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ALTER, European Journal of Disability
Research xxx (2009) xxx–xxx

Alter

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Research Paper

1 Administrating disability: The case of
2 “assistance need” registration in Norwegian
3 health and care governance[☆]

4 Administrer le handicap : le cas de la mesure
5 du « besoin d’assistance » dans la politique
6 norvégienne du handicap

Gunhild Tøndel



7 *Department of Sociology and Political Science, Norwegian University of Science and Technology,*
8 *7491 Trondheim, Norway*

Received 17 July 2008; accepted 9 November 2008

9
10 **Abstract**

11 The use of quantitative measurement is a widespread method in public management to govern at distance.
12 However, this governance may cause conflict, due to the statistics themselves. In Norway, measuring dis-
13 ability for governance purposes has created a controversy about the status of disability in health and care
14 administration. The debated object is a concrete form of Norwegian health and care policy, a registration
15 system called IPLOS. It measures assistance needs based on, among other criteria, functional disability
16 levels. Authorities deem it a necessity for future planning and organization of municipal health and care
17 services. However, organizations of and for the disabled hold that IPLOS communicates a discriminatory
18 view on disability. They have used the controversy to confront authorities’ practical politics of disability, and
19 to promote their own. In this article I explore the controversy surrounding IPLOS. I focus on the relationship
20 between number and person that IPLOS requests, and the organizational and symbolic aspects of number
21 production. Due to the importance such measurement tools are given, we need a further understanding of



Q1 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
Khefif 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.

E-mail address: Gunhild.Tondel@svt.ntnu.no.

1875-0672/\$ – see front matter © 2008 Published by Elsevier Masson SAS on behalf of Association ALTER.
doi:10.1016/j.alter.2008.11.001

Please cite this article in press as: Tøndel, G. Administrating disability: The case of “assistance need”
registration in Norwegian health and care governance. *ALTER, European Journal of Disability Research*
(2009), doi:10.1016/j.alter.2008.11.001

22 what the concrete use of these statistics implies both for the counted disabled and for the public authorities’
23 way of managing disability.

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25 **Résumé**

26 Les statistiques sont aujourd’hui communément utilisées en gestion publique comme moyen de gouverner
27 à distance. Cependant, il apparaît qu’elles peuvent aussi être la cause de l’échec de la gouvernance qu’elles
28 rendent possible. En Norvège, leur introduction à la gestion des handicaps par le biais d’un nouveau système
29 de registre appelé IPLOS a créé une controverse à propos du statut de ceux-ci dans l’administration des
30 soins et de la santé. Alors que ce système, qui mesure le besoin d’assistance selon différents critères, est
31 considéré par les autorités comme un outil nécessaire à la planification et à l’organisation future des services
32 municipaux de soins et de santé, des associations de personnes handicapées le perçoivent quant à eux comme
33 le véhicule de vues discriminatoires à l’égard du handicap. Dans cet article, j’explore la controverse qui s’est
34 développée autour d’IPLOS, en me concentrant particulièrement sur la relation que ce système suppose,
35 entre « personne » et « nombre », et les aspects symboliques et organisationnels de sa production. Compte
36 tenu l’importance et l’attention donnée actuellement à ce type de système, il nous paraît essentiel de chercher
37 à analyser les implications que l’utilisation concrète de ces statistiques peut avoir, tant pour les personnes
38 handicapées comptées, que pour la manière dont les autorités publiques gèrent les handicaps.

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40 *Keywords:* Disability; Statistics; Measurement; Management; Controversy

41 *Mots clés :* Handicap ; Statistiques ; Mesure ; Gestion ; Controverse

43 **Background: a Norwegian conflict in a global context**

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

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

58 From 2006 it became obligatory for Norwegian municipal health and care services to report
59 what central authorities term “assistance needs” and “functional disability levels” of every person
60 who applies for or receives assistance from these services. These reports shall be collected from
61 below by health personnel with documentation duties, e.g. nurses and occupational therapists. The
62 reports shall be structured and systematized according to a technical tool called IPLOS, which

63 is an acronym for “Individbasert pleie- og omsorgsstatistikk”, or “statistics linked to individual
64 needs for care”. The register was implemented top-down by the Norwegian Directorate of Health
65 and is managed by the same Directorate today. The Directorate of Health (2008, p. 1) characterizes
66 the significance of IPLOS as follows:

