substantially?

Discussion

This section deals with discussions of thematic discourses (see first column of Table 2) affecting labelling, and how they might mutually influence each other. New research questions to be illuminated in further studies are also suggested.

Thematic discourses and a substantive explanation (research question 4)

If one analyses the example statements in the right column of Table 2 from a discursive perspective asking which discourses they represent, they can be labelled as in the left column. Coming to the *ethical training discourse* (comprising also *stigma*), one finds that practitioners are very aware of its impact. The figures indicate that 66 statements are categorized under this heading. One can read this as an indicator of the strong impact of ethics as a change agent in the new terminology of the diagnosis F70-79. Furthermore, support for a lively ethical discourse among the practitioners is underlined by the fact that 16 out of 36 (44%) of the spontaneous explanations belong to this category.

Next in number follows a *discourse on users' empowerment*, not least on their ability to construct terms themselves. Table 2 links 41 statements to this category. It is reasonable to interpret this relatively high figure in a similar way as the ethical explanation above. However, the interviews showed that few professionals mentioned this explanation spontaneously. It means that it is a more dormant discourse among

the practitioners. However, it might most likely be a more active discourse among users' and their relatives.

The discourse on linguistic matters (assumed to be led by linguists and users), and *the tacit discourse* among biologically-oriented scientists scored fairly equally, 26 and 24 statements respectively. Spontaneously, informants mentioned these discourses only to a small extent. They appear sporadically, respectively four and three times. At most they were provoked to surface by the interviewer's introduction of his hypothetical explanations. This indicates that these discourses are not often raised among the practitioners. But they can be easily aroused if one asks for them.

The *discourse on mass media's influence* (assumed to have journalists and mass media communicators as main actors) was not asked for by the interviewer, but it was brought up by some of the informants, who were aware of the press' discourse on the labelling of diagnoses, and they attributed its relevance and influence. It is remarkable that this point was not explicitly described in the professional literature on the naming of the diagnosis (Bachke 2006b). In other words this study reveals a new discursive perspective, which shows its power of *fertility* (Jørgensen and Phillips 2008).

The five thematic discourses related to the naming of ICD10: F70-79 underpin the validity of the discourse-analytic concept, *discursive struggle*. On the one hand, one can look at the different discourses as varying ways of explaining why terms change, and why those ways can be seen as competitive with each other on gaining explanatory power. On the other hand, it might be more reasonable to look at the discourses as explanations that play together in promoting new diagnostic terms. They, so to speak, join hands and add pressure towards the changing of labels. Figure 1 shows this coherence between the different ways of explaining terminological change. Despite this, Figure 1 contends that there is a mutual influence of many factors/phenomena affecting the labelling of this diagnosis, and it is still possible to ask whether there is a dominant discursive explanation among the practitioners. From the arguments above it is reasonable to regard the ethical-based explanation as the most substantial, because it is both emphasized by most informants, and because it is also more often spontaneously mentioned by them. The informants, so to speak, attribute power to it. This is illustrated by giving it a thicker arrow in Figure 1.

Figure 1 also raises the question whether there are some basic forces in society that provoke ongoing changes over a wider spectrum than the mere selection of terms, but which at the same time are the main force behind choice of labels. The outer circle of Figure 1 refers to such substantial forces. Some of the informants' statements above account for the same. This view is supported by Hallandvik's (2005) concepts of trends and modes. In the professional helping field, name-changing can be perceived additionally as an outcome of deep ideological shifts in scientific approach from a defectological perspective towards a more salutogenic view (cf. Antonovsky 1987). If so, then this is closely linked to how one basically understands this diagnosis, and thereby to the theory of diagnostic perspectives as described by Kittelsaa (2008), Sonnander (2005), and Grönvik (2007). This might then be a substantive explanation of change. In other words, the biologically-oriented scientists refrain from labelling this condition, leaving practitioners and users to play the game of naming by means of social constructivism, not least when stigma/ethics are underlined by many informants, and stigma is mostly a societally-derived notion.

