

# **“ALL TERMS HAVE A NEGATIVE APPENDIX” PARENTS OF OFFSPRING WITH INTELLECTUAL DISABILITY (ID) AND THEIR EXPERIENCES WITH NAMING THIS DIAGNOSIS – AN INTERVIEW STUDY**

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**Abstract.** *16 parents with offspring with ID were interviewed, using a guide that asks for their experiences of the naming the ID-diagnosis, of different labels that have been used, of how labels have changed during the last half century, of how they explain label-changes, and of whether some of the explanations might be considered substantial. Generally there is an overlap with findings of similar studies among professionals. However, parents add new nuances and emphasize in a more thorough way the substantiality of two causal explanations of the changes: the impact of ethical training and the influence of users.*

## **Introduction**

This article illuminates the labels for intellectual disability (ID - ICD10:F70-79-related terms) that parents have encountered, the terminological changes they have experienced over the past 4-5 decades, and how they possibly explain such changes. It is thought that both the naming of diagnoses, the changing of the terminology, and the explanations for doing so refer to discursive struggles both in the general society and more particularly within its helping sectors: health, social work and education. Moreover, the naming of a diagnosis has practical implications. On the one hand, to have a correctly termed condition determines in many cases whether you get access to professional services and financial support (Lundeberg, 2008). On the other hand, a diagnostic term often causes undesirable stigmas (Goffman, 1975). Changes in naming terms are not particularly linked to ID alone. It is just an example of broader “movement” affecting both diagnostic and client terminology, e.g. “mental disorders” (Foucault, 1973; Ben-Zeev, et al., 2010; Van Os, 2010); prisoners (Christie, 1982); and abbreviations describing hyperkinetic disorders (Språkspalten, The Journal of Norwegian Medical Association, 1998). Changing terminology is also seen internationally as in UN-institutions (Enns & Neufeldt, 2003).

Direct studies of the impact of different labels on ID-users and/or their next-in kin are rare. Bachke (2006/2012) looked at professionals’ use and experience of various terms for this diagnosis. One study dealt with Scandinavian professionals’ labeling in their publications (Bachke, 2006). Another study related to Norwegian professional practitioners’ choice of terms in oral discourse in their practical work (Bachke, 2012). Other researchers have indicated that the selection of designations might have a connection to whatever

is seen as the basic cause of the disability: Conditions of the individuals or of the society? This relates to different perspectives on disability: *biologically derived* or *culturally/societally derived* (Kittelsaa, 2008; Grönvik, 2007; Shakespeare, 2006; Sonnander, 2005). Terminological concepts signal the perspectives selected as a basis for the underlying definition: Either an outside perspective (from the helper's viewpoint), as in biologically derived definitions; or a subjective, from inside the client, definition. The latter is hardly observed in the literature on ID (Bachke, 2012). This lack makes it interesting to use intellectually disabled and/or their parents as informants. The fact that these people increasingly want to influence the choice of label makes such an approach of even more current interest (Bachke, 2012; Starrin, 2007; Ellingsen, 2007; Barnes, 2004). Partly because it is ethically challenging to interview persons with ID themselves (Kittelsaa, 2010), and partly because it is desirable to elucidate the naming of this diagnosis over several decades, parents were selected as informants. Additionally, to attain more systematic knowledge about the labels' impact on parents might be helpful for the professionals in the helping sectors. Parents have both an objective perspective (they do not have the diagnosis themselves) and a subjective perspective (they live daily with it; Eck, 1998).

The starting point for the present study is what Bachke (2006/2012) found in the two previously mentioned researches. His first study showed:

(A) The three most commonly used terms<sup>1</sup> in Scandinavian professionals' published writings during the decade 1995-2005 are *mental developmental disability*, *developmental disability* and *mental retardation*. The former was most frequently used, and it is also the one labeled in the Norwegian edition of ICD10.

(B) A terminological change seemed to be ongoing. There has been a tendency for *developmental disability* alone to dominate increasingly since the millennium-shift, and it was the journal of The Norwegian Association for Persons with Developmental Disabilities (NAPDD), *Et samfunn for alle* (A Society for All), that fronted this terminological change. Only to a limited extent have the professionals followed, cf. textbooks/chapters (Opdal & Rognhaug, 2004; Tidemand-Andersen, 2008; Rognhaug & Gommæs, 2008).

(C) Instead the professionals chiefly seemed to remain loyal to the term of ICD10, *mental developmental disability*. Bachke's second study (2012) confirmed these three findings.

(D) Both studies showed that the professionals had noticed a change in the naming of this diagnosis over the years: (1) From *feeble-minded* and *deficient* to *mental developmental disability*, during the period 1967-1991, and (2) from the latter to *developmental disability* between 1996-2006.

