Research Paper

Administrating disability: The case of “assistance need” registration in Norwegian health and care governance

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Abstract

The use of quantitative measurement is a widespread method in public management to govern at distance. However, this governance may cause conflict, due to the statistics themselves. In Norway, measuring disability for governance purposes has created a controversy about the status of disability in health and care administration. The debated object is a concrete form of Norwegian health and care policy, a registration system called IPLOS. It measures assistance needs based on, among other criteria, functional disability levels. Authorities deem it a necessity for future planning and organization of municipal health and care services. However, organizations of and for the disabled hold that IPLOS communicates a discriminatory view on disability. They have used the controversy to confront authorities’ practical politics of disability, and to promote their own. In this article I explore the controversy surrounding IPLOS. I focus on the relationship between number and person that IPLOS requests, and the organizational and symbolic aspects of number production. Due to the importance such measurement tools are given, we need a further understanding of this article is the first publication of the author’s PhD dissertation. For readers’ correspondence, use the mailing address given above. The project is funded by the Norwegian Research Council. Thanks to my supervisor and head of project, Professor Ann Rudinow Saetnan, for support and comments. Thanks also to fellow PhD fellow, Nadji Aïssa Kheffif for translating the abstract to French. And last but not least, thanks to Professor Lars Mjøset, University of Oslo, for inspiring comments on statistics in their production context.

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what the concrete use of these statistics implies both for the counted disabled and for the public authorities’ way of managing disability.
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Résumé
Les statistiques sont aujourd’hui communément utilisées en gestion publique comme moyen de gouverner à distance. Cependant, il apparaît qu’elles peuvent aussi être la cause de l’échec de la gouvernance qu’elles rendent possible. En Norvège, leur introduction à la gestion des handicaps par le biais d’un nouveau système de registre appelé IPLOS a créé une controverse à propos du statut de ceux-ci dans l’administration des soins et de la santé. Alors que ce système, qui mesure le besoin d’assistance selon différents critères, est considéré par les autorités comme un outil nécessaire à la planification et à l’organisation future des services municipaux de soins et de santé, des associations de personnes handicapées le perçoivent quant à eux comme le véhicule de vues discriminatoires à l’égard du handicap. Dans cet article, j’explore la controverse qui s’est développée autour d’IPLOS, en me concentrant particulièrement sur la relation que ce système suppose, entre « personne » et « nombre », et les aspects symboliques et organisationnels de sa production. Compte tenu l’importance et l’attention donnée actuellement à ce type de système, il nous paraît essentiel de chercher à analyser les implications que l’utilisation concrète de ces statistiques peut avoir, tant pour les personnes handicapées comptées, que pour la manière dont les autorités publiques gèrent les handicaps.
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Mots clés : Handicap ; Statistiques ; Mesure ; Gestion ; Controverse

Background: a Norwegian conflict in a global context

“…in the quantification oriented society of today it seems a good citizen is a citizen who can be well counted, along numerous dimensions on demand. . .” (Bowker and Star, 2001, p. 423).

The use of large data sets and quantitative measurement is a widespread method to facilitate governance at a distance in public management. Technically, the use of this method generates a multiple repertoire of numerical information collecting tools, such as statistical registers, classification systems, and software programmes. Often, these work behind the easily recognized scenes in the fields that are measured. For instance, in Norway statistical registers are treated as ordinary technologies which the general public seldom questions, even actively accepts. The registers’ employees are often proud of the statistics and the (purported) knowledge they produce. On the basis of this trust, statistics are ascribed many different roles in public sector: to gain an overview of the given field, to monitor production levels and quality, to assess and plan budgets, as decision-making support amongst service providers, politicians, and the public; to orient the public on available services; and to report and archive service history.

From 2006 it became obligatory for Norwegian municipal health and care services to report what central authorities term “assistance needs” and “functional disability levels” of every person who applies for or receives assistance from these services. These reports shall be collected from below by health personnel with documentation duties, e.g. nurses and occupational therapists. The reports shall be structured and systematized according to a technical tool called IPLOS, which
is an acronym for “Individbasert pleie- og omsorgstatistikk”, or “statistics linked to individual needs for care”. The register was implemented top-down by the Norwegian Directorate of Health and is managed by the same Directorate today. The Directorate of Health (2008, p. 1) characterizes the significance of IPLOS as follows:

“The register shall constitute the basis for national and local statistics, research and analysis of the health and care service sector. (...) Better knowledge will be important to make correct welfare political decisions, and to meet the great challenges which the health and care sector confronts. IPLOS will therefore be an important tool in the planning and further development of the health and care sector both for the municipalities and the central authorities.”

However, in the Norwegian public sphere there is no consensus about this characterization. Rather, an intense controversy has developed surrounding the data register. Even though IPLOS concerns every Norwegian citizen – as we are all likely to need care services at some time in our lives – the controversy has mainly been led by organized representatives of the disabled, but also by specific individuals with function reduction(s) who have coloured the debate in personalized ways. Activists have refused to be counted and registered, and hence acted as “not so good citizens”. As mentioned, IPLOS concerns not only those society immediately recognizes as disabled, but every Norwegian citizen. Each person who applies for or receives assistance from municipal health and care services is to be registered in the IPLOS database. It functions as a general validating device (Stone, 1984), legitimating or restricting citizens’ access to services and influencing service providers’ budget composites. Locally, what IPLOS score a person is ascribed shall determine what health and care services (s)he needs and receives. At an aggregate level, IPLOS statistics can inform budgetary decisions through feedback processes as IPLOS shall reflect the actual needs and resource use of the health and care sector’s user group. In addition to supporting the planning and further development of the health and care sector, the Directorate of Health (2008, p. 7) has planned that the IPLOS register shall also give a basis for surveillance, quality assurance, and governing of both the sector services and the managerial level and generate research.