However, it is open to discussion how many explanatory categories one should speak of. Table 2 hints at five in column one and to seven or eight in column two.
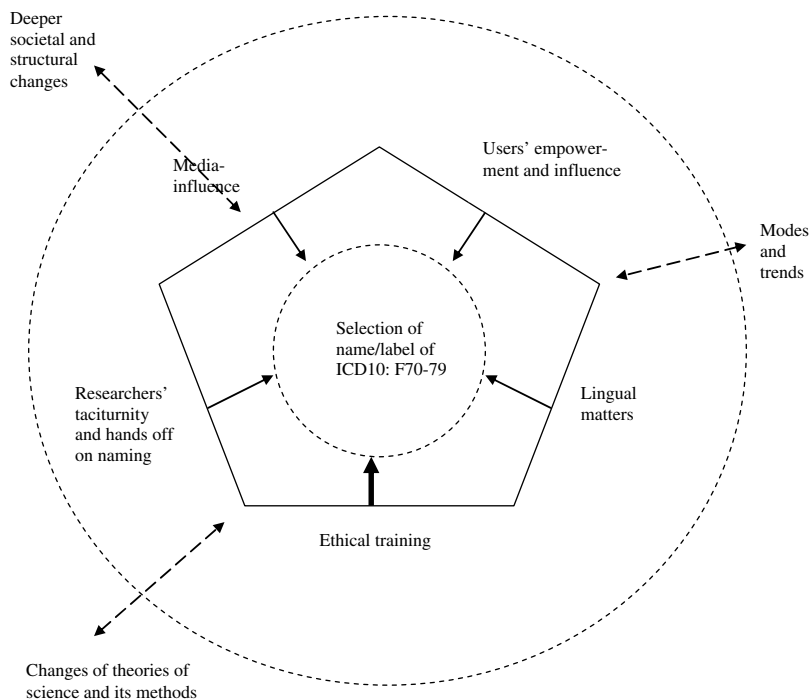
Figure 1.   The five thematic discourses influencing naming of the diagnosis F70-79 (research question 4).
Note: The peripheral phenomena are seen as' bigger' discourses both affecting each other mutually and the five 'smaller and closer' research-reported discourses. When arrows go both direction it indicates that there is a reciprocal influence. Thus Figure 1 discloses a chicken-egg question of interpretation.

Bachke (2009) proposed three main categories: one linked to the influence of users' and their supporting union; another related mostly to linguistic assessments: and a third to considerations of ethics and special foci among the professionals. Figure 1 retains five categories because their existence is substantiated in this interview study. At the same time, Figure 1's outer circle includes three more general and basic reasons for changing diagnostic names. Therefore it is hard to say how many explanatory categories promote more understanding. Moreover, will they at the same time push for the creation of a term of implying positive characteristics (Tidemand-Andersen 2008)?

    Both Table 2 and Figure 1, as well as the high number of spontaneously expressed explanations on why this diagnosis is renamed, point out that many practitioners are aware of the complex game which goes on when it comes to naming a diagnosis. They realize that many factors influence which term is selected. By implication, it underscores that many of the informants show understanding of the need for more than one thematic discourse to give a proper and fully fledged explanation of why a label changes (cf. Sonnander 2005; Grönvik 2007).

New research questions

A sample of more than 40 professionals ought to vouch for a deep, valid, and reliable knowledge as to how 'practitioners' use assignations connected to ICD10: F70-79 (*intellectual disability*), what changes of terminology they observe, and how they explain the changes in terminology going on. However, it is likely that the provision of services to people with mental disability is even broader than the sample of this study has been able to include. In Norway, there might be 'cultures of services' not covered here. Internationally there certainly will be such professional cultures and backgrounds. To include such milieus, and thereby also in a reliable way investigate the generalizing power of the findings of this study, there is a need to interview more professionals, both nationally and internationally. This would offer an opportunity to compare the positions and assertions of informants of either gender, of higher or lower levels of education, of direct or indirect practice with the clients, and so on. In particular, it would be interesting to know more about the thinking of the users of professional services and their next of kin. Do they experience having an impact on which term is in favour? And how can they play a role in labelling the diagnosis in the future? How do they explain the changes of terminology? Which explanatory thematic discourses do they raise? Moreover, which factors are seen as the major agents of change: scientific personnel, professional practitioners, users and close relatives, and/or media (cf. Figure 1)? Is it ideas or people that take the lead? And is the discursive struggle more conspicuous and vivid than shown here? It could also be of interest to ask what will serve this diagnostic field best: To have a variety of names for the same diagnosis, or to look for one common and mostly accepted and used term, nationally and internationally?