67 “The register shall constitute the basis for national and local statistics, research and analysis
68 of the health and care service sector. (. . .) Better knowledge will be important to make correct
69 welfare political decisions, and to meet the great challenges which the health and care sector
70 confronts. IPLOS will therefore be an important tool in the planning and further development
71 of the health and care sector both for the municipalities and the central authorities.”¹

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

89 A significant and important situation for such statistics’ validity, and hence the validity of
90 the practical politics which builds upon the numbers, is the registration moment. In theory the
91 quantified data about the counted ones’ assistance needs are extracted from a cooperative and
92 interactive consensus-making situation between the local IPLOS data reporter and the one to be
93 reported. A core theme among participants in the controversy has been whether the promised
94 cooperativeness and consensus behind the registration has been fulfilled. This is reflected in mass
95 media where IPLOS has been attacked under headlines such as “Registered against her will”
96 (*Bladet Tromsø*, 2007), “Feels insulted by handicap-statistics” (Bakke, 2008), “Intimate details
97 in care register” (Bore, 2007), and “What number for soul pain?” (Harstad Tidende, 2007).²

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).

98 This controversy illustrates some challenges of counting disability for governance objectives.
99 Statistical numbers gain autonomy and credibility through their alliances with science and its
100 ideals of realism, objectivity and neutrality. If IPLOS statistics had not only been presented, but
101 also been experienced as such, the controversy might never have emerged. Critics emphasized
102 that:

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

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

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

131 Method

132 This article is based on in-depth qualitative interviews with representatives for organizations
133 of and for disabled that have been active in the controversy surrounding IPLOS. Some of them
134 had a functional reduction themselves and a personal rationale for their activism. My data also
135 include verbal and textual presentations organization members have made in mass media and open
136 meetings, and central authorities’ formal IPLOS documents as instruction guides and incentive
137 reports. I have used a purposive snowball sampling strategy in the organizations to insure that
138 the informants have had key positions in the interface between the organizations, the controversy,
139 and the central authorities. This strategy was initiated by contacting persons presented as key
140 communication representants for the organizations on their public web site. The interviewed

141 disabled persons were also working in the same organizations, and were suggested by either key
142 representatives or other informants. They were interviewed first and foremost due to their position
143 in the organization, and not to their disability. The disabled persons were administratively and
144 functionally defined as disabled, as they received formal assistance in some way. Yet, they did
145 not necessarily identify themselves subjectively in accordance with how the bureaucratic and
146 professional apparatus did, even though their respective disabilities were related to impairment
147 and associated with function limitations.

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

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

160 **First conflict: translating assistance need into numbers**

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

165 Through the controversy surrounding IPLOS, the disabled got the opportunity to put several
166 important themes concerning their everyday life situation on the public agenda. What kind of
167 (in)dependence do disabled people experience? How are their lives affected by welfare bureau-
168 cracy gate-keeping practices? What characterizes the relations between individuals with a function
169 reduction, professional service providers and the welfare bureaucracy (a question also discussed
170 by Helgøy, Ravneberg, and Solvang (2003))? Do we need another society to meet disabled as equal
171 citizens, or can we build our society further upon the present welfare system structure? Through
172 what mechanisms are persons disabled? Is IPLOS, and what it represents, such a mechanism? And
173 what does IPLOS represent: power, politics, knowledge? From the central authorities' perspective
174 these questions are vital, but necessarily secondary to IPLOS' main task: to solve challenges and
175 problems of coordination, cooperation, and stabilization of the relationship(s) between health and
176 care services internally in the municipalities, externally between municipalities, and between these
177 local contexts and the central authorities' political decision making forums. This aspect is neatly
178 captured in a headline of the Directorate of Health's (2008) IPLOS instruction guide: "Common
179 understanding – Individual registration".³ How can we create good welfare political decisions
180 that contribute to the development of equal and effective services and simultaneously utilize the
181 available resources well (Directorate of Health, 2008, p. 5), within a health and care sector that
182 must manage individual needs with standardized tools built for the making of just distribution of

³ My translation from Norwegian.

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

191 *Person–number: technical matters*

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

198 IPLOS' core document is a registration form which for each registered individual becomes part
199 of their patient record when filled-out. The main IPLOS categories are (Directorate for Health
200 and Social Affairs, 2005)⁴:

- 201 ● personal information and housing conditions;
- 202 ● assessment by the relevant health professionals;
- 203 ● functional disability level;
- 204 ● diagnoses;
- 205 ● health and social services received from local authorities;
- 206 ● 24-hour care from non-local authority source.

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

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

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 above (“social participation”, “decisions in everyday life”, “maintain own health” and “move outdoors”) are taken to represent disability.