A significant and important situation for such statistics’ validity, and hence the validity of the practical politics which builds upon the numbers, is the registration moment. In theory the quantified data about the counted ones’ assistance needs are extracted from a cooperative and interactive consensus-making situation between the local IPLOS data reporter and the one to be reported. A core theme among participants in the controversy has been whether the promised cooperativeness and consensus behind the registration has been fulfilled. This is reflected in mass media where IPLOS has been attacked under headlines such as “Registered against her will” (Bladet Tromsø, 2007), “Feels insulted by handicap-statistics” (Bakke, 2008), “Intimate details in care register” (Bore, 2007), and “What number for soul pain?” (Harstad Tidende, 2007).

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1 My translation.

2 My translations. The resistance has been well coordinated. Simultaneously as the Directorate of Health published the first IPLOS statistics in 2008, several prominent organizations working for the disabled rejected its legitimacy, even though some of them had participated in the technical development of IPLOS carried out on an assignment from the Directorate. Following the publication the Collaborative Forum of Organizations for the Disabled (SAFO), the Norwegian Association of Pensioners (Pensjonistforbundet), the Norwegian Federation of Organisations of Disabled People (FFO), and the Norwegian Union of Municipal and General Employees (FAFO) delivered a collaborative press release. They informed that they rejected to participate in a meeting with the Directorate to receive an orientation about the publication due to “IPLOS’ humiliating content and design” (SAFO, 2008, p. 1). However, other organizations have also been active in the controversy, such as The Norwegian Association of Disabled (NHF) and ULOBA. The latter organization is a cooperative owned and run by disabled people according to the philosophy of independent living (ULOBA, 2008).
This controversy illustrates some challenges of counting disability for governance objectives. Statistical numbers gain autonomy and credibility through their alliances with science and its ideals of realism, objectivity and neutrality. If IPLOS statistics had not only been presented, but also been experienced as such, the controversy might never have emerged. Critics emphasized that:

- IPLOS does not validly measure “assistance needs” of applicants for and receivers of municipal health and care services (due to both inherent difficulties in measuring abstract “abilities” and to “distortions” inevitable to “high stakes” registrations);
- IPLOS registration is demeaning to those counted, robbing them of dignity and the right to self-definition and self-presentation;
- IPLOS is therefore not a serviceable tool for planning and further development of the health and care sector.

In this article I map the controversy surrounding IPLOS. The controversy’s tension level signals that behind its local and particular traits, there are aspects of general interest. I find that the conflict surrounding IPLOS statistics may be analytically divided into three thematic fields; the translation of person to number, the organization of the local setting which conditions the numbers produced within, and the symbolic aspect of what it means to be counted as related to the right to one’s own identity. These fields are intertwined, which illustrates the context dependency of numbers. However, the authorities’ use of statistics does not necessarily imply that they reject this characteristic.

The IPLOS controversy illustrates the interaction between two ways of knowing disability: one held by central authorities and one by representatives for disabled in Norway. More generally, IPLOS is an expression of what Walker (2007) denotes the evidence-for-policy wave, or in the words of Gray & Hood (2007, p. 89) “a visible tip of the formidable iceberg of quantitative performance measurement that has grown over the past quarter of a century and which is now a dominant feature of the seascape of public services management”. Through this management, numbers are given prominent roles as determination markers in the distribution of scarce resources in public sector. Because of numbers’ importance in health and care governance, it is important that researchers working with themes such as disability, age, health, and welfare have an understanding of the context of data such as IPLOS, both for what it can tell us about the situation of the counted ones and for how it can illuminate the processes by which governments utilize so-called objective evidence, official statistics (Abberley, 2008, p. 4) (on the importance of context, see Albrecht, Devlieger, and Hove (2007)), to organize the service apparatus.

**Method**

This article is based on in-depth qualitative interviews with representatives for organizations of and for disabled that have been active in the controversy surrounding IPLOS. Some of them had a functional reduction themselves and a personal rationale for their activism. My data also include verbal and textual presentations organization members have made in mass media and open meetings, and central authorities’ formal IPLOS documents as instruction guides and incentive reports. I have used a purposive snowball sampling strategy in the organizations to insure that the informants have had key positions in the interface between the organizations, the controversy, and the central authorities. This strategy was initiated by contacting persons presented as key communication representants for the organizations on their public web site. The interviewed
disabled persons were also working in the same organizations, and were suggested by either key representatives or other informants. They were interviewed first and foremost due to their position in the organization, and not to their disability. The disabled persons were administratively and functionally defined as disabled, as they received formal assistance in some way. Yet, they did not necessarily identify themselves subjectively in accordance with how the bureaucratic and professional apparatus did, even though their respective disabilities were related to impairment and associated with function limitations.

Organizations have entered the controversy at different times, and been involved in IPLOS in different ways. Some have left the controversy for a while to enter it again at some later point. Some have participated in the development of IPLOS while others have not. Hence, my informants represent multiple organizations, not all of which are otherwise mentioned in this article, nor are all organizations mentioned as parties to the conflict represented here with quotes from my interviews. I have chosen not to identify the organizations further to maintain the anonymity of my informants.

Obviously, the data I build my analysis on represent a point of view. They do not portray what IPLOS is in some objective sense, but how IPLOS is perceived by key actors (individuals and organizations) representing those who are IPLOS registered. Official documents on and from IPLOS give another point of view. I use both sources – interviews and documents – not to triangulate my way to an objective view, but to show that multiple views are possible.

First conflict: translating assistance need into numbers

Disability is a difficult social status to manage in an administrative system. All of us could be considered as disabled to some extent. Thus, categorizing someone as disabled involves deciding how far ability has to be impaired to constitute a disability (Lancet, 1999). Such decisions are not purely medical, but equally questions about politics, values, and welfare.

