European Parliament
DISABILITY SUPPORT GROUP

Disability-Support@europarl.europa.eu

JSIS consultation - OI/4/2016

Reply of the European Parliament Disability Support Group

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Contents

1. Introduction

The EP Disability Support Group **welcomes the great effort and sharp analysis** of the Ombudsman in this inquiry. We **greatly appreciate the work of her team and their openness** to the Disability Support Groups all through the process. In this document, we concentrate on areas where we see **scope for stronger conclusions**. Some factual errors need to be ironed out, too.

2. Key EP DSG Conclusions

Our analysis strongly suggests that the Commission does **not meet the standards of truthfulness** required in public administration in its answers to this inquiry. The main thrust of its answers is **evasive** and **deceptive**.

The Commission shows **no concern** over the **appropriateness of health outcomes**, **discrimination, fairness of the insurance system, or compliance with the UN CRPD**.

Six conclusions immediately stand out:

- where the **Ombudsman relies on the Commission's answers**, she risks not attaining the aims of the inquiry and **narrowing the opportunities of rights holders to claim their rights**.
    - The Commission uses the Ombudsman's site to disseminate a deeply flawed account of its obligations as well as the rights of rights holders.
- Where there is a **gap between the Ombudsman's suggestions and the Convention** or consensus recommendations by bodies mandated by the UN, the inquiry also **risks falling short of promoting the aims of the UN CRPD**.
- Suggestions (recommendations) in the non-JSIS need to be firmer, given a **years of manifestly insufficient respect of the UN CRPD and other obligations.**
    - An example that illustrates the UN CRPD gap and an area where more firmness is requested by us:

- All **policy processes** should be asked to be **inclusive** at **all levels** and, for inter-institutional matters, each of the three DSGs and the EDF should be asked to be involved (Article 4(3)).

3. A Proportionate Reaction from Ombudsman

We would respectfully ask the Ombudsman to **react commensurately**, and to

- state that "the assistance which he requests is not forthcoming" (Article 3(7) of the Statutes of the Ombudsman),
- make a finding of **maladministration** on that and other counts,
- make a **finding** of or raise a **presumption of discrimination**,
- make **recommendations** rather than suggestions,
- ask the Commission to carry out an **independent** assessment to identify which provisions of the GIPs and/or the related forms, need to be revised in view of the UNCRPD and the UNCRPD Committee's concluding observations in 2015.
    - The process to assign the assessor should be inclusive, otherwise it would certainly be sabotaged.
- the assessor should closely co-operate with all three disability support groups, the EDF, and solicit the assistance of WHO/EUROPE and, if it deems expedient, the technical assistance of the UN Committee.
- **We ask the Ombudsman to strongly and explicitly reinforce the concluding observations** of the UN Committee.

4. Discrimination and Equal Treatment

The inquiry must obviously address four constraints or prohibitions concerning discrimination, unequal treatment, and the non-enjoyment of rights:

1. **Unlawful exclusion on the grounds of disability**: the Commission cannot justify a health care system that excludes persons with disabilities from any type of

reimbursement merely on the grounds of their disability (rather than their health needs or other justifiable criteria).

   a. Two examples should suffice. The **explicit exclusion** of items within the JSIS that **compensate** for the loss of function (sight, hearing, speech, mobility) is a serious example of **profound discriminatory exclusion** that is evidently made on the grounds of disability. The **use of outdated concepts** – and even degrading language – is **dissuasive and thus exclusionary**.

2. **Unlawful favouring on the grounds of non-disability**: the Commission is not allowed treat **persons without a disability more favourably** just because they are not disabled, in comparison to persons with disabilities with equal or more serious health needs (25(a)).
   a. The JSIS rules are a form of favouritism and facilitation for the non-disabled and those with less intensive needs. The Commission admits that rules concerning the able or the less disabled are more precise, actionable, and opposable, than the deliberately vague, or entirely absent ones, that are relevant in case of disability.

3. **Not reaching the base line:** The JSIS cannot leave persons with disabilities without the type and level of health care safeguarded by the legal obligations of the EU institutions, including those created by the UN CRPD.
   a. The possibility to exclude contract staff with disabilities on recruitment from any reimbursement associated with their “invalidity” according to the Joint Rules is a glaring example because it is expressly worded in terms of “invalidity” i.e., disability. The JSIS also does not aim to guarantee a minimum of appropriate health care, and the **shortcomings will be the greatest where the costs are highest but the reimbursements are not**.

4. **Specific services:** The JSIS rules must enable the provision of “health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons” (25(b).

a. The JSIS has effectively no provisions concerning persons with disabilities (except those concerning serious illness). Specific health care provision is impossible without specific provisions on health care.

We **ask the Ombudsman to** conclude the GIPs and the Joint Rules of the JSIS are **designed so as to violate, or make the violation extremely probable, depending on the case, of each of the four prohibitions of discrimination, unequal treatment, and denial of the right to appropriate health care**.

Health insurance rules that fail the four criteria of non-discrimination and appropriate care cannot be considered fair and reasonable as per the UN CRPD.

5. Deliverables and anticipated Consequences

The Ombudsman should prepare for the eventuality that the Commission keeps flaunting its obligations and **build in a strategy into her proposals** for the next steps. We would prefer proposals that signal **success conditions**. Such a path would involve **more clearly identifiable**

- deliverables,
- procedural changes,
- indication of best practices,
- the collection of statistics by the Commission (the JSIS) that measure improvement (or the lack of it).

References to **specific instruments** of the World Health Organisation, key EU strategy documents, such as the European Disability Strategy 2010-2020, and the UN CRPD, **should be added**.