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<sup>1</sup> The reported terms are literal translations of the Norwegian terms *psykisk utviklingshemming*, *utviklingshemming* and *mental retardasjon* in described sequence

(E) Bachke's second study (2012) tested five hypothetical explanations of why these changes of terminology occur: (1) Increased awareness of terms' stigmatizing effects; (2) increased ethical awareness; (3) users' controlled social - constructionism; (4) language-related circumstances; and (5) the emergence of new sub-diagnoses/syndromes. These hypotheses were presented to 41 professional informants, after they had been asked to explain spontaneously why terminological changes occur. By means of a discourse-analytic approach to their explanatory statements Bachke deduced two main categories of explanations and a total of eight modificatory reasons:

A. Five "direct" actor-driven discursive explanations. Changes occur because of:

1. An intensified ethical training discourse (reducing stigma)
2. A client-based discourse related to empowerment
3. Language-related discourses related to simplicity of pronunciation and euphemism
4. A tacit discourse on choice of terminology among expertise
5. A discourse on mass-media's influence on terms

B. Three more "indirect" and societally based explanations. Changes occur because of:

6. Influence of modes and trends
7. Modifications of theories of science and its methods
8. Deeper societal and structural changes

These analyses led to the construction of a theoretical model which illustrates how the different discourses interrelate and influence the actual selection of names for this diagnosis (Bachke, 2012). The model mainly shows how different ways of explaining changes in labeling seem interwoven, and concludes that there is a discursive struggle on-going within the field. Another part of the analyses focused on whether any substantial explanations exist. A preliminary conclusion is that the study did not give an unambiguous answer to the question. However, since *ethical training* as a causal explanation both spontaneously and when presented, was mostly supported by the professional informants, it is hypothesized that this so far appears to be the most substantial. To discover more about the substantiality of explanations, as well as look at naming's impact on parents' experiences with the diagnosis the following research questions are raised:

1. *Which professional and demotic terms have the parents encountered?*
2. *(a) Which term do they themselves use, and (b) which do they hear professionals use?*
3. *Have they experienced any changes of the terms in use; and in case yes, which?*
4. *How do they explain such changes?*
5. *To which extent do their statements establish a basis for contending substantial explanations of changes?*

To set a criterion for what is a *substantial explanation* is difficult, since there is no exact norm for it in such methodically mixed study-design. Though somewhat arbitrary it here refers to the frequency of mentioning of an explanation; i.e. at least half of the informants must point to it.

## Method

Kvale (2007) recommends use of a hermeneutic approach and qualitative interviews in research areas where one wants to look at internal discussions and changes, where concepts like *discursive struggles* and *investigations of change* are used (e.g. Jørgensen & Phillip, 2008). These concepts apply well to the selected informants because they are all active members of the NAPDD. After much discussion the organization skipped the term *mental* from its name in the late 1990-ies. It has also asserted the same simplification among the professionals through its journal, *A society for all*. Since this study is an extension of similar studies done with professionals as informants, it has partly a replicatory form which implies that possibly new findings are mirrored in the light of findings from the former studies. Knowledge revealed by the professional informants is tested on its validity amongst parent-informants. This fact implies a certain use of qualitative elements, which means that the present study is both qualitative and quantitative. According to Creswell (2003) such a mixture is not uncommon in exploratory studies.

### Selection of informants

The researcher used a combination of theoretical and network sampling (Ringdal, 2001). “Theoretical” refers to the selection of members from NAPDD in two counties, East- and West-Agder, as the entire population. Such members are expected to be rich on relevant information since they for years daily have “lived” with the ID-diagnosis, and since they through their active membership receives regular relevant information.

The informants were selected by “network sampling” in a two-step process. Firstly, the researcher contacted the respective county-leaders by phone and e-mail. The latter contained a copy of the interview guide, a letter of consent, and a question which asked the leader to pick members from their county-organization to participate in the study. Secondly, the willing members’ names were conveyed to the researcher. He contacted them by phone to confirm their willingness to participate and to make appointments for the interviews. On the phone the leaders admitted that they had mostly asked members they knew well and whom they thought were rich in topical knowledge. It is not known to the researcher whether the leaders contacted other members who refused to be interviewed. Therefore it is hard to say anything about dropout rates, or how representative the sample was for the total memberships of the organization in Agder. The sampling procedure applied to the category of non-probability strategies.

A total of 16 persons were interviewed; 5 from West-Agder and 11 from East-Agder. The low number of informants requires to cautiousness in generalizing the findings.

### **The interview-guide**

The interview-guide was based on a similar guide used for interviewing the professionals (Bachke, 2012). Two minor changes were made: The parent-informants were asked about terminological changes during their life-time, while the professionals only during their time-span of working. Additionally, the parents were challenged to tell about terms applied to their own offspring.