Through the controversy surrounding IPLOS, the disabled got the opportunity to put several important themes concerning their everyday life situation on the public agenda. What kind of (in)dependence do disabled people experience? How are their lives affected by welfare bureaucracy gate-keeping practices? What characterizes the relations between individuals with a function reduction, professional service providers and the welfare bureaucracy (a question also discussed by Helgøy, Ravneberg, and Solvang (2003))? Do we need another society to meet disabled as equal citizens, or can we build our society further upon the present welfare system structure? Through what mechanisms are persons disabled? Is IPLOS, and what it represents, such a mechanism? And what does IPLOS represent: power, politics, knowledge? From the central authorities’ perspective these questions are vital, but necessarily secondary to IPLOS’ main task: to solve challenges and problems of coordination, cooperation, and stabilization of the relationship(s) between health and care services internally in the municipalities, externally between municipalities, and between these local contexts and the central authorities’ political decision making forums. This aspect is neatly captured in a headline of the Directorate of Health’s (2008) IPLOS instruction guide: “Common understanding – Individual registration”. How can we create good welfare political decisions that contribute to the development of equal and effective services and simultaneously utilize the available resources well (Directorate of Health, 2008, p. 5), within a health and care sector that must manage individual needs with standardized tools built for the making of just distribution of

3 My translation from Norwegian.
scarce resources? How can we adjust a public service structure to satisfy individual needs and yet secure that a given individual assistance solution is universally independent of its’ geographical localization and formal decision makers? How can we integrate the sake of specific needs within a regime of equality? Each of these questions is important in its own right; however, one question seems implicitly central, or summational, to them all since our point of departure is a statistical tool, namely the question of validity: how can we translate a personal and individual-dependent situation of lived disability into numbers? Or, turning this around: what would such a number mean?

**Person–number: technical matters**

To create administrative categories that capture the complexity of lived experience in simple numbers is a pragmatic challenge. Simultaneously as the categories shall function as neutral technical tools, they also ascribe identity characteristics to the categorized ones. The designers must balance the question of representation with the need for information that the multiple system users request, and relate the categories to each other in a flexible network that satisfies every task the category system is delegated.

IPLOS’ core document is a registration form which for each registered individual becomes part of their patient record when filled-out. The main IPLOS categories are (Directorate for Health and Social Affairs, 2005):

- personal information and housing conditions;
- assessment by the relevant health professionals;
- functional disability level;
- diagnoses;
- health and social services received from local authorities;
- 24-hour care from non-local authority source.

Of these, it was the measurement of “functional disability level” which generated the first wave of criticism from the disabled. Critics focused on what indicators the Directorate found relevant to map the degree of functional disability level, how the indicator definitions were formulated, and how the measurement scale in itself portrayed disability. As of 2005, the two most controversial indicators in this section concerned eating and personal hygiene. After revision in 2007, debate moved towards issues of measurement more generally, with the old controversies still serving as rhetorical examples. The following are four examples from the revised list of 17 indicators (Directorate of Health, 2007, pp. 16–17, my translations):

- “social participation”: in need of assistance to strengthen and maintain a social network, have/take contact with family, friends, colleagues and persons in local environment;
- “decisions in daily life”: in need of assistance to make decisions and organize daily tasks, make choices between alternatives, plan the timing of tasks and integrate unexpected events;

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4 The reader must appreciate that the system is under revision. A debate concerns for instance whether IPLOS shall contain information on diagnosis or not. Some indicator definition formulations are also under revision, yet the same main indicator categories, for instance illustrated by example 1–4 above (“social participation”, “decisions in everyday life”, “maintain own health” and “move outdoors”) are taken to represent disability.
“maintain own health”: in need of assistance to manage own disease, injury or functional impairment, to take contact with treatment apparatus when symptoms or injury occurs, follow treatment schedule and manage own medication;

“move outdoors”: in need of assistance to move outside own residence, up and down stairs, curb stones, on uneven ground, etc. Outside own residence encompasses everything outside own entrance door, including outdoor stairways and thresholds.

In all 17 such sub-categories are taken to indicate a person’s status of function level and assistance need. Hence, they are treated as reference categories for disability. The categories are related to each other through an individual based average IPLOS score summarizing the 17 reported variable outcomes. The outcomes vary on a discrete measurement scale from 1 to 5 – ranging from “no assistance need” (1) to “total assistance need” (5). Values 1–2 are defined as not restricted in such a way that they can release a legitimate claim for public assistance. This implies that IPLOS employs three categories of administratively acknowledged disability (see Directorate of Health, 2007, p. 16, my translations):

- medium need of assistance: manages partly by oneself, but needs assistance to the remaining parts of the activity. Intermittent assistance may be adequate;
- large need of assistance: manages partly by oneself, but with assistant present throughout the activity. Assistant is present for guidance/adjustment/assistance;
- total need of assistance.

So, what is actually a functional disability level number 3? 4? 5? And where do these categories come from? In the current IPLOS documentation which health personnel receives as support material, the Directorate of Health does not explain their stories, but presents them as natural categories. Health personnel, who formalize the registration work, must to a large degree ascribe meaning themselves to the different disability levels. Yet, regardless of the organizations’ questioning of IPLOS statistics’ validity, according to the Directorate for Health and Social Affairs (2005), tests have shown that IPLOS makes it easy [emphasis added] to ascertain an applicant’s disability level and provide adequate personal records. Statistics Norway (Gabrielsen, Otnes, and Sundby, 2008) claims that IPLOS promotes the opportunity to quantify the number of receivers of one or several health and care services, measure the number of hours individual users of home services receive every week, and compare this in relation to variations in users’ assistance needs and household situations. These beliefs imply the assertion that the numeration work undertaken by the data reporters produces standardized measured outcomes. Meanwhile, an organization representative and IPLOS registered informant reflects:

“How can you fill out an IPLOS form? What is a 4 [emphasis added]? A 5? . . . What picture of the clients do the readers and users of the statistics read out of the scores and variables? ( . . . ) We are humans, not packages.”