- 219 ● “maintain own health”: in need of assistance to manage own disease, injury or functional
220 impairment, to take contact with treatment apparatus when symptoms or injury occurs, follow
221 treatment schedule and manage own medication;
222 ● “move outdoors”: in need of assistance to move outside own residence, up and down stairs,
223 curb stones, on uneven ground, etc. Outside own residence encompasses everything outside
224 own entrance door, including outdoor stairways and thresholds.

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

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

238 So, what is actually a functional disability level number 3? 4? 5? And where do these cat-
239 egories come from? In the current IPLOS documentation which health personnel receives as
240 support material, the Directorate of Health does not explain their stories, but presents them as
241 natural categories.⁵ Health personnel, who formalize the registration work, must to a large degree
242 ascribe meaning themselves to the different disability levels. Yet, regardless of the organizations’
243 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
244 disability level and provide adequate personal records. Statistics Norway ([Gabielsen, Otnes, and Sundby, 2008](#)) claims that IPLOS promotes the opportunity to quantify the number of receivers
245 of one or several health and care services, measure the number of hours individual users of home
246 services receive every week, and compare this in relation to variations in users’ assistance needs
247 and household situations. These beliefs imply the assertion that the numeration work undertaken
248 by the data reporters produces standardized measured outcomes. Meanwhile, an organization
249 representative and IPLOS registered informant reflects:
250
251

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

⁵ According to the [Ministry of Social and Health Affairs \(2000\)](#), during the initiate de  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.

255 The filled-out IPLOS form represents a measure of a client's assistance needs based upon
256 a summarization of the client's score on the variables of need of assistance – 1 to 5 – included
257 in IPLOS. The persons who get to read the forms get to know the individual client as (s)he is
258 presented through these scores. IPLOS statistics are in theory disconnected from the individual
259 IPLOS registration forms through aggregation and pseudonymization.⁶ Yet, at a local level these
260 forms circulate within the municipal's health and care services and the management. At a national
261 level registered persons have recognized themselves in the supposedly anonymous statistics due to
262 their having rare combinations of physical reduction and social characteristics in their area. They
263 have not always identified themselves with how they are represented, and have thereby questioned
264 the relationship between number and person. This informant questions the standardization logic
265 behind the belief in the numbers' ability to accurately represent applicants' for and receivers' of
266 health and care services assistance needs. She points to a fascinating aspect of numbers that they
267 present themselves as objective and natural while at the same time opening up for what Becker
268 (2007) terms data reporters' and readers' "interpretive possibilities". According to the informant,
269 packages could have been counted in this way, humans cannot. Implicit in her statement we find the
270 belief that central authorities view disability as a physical terrain that can be easily mapped, given
271 the right tool. Numbers are a key element of such a tool – self-determining and self-explanatory.
272 Health professionals' estimates are seen as valid; therefore, numbers produced by them are good
273 enough to be used as facts. If they are treated statistically correctly they can function as ready-
274 made, trustworthy representations of the counted ones and the activity of the local health and care
275 services. We just have to find a way to count – IPLOS – which realistically rewrites disability into
276 numbers for administrative purposes.

277 The authorities' way of looking at numbers differs from the IPLOS critics' on the basis of
278 a different point of departure. This difference tailors the two agents' way of reporting IPLOS
279 in opposite directions. Consider organizations of and for the disabled and the central authorities
280 looking at some IPLOS statistics tables. They both see the same objects in the world, they both
281 direct their attention and their remarks at the same things (Bloor, 1991, p. 173, see his discussions
282 of "facts"); but the Directorate (2008, p. 2) says: the numbers show that "disabled who only receive
283 practical assistance have in average the lowest assistance need", and the organizations say: "the
284 numbers tell nothing yet".⁷ Following the Directorate's view the numbers can consequently and
285 un-problematically be given a prominent role to "provide a basis for inter-service-coordination
286 on providing services at an individual level, and give a fuller picture of the overall demand for
287 services on which better planning decisions could be made" (Directorate for Health and Social
288 Affairs, 2005). But, also the organizations' view represents an underlying kind of representational
289 realism in that they suggest numbers might be developed that *could* describe assistance need, if
290 only the social dimension were inscribed into IPLOS. Since this dimension is put aside in the
291 current IPLOS version, the numbers are not valid.

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."