The guide consisted mostly of open-ended questions. It constituted four parts (1) Question 1 related to the demographics of the informant; (2) questions 2-4 dealt with experiences of naming the diagnosis; (3) questions 5-7 focused on experiences of changes in terminology and explanations of changes; and (4) question 8 referred to positive experiences with inclusive education, which is excluded in this article. In the spring 2009 the interview-guide and the research was approved by NSD: Tape-recorded data was deleted by the end of the same year.

### **Data collection**

The interviews were conducted from June to October 2009. Three interviews were carried out at the researcher's office, one in a café, and twelve at informants' homes. Among the 16 informants there were six couples. Five of these were interviewed jointly. The disturbances during the interviews were few and small, and did not harm the data collection.

The researcher conducted all the interviews himself. Except for interviews with one couple where recording was done by hand written notes, all the interviews were tape-recorded and later on transcribed. Each interview started with informal small-talk to build an atmosphere of openness and trust. Then it proceeded sequentially through the three main parts described above. Although the interview guide, handed out in advance of the interviews, had a clear structure, the practical interviews in some cases deviated from this fixed sequence. Some informants unsolicited answered more than one question at a time; or they told stories and related examples with contents beyond the scope of interview topic.

It took on average about 20 minutes to cover the seven questions in each interview. For all the 16 interviews the relevant transcribed text amounted to approximately 40 pages.

### **Analyses of data**

The transcript was read several times. To interpret the text a selective/focused codification was used (Chamaz, 2006; Fejes & Thornberg, 2009), based on Bachke's findings (2012). In particular to statements concerning explanations of term-changes the eight previously mentioned codes were applied. Besides, new explanations and points of view voiced by the informants were looked for, to challenge the *fertility* of the study (Jørgensen & Phillip, 2008).

### **Validity and reliability**

*External coherence* is vital for the external validity of a study. Since this study partly hinges upon a similarly designed approach with professional informants, a level of concordance with those findings adds to the external validity. An overlap in findings is clearly shown on each of the sub-questions. Labels encountered, changes experienced in naming, and voiced explanations for such changes have a high level of similarity. However, this might be caused by the egg-hen connection between the author's studies, both methodically and theoretically. As a result more external validation of the findings by researchers using different samples of informants and possibly other methodological approaches as well is needed.

*Internal coherence* refers to similarities in the use of terminology within the study's sample of informants. The present study reveals that this coherence is broadly valid among parents with offspring with ID since the informants at large refer to the same categories of labels, name-modifications and explanations for change.

The study's *fertility* is underscored by the fact that the parent-informants partly introduce new terms like *persons with need of assistance*, and partly suggest new types of explanation and indicate that more than one explanation is substantial. All in all this also makes the study more valid.

*Concept-validity* in this study applies particularly to two concepts: *Intellectual disability* and *substantiality*. The former was not referred to explicitly in written information to the informants. However, it was mentioned at the top of the interview-guide, which the informant received beforehand. As an introduction to the interview it was talked about, and thereby the concept-validity was strengthened. *Substantiality*, on the other hand was not presented to the informants during the interview. It was constructed afterwards as a mean of analyzing the data. Hence it is not confirmed whether the informants held an explanation to be substantial or not. The validity of this concept is consequently researcher-bound, which is a conceptual weakness. In a replicatory study the researcher should take account of that.

In interviews like these at times informants utter contradictory statements. It is not unexpected since current research discloses an on-going discursive struggle (Bachke, 2012). According to Jørgensen & Phillip (2008) such contradictions strengthen the validity and thereby also the study's *reliability*.

Reliability of informants' statements is also increased by the time spent introducing the study through small-talk intended to create a safe climate and good relations between the interviewer and his informants. That the interviews mostly took place in informants' homes also contributed. The reliability of statements was also strengthened by the researcher's summing up of answers to questions, inviting informants to confirm, correct or revise his conceptions, or add to or revise something at the end of the interview. Hardly any corrections or additions were offered. This is interpreted as a sign that the informants had

given voice to reliable points of view. The fact that informants had received the interview-guide in good time before the interview, and that most couples had even discussed it in advance strengthens the assertion warrant that their points of view are reasonably stable and hence reliable over time. Therefore, combined with the arguments above on external coherence, it is reasonable to claim that data are quite valid and reliable.

The selected informants have an average age of 56.4 years, which indicates that most of them have personally experienced changes of naming over time, and therefore describe modifications of terminology in a reliable way. Informants are not very biased with respect to educational level, occupation, gender, years of parenthood, and experience of boarding work within the NAPDD. This suggests a certain level of randomness which should add positively to the reliability. However, the total of 16 informants is far too low to do any statistical analyses to verify such representativeness.