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5 According to the Ministry of Social and Health Affairs (2000), during the initiate design phase the technical engineers of the functional disability categories and variables for assistance need were inspired from international systems as RAI (an information system which maps medical data, information about physical and psychical functional abilities and cognitive and social aspects of elderly patients or clients), ADL (“Activities of daily living”), and IADL (“Instrumental activities of daily living”). This design phase was carried out by a group working for the then Ministry of Social and Health Affairs. The working group consisted of representatives for the Ministry and other state agencies, municipal authorities, medical authorities, researchers . . . but not yet organizations of and for the disabled.
The filled-out IPLOS form represents a measure of a client’s assistance needs based upon a summarization of the client’s score on the variables of need of assistance – 1 to 5 – included in IPLOS. The persons who get to read the forms get to know the individual client as (s)he is presented through these scores. IPLOS statistics are in theory disconnected from the individual IPLOS registration forms through aggregation and pseudonymization. Yet, at a local level these forms circulate within the municipal’s health and care services and the management. At a national level registered persons have recognized themselves in the supposedly anonymous statistics due to their having rare combinations of physical reduction and social characteristics in their area. They have not always identified themselves with how they are represented, and have thereby questioned the relationship between number and person. This informant questions the standardization logic behind the belief in the numbers’ ability to accurately represent applicants’ for and receivers’ of health and care services assistance needs. She points to a fascinating aspect of numbers that they present themselves as objective and natural while at the same time opening up for what Becker (2007) terms data reporters’ and readers’ “interpretive possibilities”. According to the informant, packages could have been counted in this way, humans cannot. Implicit in her statement we find the belief that central authorities view disability as a physical terrain that can be easily mapped, given the right tool. Numbers are a key element of such a tool – self-determining and self-explanatory. Health professionals’ estimates are seen as valid; therefore, numbers produced by them are good enough to be used as facts. If they are treated statistically correctly they can function as ready-made, trustworthy representations of the counted ones and the activity of the local health and care services. We just have to find a way to count – IPLOS – which realistically rewrites disability into numbers for administrative purposes.

The authorities’ way of looking at numbers differs from the IPLOS critics’ on the basis of a different point of departure. This difference tailors the two agents’ way of reporting IPLOS in opposite directions. Consider organizations of and for the disabled and the central authorities looking at some IPLOS statistics tables. They both see the same objects in the world, they both direct their attention and their remarks at the same things (Bloor, 1991, p. 173, see his discussions of “facts”); but the Directorate (2008, p. 2) says: the numbers show that “disabled who only receive practical assistance have in average the lowest assistance need”, and the organizations say: “the numbers tell nothing yet”. Following the Directorate’s view the numbers can consequently and un-problematically be given a prominent role to “provide a basis for inter-service-coordination on providing services at an individual level, and give a fuller picture of the overall demand for services on which better planning decisions could be made” (Directorate for Health and Social Affairs, 2005). But, also the organizations’ view represents an underlying kind of representational realism in that they suggest numbers might be developed that could describe assistance need, if only the social dimension were inscribed into IPLOS. Since this dimension is put aside in the current IPLOS version, the numbers are not valid.

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6 In fact, the entire register is pseudonymized, since names and public register numbers (the Norwegian equivalent of US Social Security numbers) are replaced by an automatically generated random code.

7 The Directorate’s statement is taken from its first publication of IPLOS statistics which I referred to in the introduction of this article. Similarly, the second statement reflects some organizations’ view on the IPLOS statistics in general. In a newspaper the day after the Directorate’s release a representative for one of the involved organizations that refused to accept the legitimacy of this publication expressed (Bakke, 2008, my translation): “The statistics only concentrate on registered diagnoses and keep areas such as social participation outside the mapping. In many cases a nurse has filled out the IPLOS scheme in a hurry without even talking with the applicant. Therefore the statistics are useless.”
Telling about disability

What differs about the authorities’ and the critics’ view is their underlying concept of the functionally “below-average” man and how you get to know this man. As one organization representative reflected:

“[T]hey [Directorate of Health] are busy measuring people’s bodies... from an understanding that... with the underlying assumption, implicitly, that people cannot judge themselves. (...) they think disability is a body phenomenon. We think it is a social phenomenon.”

The representative repeats a re-repeated basic thesis in disability studies and activism, that disability is a consequence of particular social systems rather than essentially a property of individuals (Abberley, 2008). According to Albrecht et al. (2007) these practice fields have been paralyzed by disability model battles, with the medical and the social model representing perhaps the best-known opponents. Other examples are the rehabilitation model and the social barriers model of disability. We also find different definitions of disability underlying the different modelled disability understandings, as the functional, relative, administrative, subjective (Grönvik, 2007; Finkelstein, 1993; Loeb, Eide, and Mont, 2007) and so on. IPLOS shares the dominant feature of seeing disability as residing in the individual, with the implication that when administering disability services, disability gets defined in functional terms (Abberley, 2008, p. 4).

This is relatively clearly expressed in the IPLOS indicator definitions mentioned above. Take for instance the variable “move outdoors”. It promotes the individual as the one in need of assistance to adjust when moving outside own residence, not the outdoor surroundings in need of assistance to adjust to meet the disabled. This focus on the individual implies measuring the interaction between individual and environment with a focus on the individual. The material world is seen as a solid and ready-made surrounding while it is the individual who physically moves and adapts.

The two ways of claiming a relationship between number and person or number and disability seem to affect the criteria for causality employed when assessing the utility of IPLOS. An organization representative explained:

“A colleague of mine said... IPLOS, it is as if you wanted to explore whether primary school filled its purpose and you asked questions about what every pupil weighed. And then you would have found out a lot about average weight and perhaps something about height and distribution of gender...”