292 *Telling about disability*

293 What differs about the authorities' and the critics' view is their underlying concept of the
294 functionally "below-average" man and how you get to know this man.⁸ As one organization
295 representative reflected:

296 " [T]hey [Directorate of Health] are busy measuring people's bodies. . . from an understand-
297 ing that. . . with the underlying assumption, implicitly, that people cannot judge themselves.
298 (. . .) they think disability is a body phenomenon. We think it is a social phenomenon."

299 The representative repeats a re-repeated basic thesis in disability studies and activism, that
300 disability is a consequence of particular social systems rather than essentially a property of indi-
301 viduals (Abberley, 2008). According to Albrecht et al. (2007) these practice fields have been
302 paralyzed by disability model battles, with the medical and the social model representing perhaps
303 the best-known opponents. Other examples are the rehabilitation model and the social barriers
304 model of disability. We also find different definitions of disability underlying the different model-
305 led disability understandings, as the functional, relative, administrative, subjective (Grönvik,
306 2007; Finkelstein, 1993; Loeb, Eide, and Mont, 2007) and so on. IPLOS shares the dominant
307 feature of seeing disability as residing in the individual, with the implication that when admin-
308 istrating disability services, disability gets defined in functional terms (Abberley, 2008, p. 4).
309 This is relatively clearly expressed in the IPLOS indicator definitions mentioned above. Take for
310 instance the variable "move outdoors". It promotes the individual as the one in need of assistance
311 to adjust when moving outside own residence, not the outdoor surroundings in need of assistance
312 to adjust to meet the disabled. This focus on the individual implies measuring the interaction
313 between individual and environment with a focus on the individual. The material world is seen as
314 a solid and ready-made surrounding while it is the individual who physically moves and adapts.

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

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

322 However, you would not have found anything about how weight corresponded to learning. Or
323 how assistance needs correspond to the overall situation of the disabled. But, who is right? Becker
324 (2007, p. 285) says there is no best way to tell a story about society. Instead of ideal ways to do
325 it, the world gives us possibilities among which we choose; every way of telling about society
326 does some of the job superbly but other parts not so well. Hence, the question of how we can
327 translate a personal and individual-dependent situation of lived disability into numbers depends
328 on our purpose (Grönvik, 2007, see also Loeb et al., 2007 and their discussion of how reported
329 disability prevalence rates are dependent both on the definition or aspect of disability being
330 targeted and on the intended purpose for collecting disability statistics). Practicing quantification,
331 the choice of disability definition has direct implications for the operationalization; management
332 and interpretation of the overall question of how one translates one social category into another.

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.

378 In the IPLOS case, expressions of these transformations became visible through disabled
379 refusing to subjectively accept the functional disability levels they were ascribed. Krokan (2008,
380 p. 1), a woman with a function reduction, described her personal experience of IPLOS registration
381 to the Norwegian Privacy Protection Commission (PVK) in a lecture about IPLOS on 19 May
382 2008:

383 “I had planned to show you my own IPLOS registration, but I did not find it. There it says
384 –I had not participated in the registration, and I did not know that it was done before I called
385 the municipality and asked – there it says that I had scored a bit low on ‘indoors movement’
386 – something I had absolutely no problem with –but ‘outdoors’ went ok: I had an electric
387 wheelchair, it said. I have used a manual wheelchair for forty years, but I have never owned
388 a motorized one. I also had a low score on ‘takes care of own health’, that I am totally
389 unfamiliar with, and I don’t know who else takes care of my health.”⁹

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

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

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

407 “I suspect it is a general phenomenon that the receiver of services has a greater assistance
408 need in the register than what one actually receives services according to! Funny: When I
409 apply for a service I have to blow up my problems and mostly magnify them, to get the
410 services I need. Because none get what they apply for – that is common knowledge. This is
411 a part of the game. And through IPLOS one has set up to the same kind of game between
412 municipality and state: exaggerate your needs to get what you require”¹⁰.

413 Another IPLOS registered organization representative reflected upon the same drama:

414 “Measurement of services is not a new phenomenon, or the struggle to receive what you
415 need. I remember a girl who absolutely wanted me to admit that I could butter my slice of
416 bread by myself. And I gave a flat refusal, because I knew that then I would lose at least
417 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 below¹¹ 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 strategic 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



below¹¹ 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.