## **Results and Discussions**

This section is divided into seven sub-points including a description of informant- demographics, and in sequence replies to research-questions 1, 2a, 2b, 3, 4 and 5.

### **Informant-demographics**

These variables are described in some detail as a help to other researchers to replicate a similar study.

The sample consisted of ten women and six men. Average age was 56.4 years, varying from 37 to 71 years. The average age was 59.8 years for men and 54.4 years for women. All informants had at least ten years' experience as parents of children with ID. The average was 25.8 years, with a range between 10 and 44 years. All the parent-informants' offspring with ID had either a moderate or mild condition. The relatively aged sample might suggest a strength, due to their long term experience of terminological changes, and thereby possible alertness to factors provoking alterations.

The informants had experience from the administrative boards of the NAPDD too. Since many of the informants were not able to remember accurately the number of years involved, it is not easy to state the average score of years. However, a cautious calculation indicates at least an average above 13 years. Four of the informants had participated in public committees of schools. These experiences might be essential since they have had extra opportunities to meet with parents of "normal" children, school-politicians and –officials and listen to their discourses on the naming of the diagnosis; as well as discuss it with them. Such opportunities most likely intensify the informants' awareness of the matter. In sum, informants' experiences are interpreted as suggesting weight to their statements.

Informants' level of education is divided in two major groups: Seven had 12 years or less while nine had 14 years or more. Five of the informants had occupational experience of health care work, four of technical work, three of trade, and the rest of various occupations. At the time of the interviews, about half of the informants had paid work while the others either were pensioners or were working at home without salary. Fourteen informants lived in urban municipalities (7,000 – 80,000) and two in rural. However, among the former, eleven lived in rural suburbs. This sample lacks people living in the biggest cities of Norway (more than 100,000 people). Most of the informants, 13 of 16, had been raised in the region of the research where they continue to work and live. The remaining three have lived there for more than 30 years. Subsequently, a reasonable conclusion is that the informants represent the Agder region well. However, the number of informants is low. Therefore one can hardly from this study alone deduce how demographic factors impact the findings.

**Sub-question 1: Which professional and demotic terms have the parents encountered?**

Concerning *professional terms* the informants stated that they had heard the following used (the figures in brackets indicate how many informants expressed this name):

(A) Those mostly in use years ago:

- a. Feeble minded (9)
- b. Mongoloid (8)
- c. Idiot (6)
- d. Mentally deficient (4)

(B) Those still in use:

- a. Mental developmental disability (9)
- b. Developmental disability (6)
- c. Mental retardation (6)
- d. Down's syndrome (6)
- e. Person with developmental disability/functional impairment (2)
- f. Cognitive developmental disability/deficiency (2)

Informants pointed to a variety of *demotic terms* like “mongo” (8); fool (3); “inhibited” (2); “PU” (an abbreviation of the Norwegian diagnostic name *psykisk utviklingshemmet*); halfwit (1). Some expressions refer more to group-tainted words like places where people with this diagnosis receive help: e.g. “house of madness”; “pupils at the pavilion”/“in the special educational class”; “those from the residence”. Most such words have their origin among people who mostly are at a distance from “carriers” of this diagnosis. However, the informants also reported demotic terms created among people with the diagnosis: “such like me” and “ups and downs”. Six informants expressed spontaneously that they dearly wanted a new term which actively focuses on developmental possibilities instead of limitations. Sadly enough, one stated this appraisal conclusion: “All terms have a negative appendix.”



### **Sub-question 2 a: Terms the informants use**

The mostly used terms are: Developmental disability/people with developmental disability (15); mental developmental disability (8); people with special needs/remedial actions (5). Other expressions mentioned are cognitive deficiency, dysfunctional shortfall, brain-feeble. Five informants also explained that the choice of terminology depends on who they talk to and the context. Some informants were still satisfied with the old name, *mental developmental disability*, and they had not observed the change of name in their own support organization. Still others regretted that the professionals had not noticed the name-change in the organization (which skips the word “mental”). It is remarkable that some parents emphasized the use of their child’s proper name instead of the diagnostic term. In sum, we find three major tendencies among the informants: (1) Those who were very concerned about the correct use of term, i.e. the name the NAPDD introduced in 1997; (2) those who are satisfied with the old expression still used by ICD10; and (3) those that at most prefer minimal use of the diagnostic term.