However, you would not have found anything about how weight corresponded to learning. Or how assistance needs correspond to the overall situation of the disabled. But, who is right? Becker (2007, p. 285) says there is no best way to tell a story about society. Instead of ideal ways to do it, the world gives us possibilities among which we choose; every way of telling about society does some of the job superbly but other parts not so well. Hence, the question of how we can translate a personal and individual-dependent situation of lived disability into numbers depends on our purpose (Grönvik, 2007, see also Loeb et al., 2007 and their discussion of how reported disability prevalence rates are dependent both on the definition or aspect of disability being targeted and on the intended purpose for collecting disability statistics). Practicing quantification, the choice of disability definition has direct implications for the operationalization; management and interpretation of the overall question of how one translates one social category into another.

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8 A parallel to the French statistician Quetelet’s concept of “l’homme moyen” or the average man (Davis, 1997).
While central authorities claim that IPLOS gives fruitful information suited for their governance purposes, critics among the disabled refuse to see any value in measurements such as IPLOS, or they support the more moderate critique that IPLOS asks the wrong questions. However, in practice neither the authorities nor the organizations present “the true story” about IPLOS. Rather, IPLOS clashes into a public form based upon their dispute. Depending on context, the numbers mean both neutral – but political – tools for administratively understanding match and movement between person and social organization and tools for individualizing disability in less constructive ways. In the next sections I elaborate on the organizational context’s significance for the numbers’ relation to the individual representations in IPLOS and the numbers’ symbolical presentations of disability.

Second conflict: collecting numbers from an organizational context

The context-specificity of numbers in health and care management seems to be an inbuilt characteristic of official social statistics. This is a function of them being used by the state to distinguish between those who legitimately claim assistance and those who do not. The simple distinction between those unable and those unwilling to work, the deserving and the undeserving poor, has, with increased sophistication in the division of labour, similarly become more refined, with new definitions, based on clinical or functional criteria, being employed (Stone, 1984; see also Abberley, 2008, p. 4). This refinement practice is materially visible through IPLOS; the system makes visible categorizations and characterizations that may well have been tacitly at work all along. Or, as an interviewed IPLOS registered organization representative uttered, “Is this the way they look at us, the disabled.” However, distinction technologies such as IPLOS are not necessarily real pictures of actual practice. Or, that depends on what statistics user we listen to.

The practical act of deciding how numbers can represent individuals entails different views on ability, disability, and inability. It also involves different approaches to what problems statistical data such as IPLOS may cover and promote valid and reliable answers to. A Norwegian person’s claim about his right to, or at least need for, assistance is now dependent upon his IPLOS score. But, why is the boundary drawn between 2 and 3? Why are functional disability level 2 and 3 defined as they are? The outcome of applications for assistance is partly designed in the first place by central authorities’ accreditation of the functional disability levels’ definitions as they appear in the current IPLOS version. Abberley (2008) and Bowker and Star (1999) point out that categorizations are not banal matters; they are highly political, at least in their implications. If it is not a conscious political decision in itself to define and demarcate groups of people into such categories, it does at least have organizational consequences.

IPLOS data are collected in an organizational context which conditions the number production in ways central authorities cannot control directly, neither through IPLOS’ design nor through the numbers themselves. In traditional ethnomethodology and social phenomenology it has been held that official statistics are assembled by bureaucratic apparatuses which process the initial observers’ reports through a whole series of modifications and transformations to produce the final tabulated results (Hindess, 1973, pp. 10–11). Transformations that take place during these series, which affect the ascription of number to person, are often hidden behind the numbers themselves. As one kind of report on society, numbers are, in Becker’s (2007) terms, “frozen remains of collective action”. The remains have direct consequences for the counted ones through being used in calculations of assistance volume. But they also have consequences for the numbers themselves as they are further treated through feedback processes directed from authorities towards the services which produce them in the first place.
In the IPLOS case, expressions of these transformations became visible through disabled refusing to subjectively accept the functional disability levels they were ascribed. Krokan (2008, p. 1), a woman with a function reduction, described her personal experience of IPLOS registration to the Norwegian Privacy Protection Commission (PVK) in a lecture about IPLOS on 19 May 2008:

“I had planned to show you my own IPLOS registration, but I did not find it. There it says – I had not participated in the registration, and I did not know that it was done before I called the municipality and asked – there it says that I had scored a bit low on ‘indoors movement’ – something I had absolutely no problem with – but ‘outdoors’ went ok: I had an electric wheelchair, it said. I have used a manual wheelchair for forty years, but I have never owned a motorized one. I also had a low score on ‘takes care of own health’, that I am totally unfamiliar with, and I don’t know who else takes care of my health.”

Why would someone register this woman with a lower level of functional disability in IPLOS than she experienced herself? And why did they combine this low score on “takes care of own health” and “indoors movement” with wrong information about wheelchair type? It could have been a coincidence or a mistake. Many municipalities did not follow central authorities’ instructions for how they should collect, register and report IPLOS data. Data reporters are instructed to register the applicant or receiver on the basis of a face-to-face conversation between them where the reporter maps applicant’s or receivers’ functional disability level in accordance with the IPLOS indicators. That some municipalities neglected to follow this specific instruction frustrated and provoked both the disabled and the organizations for disabled people.

“You cannot map someone’s assistance need without actually asking them! Today one maps people’s assistance needs without seeing them!” (Informant, organization representative).

While some municipalities did correctly follow the instructions for IPLOS registration, others ignored them as in the case mentioned above. They apparently viewed IPLOS as not concerning the registered individual at all. This may also represent a way municipalities perform opposition to IPLOS, i.e. by not obeying their “users”, be they the State or the municipal service clients. Some municipal service providers transformed the registration opportunity into practical politics. Krokan (2008, p. 1), the woman who spoke to PVK, uttered the following hypothesis:

“I suspect it is a general phenomenon that the receiver of services has a greater assistance need in the register than what one actually receives services according to! Funny: When I apply for a service I have to blow up my problems and mostly magnify them, to get the services I need. Because none get what they apply for – that is common knowledge. This is a part of the game. And through IPLOS one has set up to the same kind of game between municipality and state: exaggerate your needs to get what you require”.