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

462 **Third conflict: stigmatizing (?) disability by numbers**

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

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

479 *Interpreting numbers' source*

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

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

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

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

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

517 *Dependence through silence*

518 Numbers symbolize and may enforce identities and group affiliations upon the counted ones.
519 Being ascribed a 3 means, in any formal case, something very different than a 4. When the
520 different numbers qualify for different rights simultaneously, as you must accept characteristics
521 of you which the numbers bring with them to get the rights you need, the numbers may in
522 their nature seem incapable of neutrality. This incapability is not necessarily a negative one. It
523 depends upon what other population groups you are categorized with, and whether you experience
524 this categorization as beneficial in some way; a personal evaluation that may seem cynical
525 on behalf of those one marks distance from. An IPLOS registered organization representative
526 reflected upon what target group the IPLOS indicator formulations seemed to be defined for:
527

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

535 Why should it create reactions? The informant interpreted IPLOS as an identification marker
536 that grouped her into the same category as seriously needy and underprivileged individuals
537 – individuals she define as patients – a term she resists using to refer to herself. But, what is prob-
538 lematic about being in the same referential room as someone with dementia? The social democratic
539 model of the Norwegian welfare state is characterized by a comprehensive state, strong citizens'
540 rights and universal welfare arrangements (Helgøy et al., 2003). A significant amount of the costs
541 generated by the health system are shared by society through individually based public tax pay-
542 ments. The system is decentralized and recognized as a significant important part of a totality
543 meant to level Norwegians' playing field. Every citizen is to meet the same demands and share the
544 same rights. On this background the expectation of the Norwegian authorities that IPLOS would
545 glide unproblematically into measurement practice reflects the silent contract between state, soci-

546 ety and individual citizens that we shall not receive special treatment compared to others in the
547 same situation, here broadly restricted to the category “citizens with an assistance need” in the
548 public apparatus due to individual characteristics. In this way, IPLOS numbers might be seen
549 as symbolizing equality. However, the informant’s resistance reflects a wish of being seen and
550 treated as an independent citizen even though she receives public assistance to function in every
551 day life. According to Helgøy et al. (2003, p. 483) independence is an underlying ideal among
552 disabled people, a logical consequence being that the best way of living for disabled people is to
553 manage with as little practical help as possible. The informant’s identification of IPLOS as rep-
554 resenting patients rather than citizens implies the presumption that patients and citizens invoke
555 different associations. When a “citizen” receives practical assistance it represents a kind of social
556 assistance and the invocation of a universally shared right. When a “patient” receives assistance
557 it represents a medically oriented assistance given on unequal terms, unequal because the patient
558 is restricted in her or his way of living which the assistance cannot equate. In spite of assistance,
559 a dement person will not function as she or he did before the dementia due to memory loss, while
560 ideally, assistance should render a physically function-reduced person able to function as “the
561 average man”.

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

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

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

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

588 What we can see from these quotes is that silences “speak”. Those who notice them, who feel
589 affected by them, fill them with meaning(s). Here the IPLOS registered have ascribed meanings
590 such as oppression, guilt, and exclusion to the silences that signalled IPLOS’ implementation.

591 Disabled have perceived the method of uninformed registration as humiliating, de-humanizing,
592 and disenfranchising. The absence of information and participation symbolized for them a deval-
593 uation of them as a population group and a public statement of their being dependent beings
594 ready to be managed by the population's remaining independent beings. As Finkelstein (1993,
595 p. 34) says, there may be something profoundly undemocratic about able-bodied people con-
596 structing and systematically counting, scoring, and registering "not so able-bodied" people, even
597 though the objective is good. The contrast in the representative's statement of officials in charge
598 peacefully eating cosy cookies – while they perform a ritual that for him represents a deval-
599 uation of the registered ones as citizens and an evaluation of them as packages of meat to
600 be managed independent of their free will and subjective life situation – is an allusion to the
601 history of disability registration during Second World War mentioned above. But, more interest-
602 ingly, it underscores the fascinating contrast between IPLOS statistics being given a significant
603 important role for the future health and care policy and at the same time being manufactured
604 during a deafening silence from the administrative apparatus' side. Following the representa-
605 tive's side of the story, what does this symbolize for the disabled if not the kind of everyday
606 discrimination which, through it being performed in naturalized and unspectacular ways, repeats
607 the stigma of disability understood for them as undesirable otherness? Yet, symmetrically, the
608 practice also symbolizes the insignificance of being registered. If the representative had sub-
609 jectively felt himself as an equal citizen, he could have come to support this latter side of the
610 story instead. This arouses the ever-present actuality of the well-known Thomas theorem: if one
611 defines situations as real, they are real in their consequences. Or, as in this case, if we treat
612 ourselves as equal citizen beings, we may all the faster become equal in our way of living the
613 society.

614 Conclusions

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

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

636 controversy surrounding IPLOS, at least in its back rooms, through:

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

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

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

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