### **Sub-question 2b: Terms parents hear the professionals use**

The following terms were frequently reported: Mental developmental disability (13); developmental disability (7); and mental retardation/cognitive deficiency (4). Some informants had encountered the abbreviation “PU” used both by professionals and politicians, and it annoyed them because it spreads negative connotations among the public. On the other hand, some informants were satisfied with professionals who very consciously used the child’s proper name only. Some rather rare terms were also encountered: “Unspecified brain damage”, “only a bit slow” and “impressive language dysfunctions”.

The most conspicuous difference between informants’ own use of terms and the professionals’ ditto is that the former at most emphasizes the term “developmental disability” while the latter expressively remain faithful towards the ICD10:F70-79 designation “mental developmental disability”. This signalizes a discursive struggle on naming which might have deeper roots in belief in what facilitates and/or brakes positive development for the users personally and for the collective society around them.

### **Sub-question 3: Changes of terms experienced**

Three major changes were reported:

1. From *feeble-minded/deficient/idiot* to *mental developmental disability* (1970-97)
2. From *mental developmental disability* to *developmental disability* (after 1998)
3. From *developmental disability* to *person with need for assistance* (2005 →)

Particularly change 2 had been observed by many (13 informants), while 11 had noticed change 1. Only two informants had picked up change 3. In response to this question some informants told about painful experiences, and they

consequently asked for a term that reduced the first impression that this is an illness. Instead they wanted a term that underscored the positive and functional sides of their child.

#### **Sub-question 4: Explanations of name-change**

Table 1 shows both concrete examples of explanations offered by the informants, and how they are distributed among six (category 1, 2, 3, 5, 6 and 8) of the eight theoretical categories described by Bachke (2012). The two missing categories, no 4: *the tacit discourse among scientists*; and no 7: *changes of theories science and its methods* were not mentioned by the parents. This is not surprising since these reasons for changing terminology are more linked to professionals' conceptual worlds than to the users' and the general publics'.

The 67 explanatory statements are uneven distributed among the informants, varying from one to ten statements and with an average of four utterances per informant. This means that in some cases the same informant has stressed the same explanatory category more than once, using different words, but hinting at the same content of meaning. Such repetitions strengthen both the validity and reliability of these informants' explanations.

Two explanatory categories are highly rated by the informants: *Ethical training* and *users' influence* with 31.3 % (21) and 28.4 % (19) utterances respectively, and together they amount to 59.7 % of the total statements. Indeed, the dispersion of these categories among the 16 informants shows that only three had *not* referred to them. Since the responses of more than four out of five informants (= 81.3 %) were in these two categories it is most likely that they represent substantive explanations amongst the membership of Agder NADPP as to why the diagnostic terminology has changed.

Three other categories, *language matters, modes and trends* and *deeper societal and structural changes* were underscored by a little less than half of the informants, 6, 7 and 7 respectively. It means that neither of these reaches the stated criterion for substantiality. However, the strong support they attained shows that the informants, in spite of their strong support to the two major categories, appear open-minded towards other ways of explaining terminological changes. Of the two superior categories of explanations (A and B), it may be noted that 50 (74.6 %) of the statements belong to category A. The remaining 17 (25.4 %) belong to category B. The presence of both categories of explanatory statements among parent-informants adds support to Bachke's theoretical model (2012, see figure 1).

Table 1

**Examples and number of explicatory statements why terms change**

<b>Explanatory categories</b>	<b>Ns/Ni</b>	<b>Examples of parental statements</b>
<b>(1) Ethical training/de-stigmatization</b>	21/13	<ul style="list-style-type: none"> <li>• <i>Awakening and training require an alternative attitude</i></li> <li>• <i>Much has been accomplished by the school system</i></li> <li>• <i>It is screened in a different way..., more tolerable</i></li> <li>• <i>To look for something apposite, but not stigmatizing</i></li> <li>• <i>That terms somehow vitiate people</i></li> </ul>
<b>(2) Users' empowerment and influence</b>	19/13	<ul style="list-style-type: none"> <li>• <i>NAPDD has done an enormous job</i></li> <li>• <i>NAPDD's resolution has a share in changing this concept</i></li> <li>• <i>NAPDD tries to educate people's vocabulary usage</i></li> <li>• <i>It must be the next-of-kin who front a different way of naming/the parents push and sway the professionals</i></li> <li>• <i>The ID themselves have started to lower their feet</i></li> <li>• <i>Themselves, it is interesting what they name each other</i></li> <li>• <i>The ID themselves have become more aware</i></li> </ul>
<b>(3) Linguistic matters: Simplifying pronunciation and euphemism</b>	7/6	<ul style="list-style-type: none"> <li>• <i>ID is selected to simplify and to make it less particular</i></li> <li>• <i>It is easy to mix mental disorders and mental developmental disability</i></li> <li>• <i>It is important to use vocabulary correctly</i></li> <li>• <i>"Feeble-minded" is not a respectable word</i></li> </ul>
<b>(5) Media-influence</b>	3/3	<ul style="list-style-type: none"> <li>• <i>Media's role and influence</i></li> <li>• <i>Media have always been powerful</i></li> <li>• <i>Media have also... shown positive images of this group from time to time in various settings</i></li> </ul>
<b>(6) Modes and trends of ideological and value-connected significance</b>	8/7	<ul style="list-style-type: none"> <li>• <i>It has been more on the agenda</i></li> <li>• <i>The concept of human dignity is focused, and it forces terminological changes</i></li> <li>• <i>Movements and ideologies from abroad influence</i></li> </ul>
<b>(8) Deeper societal and structural changes</b>	9/8	<ul style="list-style-type: none"> <li>• <i>I believe that is caused by the huge reform from 1991/Certainly it has contributed</i></li> <li>• <i>It is a matter of fact that the whole society changes in how it tolerates diversity</i></li> <li>• <i>A societal change/it was that developmental element, yes</i></li> <li>• <i>Contributions from various instances</i></li> </ul>
<b>Total number of statements</b>	67/52	