Another IPLOS registered organization representative reflected upon the same drama:

“Measurement of services is not a new phenomenon, or the struggle to receive what you need. I remember a girl who absolutely wanted me to admit that I could butter my slice of bread by myself. And I gave a flat refusal, because I knew that then I would lose at least five hours of personal assistance at once. (…) I know how the system works so I knew why

9 My translation.
10 My translation.
she pestered me for that. But others have probably been caught in that trap, and receive less assistance than they need because of that.”

There is a budget-generated game at below\(^{11}\) in the health and care services. Beneath the surface of documentation we find a network of actors working to find a best way to present disability and assistance need in each case. What is “best” may differ from situation to situation due to local conditions, and from recorder to recorder due to values. Service providers, such as home-help nurses who often register with IPLOS, play a gate-keeping role in the welfare system (Helgøy et al., 2003, p. 482). In Krokan’s and the other informants’ view this strategical negotiation course with providers is well known among disabled people enrolled in the health and care service apparatus. They present it as a necessary (if absurd) ploy for the disabled to receive needed assistance.

Ironically, critics of this aspect of IPLOS – the “inaccuracies” created through a context of exaggeration for negotiation purposes – regard it as something both worthy of criticism and at the same time ordinary and acceptable, even necessary or useful. They wave a rhetorical fist against being portrayed as more helpless than they actually are; yet, by their own admission, it is not only a disadvantage for the counted ones or the local health personnel. It may create a situation where service users are described more systematically in ways that does not correspond well with their situation. At the same time this situation may become easier for them to manage since it gets documented in (exaggerated) detail. Achieving a lower function disability level score in IPLOS than needed makes it “objectively” necessary for the local officials in charge to provide more assistance to the disabled person than they otherwise might have done. Aggregated, such a registration practice also affects the economic and managerial feedback from central authorities to the local services.

What is at stake may be covered by two questions: how much dignity resides in the numbers, and to what degree must users of public services give up control of their self presentation in health and care documentation to get assistance? First, if IPLOS continues the budget related battle at below, IPLOS may be experienced as a public enactment of negative tensions and episodes the disabled have experienced before when confronted with organizational health assistance measurement practices. As one interviewed IPLOS registered representative uttered, “IPLOS was the final straw”. Second, both disabled and service provider might have power in the relationship between the disabled and his or her ascribed numbers; yet, this relationship is weakest for the disabled that most need it (Helgøy et al., 2003, p. 482). The service provider controls and registers the final numbers that get reported into the formal documentation system, while it is the disabled who relies on the assistance provision outcome based on those numbers.

IPLOS implies that one’s registered numbers are stored with an unlimited time aspect. Since they are used in official publications of the status of the health and care sector they never cease to exist; once frozen, they remain always outside the disabled person’s reach, ready to be redefined to fit new purposes in the public sphere without the consent of the counted one. They are no longer only the sole property of the disabled but have become public property through IPLOS statistics publications in easily accessible forums such as mass media. When published, the statistics are to be rendered anonymous, but they may not always be experienced as such by the counted one since (s)he knows that the numbers presented are in some way still connected to her/his being. Furthermore, breakdowns of aggregated data into small geographical sectors may expose

\(^{11}\) "At below¨is a neologism. It is meant to include both “from below¨, as when grassroots level actors exercise agency, and “bottom down¨, as when control is exercised from above and its effects are experienced at the grassroots level.

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individuals to identification through rare category values, e.g. rare diagnoses, disabilities, service provisions, or combinations of such categories.

Third conflict: stigmatizing (?) disability by numbers

We are surrounded by numbers. We take them with us into our most private sphere. According to Davis (1997) there is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated. At a general level, citizens are used to thinking about themselves as one waiting in a line, or as one citizen among millions, or as one citizen–one vote. However, we seldom think of ourselves as numerical objects per se, and we are more sensitive about accepting the intrusion of numbers into some areas of daily life than others. Our reactions to being enumerated are situationally conditioned, since measurement means different things dependent on context.

The disabled hesitated to be counted and registered in IPLOS. As we have seen, central authorities presented and defended the relationship between number and person as neutral, natural, and objective – in marked contrast to how disabled experienced the situation of being registered. Perhaps it was this contrast that strengthened their feeling of being humiliated through numbers. Numbers are namely less concrete symbols than what the authorities expect them to be. The question is – as Abberley (2008) points out as often begged in discussions of data – should it be gathered at all? Principally, what does it mean to be counted, when others are not? When is quantification a common good and when does it become stigmatizing in its effects?

Interpreting numbers’ source

The combination of numbers, registration and disability gives an aftertaste due to the social history of disability. It partly pre-arranges for a critical interpretation of IPLOS as a straightjacket which mercilessly strips one of equal citizenship:

“[I]t is crystal clear. It would have been very practical for Hitler to have such a system when he picked out the disabled in Germany during Second World War.” (IPLOS registered organization representative).

“Hadamar . . . [German Nazi concentration camp] . . . they came in with urinary infection and then they were killed. It was said that they died of the infection. But they were killed because of . . . bodily aberrations from the strong . . . posters hang around there with propaganda . . . if you get one like that it will cost so and so much for you, right, then you had to pay for a child to . . . he couldn’t work right and was dependent upon the public. IPLOS is not there, but it deals with . . . when calculations and punctuations of that and that . . . really we are too expensive to live at all.” (IPLOS registered organization representative).