Conclusions

This interview study of 41 Norwegian professionals showed that:

(1) There are many terms in use related to the diagnosis ICD10: F70-79. The most used terms are 'mental developmental disability', 'developmental disability', 'person with (mental) developmental disability', and 'mental retardation'.

(2) During the period between 1970 to the present there has been and still is an ongoing and partly unsystematic change in naming this diagnosis. Two distinct changes in Norway are observed: (a) from 'feeble-minded' and 'deficient' to 'mental developmental disability' between 1970 and 1991, and (b) from 'mental developmental disability' to 'developmental disability' during the decade 1996–2006.

(3) There has been and still is confusion and uncertainty among practitioners as to which term is the correct one to use. This confusion might hinder cooperation between professionals and harm relationships to users. As one informant stated: 'The way it is at present, it is not good enough!'

(4) The findings of a former literature review on terms used in titles of articles and professional books published during the period 1995–2005 (Bachke 2006b) are to a large extent supported by this empirical work.

(5) When it comes to rationales behind changes in labels, it is found that different thematic discourses play a role. In this study the informants emphasized five:

Ethical training of professionals; users' empowerment and influence; linguistic matters; researchers' taciturnity and hands-off involvement in naming; and the influence of media. No single substantive explanation is clearly out in front, but it is argued that ethical training might be a direct major contributor.

(6) Underlying those five explanatory discourses it was pointed out that they might mirror greater societal and scientific alterations that have an impact on the naming conventions of researchers, practitioners, and users, cf. Figure 1.

(7) This study also touches upon another debate on which terminology gives both necessary rights for supportive help from the society and at the same time may unburden an assumed stigma effect. The discursive struggle between stakeholders of the biological and socio-cultural perspective respectively is obvious. One may ask which stance takes the upper hand at a certain time. In Norway it is quite evident that the users and their organizations have promoted the last main change, a removal of the concept 'mental' from the term. At present this fact indicates that it is the users' constructivist perspective that dominates. However, one should not be blind to the strong impact of the bio-medical perspective: It holds the keys to the diagnostic manuals and most likely receives the main share of research funds. Will the future offer greater possibilities for combining the two perspectives in assigning diagnostic labels, and thereby taking account of the fact that naming simultaneously refers both to a biological reality and to a social constructivism (Shakespeare 2006; Siebers 2008)?

Notes

1. A literal translation of the Norwegian concept *utviklingshemmet* or *utviklingshemming* is hard to do precisely. The meaning is either 'underdeveloped', or 'sub-developed' or more to the letter 'developmentally inhibited' or 'developmental inhibition'. In this article I have vacillated between using a literal translation from Norwegian to English in order not to violate vital gradations of meanings, findings, and stance in the Norwegian context. However, to communicate better with the international and English-speaking circle of readers and to avoid harming and confusing the actors of this field unnecessarily I have decided to use the meaning closest to already well-established assignations; i.e. I have anglicized the two Norwegian terms: 'psykisk' to 'mental' and 'utviklingshemming' to 'developmental disability'. This translation also comprises the parallel Danish term 'Udviklingshæmming' and Swedish 'utvecklingsstörning'. The complete expression 'mental developmental disability' is comprehensive, and hard to express. In the text I therefore in some places to use the older term 'mental retardation' as a synonym.
2. Mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period. These contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities (http://www.who.int/classifications/icd/en/bluebook.pdf).
3. The types of institutions are not described due to consideration of anonymity.

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