*Ns = Number of statements uttered; Ni = Number of informants*

Proceeding the individual category and particular statements, it is observed that these parents are aware of the ethical discourse going on for some time (cf. *much has been accomplished by the school system*) and the stigmatizing effect of terms (cf. *terms somehow vitiate people*). De-stigmatization is also emphasized by the fact that some of the informants stress the general upgrading of human dignity, independently of individual resources and properties, as revealed in the statement: “*You are valuable independently of manners, intelligence and outlook.*” Another informant adds: “*Everyone has equal value.*” A relevant question is whether these two statements differentiate the category *ethical training*, or whether they open up a separate new explanatory category: *Increased value-alertness?*

Example-statements of the category *users’ influence* show that the informants are highly aware of the propelling power of the NAPDD in the naming development. Moreover, the three last examples accentuate that the people affected by ID themselves are more directly involved as advocates. This might also imply that the NADPP has become more conscious of engaging them within its own ranks, e.g. as board-members. If this is the case it ought to be easier for a researcher to interview them directly to attain their views on preferable terms. Such an approach will be a step towards materializing the slogan “*Nothing about Us without Us*”, which has been emphasized by some researchers during the last decade (Aspis, 2000; Nordic network of Disability Research, 2009; Atkinson & Walmsley, 2010).

Informants’ example-statements of the categories *language matters* and *media’s influence* emphasize the same points as found in the study of professionals’ example-explanations (Bachke, 2012). From the figures one observes that there is more awareness of the former (mentioned by 6 informants) than the latter (only 3).

The indirect explanations are more concrete in this study than in the interview-study with the professionals (Bachke, 2012). E.g. concepts like “focus”, “agenda” and “movements and ideologies” are connected to the category *modes and trends*; while concepts like “societal change”, “reform” and “developmental element” are linked to the category *deeper societal and structural changes*. Such concretizing at least adds concept-validity to the categories, and makes a more explicit foundation for when and how to divide into new essentially different categories. With these interpreted placements of utterances into a category it becomes easier to discuss with users, next-of-kin as well as professionals how valid and reasonable a category is. The research so far is not comprehensive enough to fix these explanatory categories as validated.

The collected data contains also some explanatory statements which are hard to accommodate in any of the eight categories; e.g.:

- (a) “I think of celebrities like Wenche Foss and Kåre Willoch<sup>2</sup>. They are such people who exude strength, which makes people look differently at ID. It makes a difference.”
- (b) “All the time we look for something that can make it more acceptable to be what you are.”
- (c) “Possibly it is because they have become noticeable publicly and appeared near to us in a different way than previously. It is easier to define people by use of such terms when we keep them at distance.”

Example (a) might be categorized as belonging to *media's influence* because both the named persons usually are offered space in the news. However, it is also an idea to create a new category *celebrities' influence*. A third alternative is to place (a) under the category *modes and trends* since popular people often become fashion-creators and trendsetters. Example (b) might be a variant of the *stigma*-category, resulting from the increased ethical awareness among users as well as professionals. But it might also signal a new category of *increased value-alertness*. The former part of (c) contains an allusion to the huge reform and thus be interpreted as belonging to the category *deeper structural changes*. The latter full statement refers more to how stigmatization can have a public impact and create an unwanted effect. A reasonable question is: Does this statement belong to the grey-zones of any of the eight categories, or does it imply a new category? These three utterances clearly show that there are statements which are hard to interpret within existing explicatory categories. Such uncertainties might in a smaller scale be linked to the categorizing work of table 1 as well, which means more category-validated research is still required.