The gathering of data on disabled people in Nazi Germany was inextricably connected with the state’s project of genocide; today, registration of groups of citizens is undertaken at a regular basis in less extreme situations in Western countries (Abberley, 2008). The relevance of this comparison is weak because of the two totally different objectives. Through comparisons like this the activists demarcate themselves from non-disabled, when they might have used the situation to promote an understanding of themselves being as average as non-disabled citizens and hence as natural allies with citizens in general on equal terms. Instead they rhetorically marked themselves as a marginalized group. Also “non-disabled” citizens may be registered in IPLOS, if they for instance apply for a safety alarm, a requisite which hardly qualifies for the common-sense term “disabled”.

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The reference of the organized disabled to Holocaust was a rhetorical strategy in the debate. The point is not that disabled necessarily experience their situation as oppressed to the point of being life-threatened. Perhaps some individuals do, and of course their opinion matters too, but it cannot be generalized to the whole population. Rather, this reference illustrates that the problem with a registration being undertaken depends upon the registered one’s interpretation of its source – in this case the disabled person’s recognition of disadvantages, stigmas, and or pointlessness to her/himself of being registered – as underscored by Abberley (2008, p. 5) in the case of the 1978 Disabled Person’s Employment Register in Britain. It is the agent behind the numbers and the functions they fulfil which affect our experience of being counted. In the case of IPLOS we find a (at least in theory) powerful agent – the Norwegian State – with the opportunity to directly affect your daily life. Just by being registered – independent of registration system – the registering agent has made a difference in the registered one’s everyday life, regardless of whether the registered person is aware of the registration or not. The person becomes a counted person. Numbers are not the straightforward objects central authorities presume, and they never get de-connected from the counted individual.

Dependence through silence

Numbers symbolize and may enforce identities and group affiliations upon the counted ones. Being ascribed a 3 means, in any formal case, something very different than a 4. When the different numbers qualify for different rights simultaneously, as you must accept characteristics of you which the numbers bring with them to get the rights you need, the numbers may in their nature seem incapable of neutrality. This incapability is not necessarily a negative one. It depends upon what other population groups you are categorized with, and whether you experience this categorization as beneficial in some way; a personal evaluation that may seem cynical on behalf of those one marks distance from. An IPLOS registered organization representative reflected upon what target group the IPLOS indicator formulations seemed to be defined for:

“I think… without knowing for sure… that they have thought about strongly intellectual function reductions, or mentally retarded as they were named earlier, or the dement. I think they have had that group in mind. And that that is a group who lives inside their four house walls, and are by definition patients. That’s what the questions look like. And I don’t think one should evaluate someone with dementia or mental retardation like that either. And how comatose are you if you think it doesn’t create reactions?” (IPLOS registered organization representative).

Why should it create reactions? The informant interpreted IPLOS as an identification marker that grouped her into the same category as seriously needy and underprivileged individuals – individuals she defines as patients – a term she resists using to refer to herself. But, what is problematic about being in the same referential room as someone with dementia? The social democratic model of the Norwegian welfare state is characterized by a comprehensive state, strong citizens’ rights and universal welfare arrangements (Helgøy et al., 2003). A significant amount of the costs generated by the health system are shared by society through individually based public tax payments. The system is decentralized and recognized as a significant important part of a totality meant to level Norwegians’ playing field. Every citizen is to meet the same demands and share the same rights. On this background the expectation of the Norwegian authorities that IPLOS would glide unproblematically into measurement practice reflects the silent contract between state, soci-
ety and individual citizens that we shall not receive special treatment compared to others in the same situation, here broadly restricted to the category “citizens with an assistance need” in the public apparatus due to individual characteristics. In this way, IPLOS numbers might be seen as symbolizing equality. However, the informant’s resistance reflects a wish of being seen and treated as an independent citizen even though she receives public assistance to function in every day life. According to Helgøy et al. (2003, p. 483) independence is an underlying ideal among disabled people, a logical consequence being that the best way of living for disabled people is to manage with as little practical help as possible. The informant’s identification of IPLOS as representing patients rather than citizens implies the presumption that patients and citizens invoke different associations. When a “citizen” receives practical assistance it represents a kind of social assistance and the invocation of a universally shared right. When a “patient” receives assistance it represents a medically oriented assistance given on unequal terms, unequal because the patient is restricted in her or his way of living which the assistance cannot equate. In spite of assistance, a dement person will not function as she or he did before the dementia due to memory loss, while ideally, assistance should render a physically function-reduced person able to function as “the average man”.

My interpretation of disabled people’s situationally conditioned distancing through IPLOS criticism, from all physical and psychological conditions they experience as dependent upon medical intervention, is also based on their reactions to the overall silence initially surrounding IPLOS:

“I discovered IPLOS last year by a coincidence [see * below]. A colleague mentioned it. Suddenly someone dropped by with the IPLOS manual. And we read it and we were totally shocked about the questions. (…) In the beginning I didn’t react for myself, I just reacted to the questions. I thought, poor people, they cannot treat people that way. Right? And after a while, what?? Me, registered?? I sent some e-mails to my officer in charge in the municipality and did not hear back from her. I wondered whether I was IPLOS-registered. Usually she is quick to answer. That smelled like bad conscience. I understood that she wouldn’t answer my question [see ** below].” (IPLOS registered organization representative).

Silence has different functions. In this case the first phase of silence (*) was a bi-product of the authorities’ presumption that the relationship between person and number was unilateral and unproblematic, hence they acted as if IPLOS was just one of many other statistical technologies. We seldom care about these technologies; they just exist and we meet them in certain occasions. IPLOS was statistics only. The second phase of silence (**) is a bit more complicated. It is both a product of the authorities’ way of knowing the relation between person and number and the municipalities’ way of organizing IPLOS registration, and also the municipal representative’s individual ways of managing face to face – or in this case, mail to mail – interaction. Taken together, these two silences interacted to create the sense of an iron cage, robbing the individual of control and enforcing an unwanted dependence. Another organization representative gave the following situation description:

“In one municipality I know for instance, they summoned everyone, their whole staff, and they sat during one day. And they probably ate cookies. And they IPLOS registered everyone during that day.”