#### **Sub-question 5: Substantive explanations of changes**

In the paragraphs under the headline sub-question 4 it was argued that the parent-informants pointed out two major explanations for why terms change: (1) due to increased focus on *ethical training and de-stigmatizing*, and (2) due to increased *users' influence*.

The fact that all in all 21 explicatory statements out of 67 refer to implications of *ethical training* adds power to this as a substantive explanation – not least because the same explanation was also strongly emphasized by the professional informants (Bachke, 2012). One might ask why ethical training and anti-stigmatizing attitudes have become so vital both among professionals in the sectors of educational, social and health care work, and at the same time aroused so much awareness within support-organizations like NAPDD? The answers might be many. However, it is likely that the heavy focus on human rights both nationally and internationally, since the declaration in 1948 has played an important role. Not least the work of United Nations ‘organizations by dedicating special years to certain sub-groups of the world’s population, seems to bear fruit. By such means human dignity is underscored for the whole of

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<sup>2</sup> Wenche Foss was a famous Norwegian actress; Kåre Willoch is a former Prime Minister of Norway

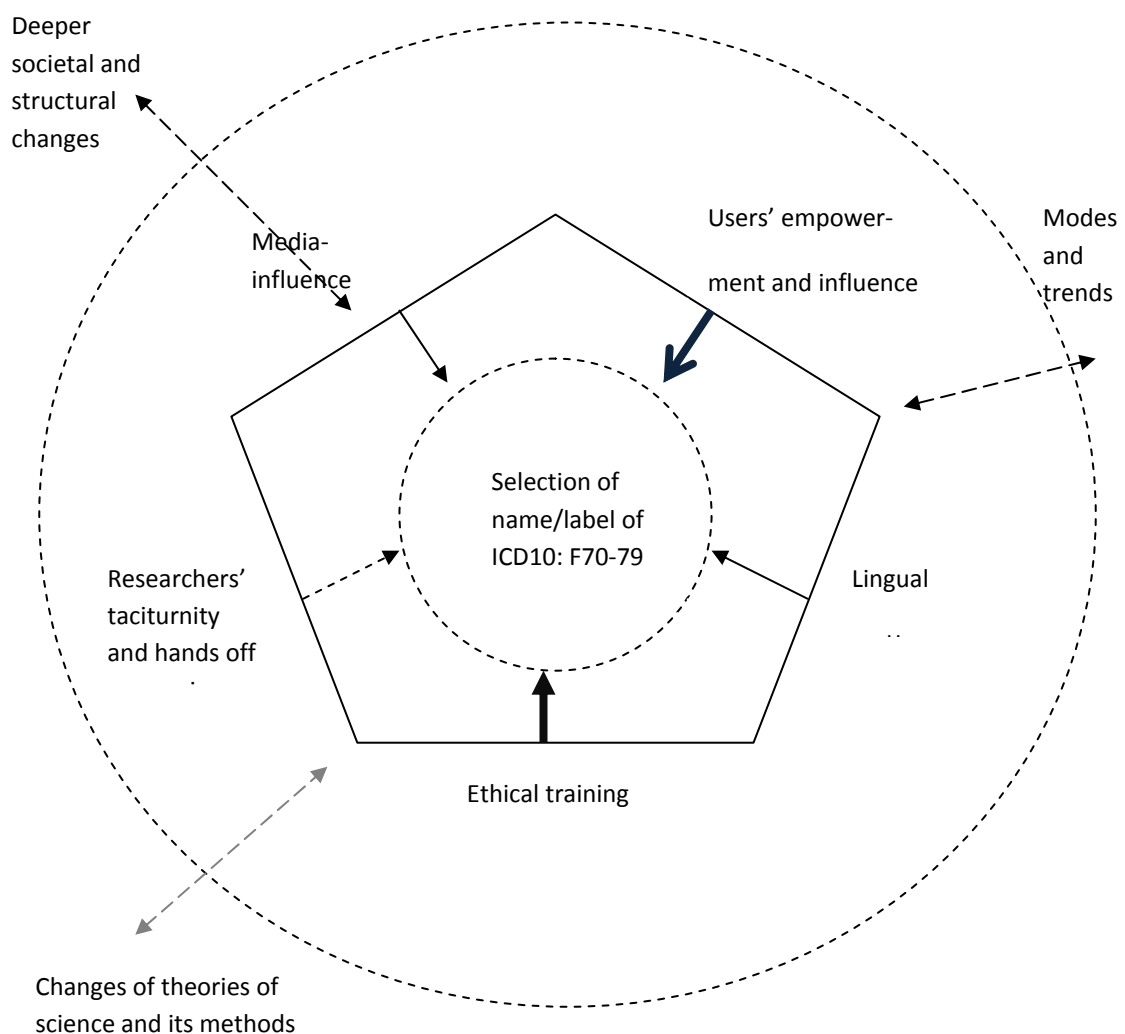
mankind regardless of skin-color, race, tribal belonging, cognitive equipment, physical resources, health conditions, socio-economic status and levels of education (Enns & Neufeldt 2003).

*Users' influence* is explicitly emphasized in the example-statements of table 1. Next-in-kin have done a tremendous work within the supporting NAPDD-organization by simplifying its name to *developmental disability*, which is more current than the old label which included the concept *mental*. In addition they have given more room to ID-affected members to stand up for themselves. Moreover, Bachke (2012) claimed that this explanation was present in dormant form also among the professional informants. It was highly scored by them (41 utterances after prompting). At that time it was hypothesized that this explanation would most likely collect much spontaneous support from users' and their relatives. This has been confirmed in the present study by 19 spontaneous utterances from 13 out of 16 informants. This proves that there are good reasons to contend that *users' influence* is also a substantive explanation. Why then is the users' voice more influential today than some decades ago? Most likely it is due to general wave of democratization flooding the society with a particular tide that also affects the expert-world of the health and helping-sectors.

However, one might still question its impact since some of these active NAPDD-members are unaware of their own organization's name-shift in 1998 and besides seem to care less about "correct" terming, cf. this utterance: "*I use only mental developmental disability, and the name does not matter so much.*" This utterance might be seen as an explicit attempt to bring old, negatively connoted concepts to the market, implying that society should be tolerant towards people who are "differently abled". Another informant went further, using the even older term *mongoloid* as an example: Those people "affected" with such a diagnosis should be taught to be proud of it and accept it as a title of honor. By speaking in this way these informants argue against term-changing at all, and do so by referring to some of the arguments emphasized by Shakespeare (2006). In spite of this partial division among the parent-informants, support for keeping *users' influence* as substantive explanation is strengthened through this study, because of its spontaneous support from 81.3 per cent of the informants, and because it is likely to be an expressed manifestation of democratic values in modern Western society.

The explanation *deeper societal and structural changes* was voiced nine times, reaching the very point of the criterion of being mentioned by half of the informants (= 8). Since this factor might be concretized as increased emphasis on the interrelated values of human dignity and democracy it adds power to two previously described explanations as substantive. However, since it was not spontaneously mentioned by many professional informants (Bachke, 2012), and since this study had only 16 informants, support for this factor alone as substantive is unconvincing. It is for the present safer to contend that the data

shows that parent-informants are highly aware of other explanatory discourses which jointly sway why a term changes – in addition to the two substantive. All in all, six of the explanations described by the professionals were pointed to by these parent-informants – without being directly mentioned to them. This fact seems supportive to the findings of Bachke 2012, and to his theoretical model. Based on this study, however, the model should be changed in two ways: (1) It should be given another thick arrow, from *users’ empowerment and influence* towards the center; and (2) the arrow from *researchers’ taciturnity and hands off on naming* should be weakened by dots instead of full line because it gained no support from parent-informants. The same weakening applies to *changes of theories of science and its methods*.



**Figure 1. The eight thematic discourses influencing naming of the diagnosis ICD10: F70-79 (sub- question 4). The three peripheral phenomena are seen as” bigger” discourses both affecting each other mutually and the five “smaller and closer” research-reported discourses. Arrows going both directions indicate a reciprocal influence. The two thicker arrows allude to substantial explanations (sub-question 5)**

## Conslusions

This study shows that parent-informants with offspring with ID have:

- (1) on a large scale encountered similar demotic and professional terms as seen in current literature
- (2) added some demotic terms, created by users; i.e. “*such like me*”, “*ups and downs*”
- (3) used the same terms as the professionals
- (4) expressed three different attitudes towards professional terms in use: (a) a strict following-up on NAPDD own selected term *developmental disability*; (b) a satisfaction with the present use of ICD-10 term *mental developmental disability*; and (c) a wish to generally avoid the use of diagnostic terms and instead use the persons’ proper name
- (5) revealed that there is an on-going discursive struggle between groups of professionals and members of NAPDD
- (6) experienced two major changes of naming: (a) from *feeble-minded/idiot* to *developmental mental disability* (ca.1970), and from the latter to *developmental disability* (after 1998). A third change is implied: From *developmental disability* to *person with needs of assistance* (around 2005). It is believed that this expression might further minimize the stigma of the ordinary diagnostic term
- (7) shown that they spontaneously validated six of the eight types of explanations established by Bachke (2012)
- (8) a deeper analysis of these causal statements indicated they insinuated two substantial explanations: (a) ethical training and (b) users’ influence

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