What we can see from these quotes is that silences “speak”. Those who notice them, who feel affected by them, fill them with meaning(s). Here the IPLOS registered have ascribed meanings such as oppression, guilt, and exclusion to the silences that signalled IPLOS’ implementation.
Disabled have perceived the method of uninformed registration as humiliating, de-humanizing, and disenfranchising. The absence of information and participation symbolized for them a devaluation of them as a population group and a public statement of their being dependent beings ready to be managed by the population’s remaining independent beings. As Finkelstein (1993, p. 34) says, there may be something profoundly undemocratic about able-bodied people constructing and systematically counting, scoring, and registering “not so able-bodied” people, even though the objective is good. The contrast in the representative’s statement of officials in charge peacefully eating cosy cookies – while they perform a ritual that for him represents a devaluation of the registered ones as citizens and an evaluation of them as packages of meat to be managed independent of their free will and subjective life situation – is an allusion to the history of disability registration during Second World War mentioned above. But, more interestingly, it underscores the fascinating contrast between IPLOS statistics being given a significant important role for the future health and care policy and at the same time being manufactured during a deafening silence from the administrative apparatus’ side. Following the representative’s side of the story, what does this symbolize for the disabled if not the kind of everyday discrimination which, through it being performed in naturalized and unspectacular ways, repeats the stigma of disability understood for them as undesirable otherness? Yet, symmetrically, the practice also symbolizes the insignificance of being registered. If the representative had subjectively felt himself as an equal citizen, he could have come to support this latter side of the story instead. This arouses the ever-present actuality of the well-known Thomas theorem: if one defines situations as real, they are real in their consequences. Or, as in this case, if we treat ourselves as equal citizen beings, we may all the faster become equal in our way of living the society.

Conclusions

The underlying way of knowing disability in Norwegian health and care governance, in the degree the IPLOS case can be generalized, reflects the strong position of the administrative bureaucracy. This is not a unique situation of the Norwegian welfare system. Recent politics in UK have been a simultaneous call for citizenship and participation and for a strengthening of administrative power; on the one hand, attention to the individual and his or her needs, beliefs and desires, but on the other for decision-making over individuals by experts (Walker, 2007), e.g. by researchers such as statisticians, economists and political scientists, and management leadership – a description which also pertains to Norway. This seems to create a milieu where products such as IPLOS are seen as necessities for governance. As Gray & Hood (2007, p. 89) write, “Huge amounts of public service activity and expenditure require for effective governance a valid, reliable and timely method of measurement.” That is, statistics. But, are they necessities? Measurement means different things and may be done in many different ways – something the Norwegian measurement of functional disability level and assistance need is a timely illustrative example of.

The IPLOS controversy displayed the organizations of and for disabled people’s problem with the interface between political will and bureaucratic outcome (Walker, 2007), as well as what themes they are oriented towards in their politics of disability. According to Oliver (1987, p. 46) this Western emerging politics has been based upon three distinct elements; a critique of existing services, a re-definition of the problem and an attempt to create alternative service structures controlled by disabled people themselves. The involved Norwegian organizations controlled by disabled and or for the disabled people brought at least the first two of these themes into the
controversy surrounding IPLOS, at least in its back rooms, through:

- criticising the existent Norwegian health care system of being controlled by administrative and professional power dependent upon displaying disability as residing in the individual;
- attempts to reformulate the administrative and functional view of disability written into IPLOS following a social perspective on disability, trying to turn the problem focus away from what is “wrong” with the individual to what the individual needs assistance with.

However, the resistance against IPLOS by the disabled works in some manner against their banner. The critique of the existing services embedded in the newly emerging politics of disability concerns for instance the lack of uniformity in levels and standards of provision at both a local and a national level: services vary from one geographical area to another, access to financial benefits can often vary as well, and the structure of services is so complex and complicated that it is difficult for individuals (including individual service administrators) to know precisely what their entitlements are and to understand the service apparatus in its totality (Oliver, 1987, p. 46). One of the central objectives with IPLOS is to correct this situation; set standards for provision of services both in and between the municipalities, and clean up the decision procedures and processes surrounding service applications. In other words, IPLOS could also be seen as an ally for disabled in need of public assistance. As we have seen, IPLOS made the status of their disability, as presented and fronted in local assistance needs measurement processes, visible. The organizations of and for the disabled found a common reason to collaborate in promoting their perspective(s) on disability to both the public and the authorities. Users of the health and care services may at every point in time use the IPLOS numbers to represent their case in situations where they cannot physically be present or able to raise their voice themselves. But first they must acknowledge how they use IPLOS numbers as spokespersons in ways which benefit their case and which they experience that they control. IPLOS does represent power, politics, and also knowledge, but the tables may yet be turned as to whose power, politics and knowledge are represented. Official statistics give internalist accounts of what and who they count and measure, and as political instruments they impose that interpretation on the social world (Bowker, 1992, p. 53), however it is not a given fact that IPLOS only functions fruitfully on the authorities’ terms. It is their way of translating lived disability into numbers that IPLOS works according to, but what this translation means is in practice a symmetrical question.

Perhaps is it the numbers’ symbolical aspect that represents the greatest barrier for the disabled to achieve a feeling of ownership to their numbers. Perhaps such ownership is a feeling not to be longed for? Disabled people are increasingly conceptualizing their lives in political terms and in this context no conceptualization of disability can be seen as “neutral” (Abberley, 2008, p. 19). By maintaining IPLOS as a controversial object they have a tool through which to promote their politics. At the same time, the state – seemingly unperturbed by the controversy – produces the decision-making material it wants and needs to plan and further develop the Norwegian health and care sector. It seems an uncomfortable detente, ripe for change one way or another.

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