Involvement of the organisations of persons with disabilities is now suggested only for low-level, day-to-day issues. This stands in contrast to the provisions of the UN CRPD, the Commission's commitment in the Disability Strategy (p.10) concerning mechanisms

required by the UN Convention, and the recommendations of the WHO for their involvement in all policy making.

6. Policy Goals to be included as Deliverables

We ask the Ombudsman to stress that the right to health includes **access to timely, acceptable and affordable health care of appropriate quality** (WHO Action Plan 2015). With the JSIS at its sole responsibility, **the Commission shall also implement the relevant goals of the European Disability Strategy 2010-2020 as far as the JSIS is concerned**.

The Ombudsman should draw attention to the "strong mandate" of the Commission to implement the strategy which is based on the the Charter, articles 10 and 19 of the TFEU, and the UN CRPD. She could point out that the EU Commission's European Disability Strategy aims **to empower persons with disabilities.** According to the strategy, EU institutions **"must work together to" "ensure that the UNCRPD is enforced" in order to "best implement the strategy".** As regards health, Commission is committed to the following:

> "The Commission will support policy developments for equal access to healthcare**, including quality health and rehabilitation services designed for people with disabilities**. It will pay specific attention to people with disabilities when implementing policies to **tackle health inequalities**; promote action in the field of health and safety at work to reduce risks of disabilities developing during working life and to improve the reintegration of workers with disabilities; and work to prevent those risks."

The Ombudsman could further underline that

> Analysis of the World Health Survey shows that, compared with people without disability, men and women with disabilities are twice as likely to find that health care facilities and providers' skills are inadequate, three times more likely to be denied health care and four times more likely to be treated

badly in the health care system. **Of all persons with disabilities, half cannot afford required health care; people with disabilities are also 50% more likely than those without disability to suffer catastrophic health expenditures (WHO Action Plan 2015)**.

The Ombudsman could **express her regret** that there is no mention of these, or **any** other **credible and meaningful objectives**, in her reply of the Commission.

7. Key Conclusions

According to our analysis,

- the Commission acted *ultra vires* in deciding not to review the compatibility of its existing provisions with UN CRPD. Given the well-grounded recommendation of the CPAS, and the manifestly differential treatment of persons with disabilities by its provisions, the HA should have given a satisfactory justification for its decision.

- the Commission has stipulated and maintains provisions that single out persons with disabilities as less entitled, **because of their disability**, to have their health needs met than other persons with equal, or less intensive, health needs.

- such manifestly unjustified measures cannot not be justified by any alleged savings. Notably, the Commission does not refer to such a need either. Their data – flawed to the core though it is – and their commentary – admittedly fanciful - give the impression that the matters on hand are **minor and marginal**,

- the Ombudsman **should not think that she is acting against the legitimate interests of the institutions** if she makes recommendations or stronger proposals. The institutions show **a manifest lack of interest**,

- "serious illness" in the GIPs is not a clinically valid concept. The Ombudsman should *a priori* give it no credence.

- the treatment of persons with a **serious illness *without* (a risk) of serious disability** has to be dealt with, too, to verify if the policies are **equitable and non-discriminatory**. Simply put, the JSIS seems to much more readily invoke a risk of serious disability to make persons without disabilities eligible for what **called 100% reimbursement**.[1]

- The threshold to satisfy the seriousness criteria is unjustifiably high, in comparative terms, when persons with disabilities submit an application.

- The **factually highly doubtful** example of autism spectrum disorders **shows conclusively** that the life-expectancy assessments by the JSIS are neither reliable nor reliably reported.

- the concept of handicap, as part of "serious illness", seems to date to the WHO International Classification of Impairments, Disabilities, and Handicaps (1980), which are also **expressly cited in Provisional Guidelines for financial assistance**. This classification was discarded by the WHO in 2001 already.

- The **outdated language and guidance of both the GIPs and other measures is dissuasive and rights-denying as such. That is a necessary and sufficient reason for their revision.**

- To offer an analogy, it is not good enough to **whisper** that you interpret 'for whites only' in an inclusive way to mean 'for blacks and whites'. The 'for whites only' plaques need to be removed, or they keep on offending and turning people away.

- the **dissuasive as well as direct and indirect discriminatory consequences of the gap** between JSIS and typical national coverage as regards serious disability should be recognised as a **serious impediment to equality in employment directly and indirectly, in the case of children and spouses**,

[1] 100% reimbursement for serious illness can actually mean some other rate, or effective rate, too, according to the PMO (oral information at PMO information session in EP 30.02.2017).

Our comments are quite detailed to help the Ombudsman see issues in depth. We would not expect her conclusions to be as detailed but we would hope them to be as **incisive.**

8. Health Care Interventions in JSIS

It is easier to discuss the tasks of the JSIS in **positive terms**, if we introduce the concept of function. Body functions, which include psychological functions, are a distinctly **medical** concept that has a role in defining **impairments** which are problems in body function or alterations in body structure – for example, paralysis or blindness (WHO World Disability Report). Impairments have a role in characterising disability, which is a broader concept (WHO & UN CRPD).

The incontestable point here is that health care interventions concerning body functions are treated differently by the JSIS depending on their association with disability as such, and with the degree of disability in particular. To understand this, it is necessary to understand that the the following objectives – from the WHO World Disability Report (2011) - of rehabilitation in particular and health care more generally belong to the scope of the JSIS:

- prevention of the loss of function
- slowing the rate of loss of function
- improvement or restoration of function
- compensation for lost function
- maintenance of current function.

If an item does not serve any of these goals, as a rule, it is unlikely to be reimbursable by the JSIS. (There are many exceptions, such as useless but reimbursable medical products, that are glossed over here).

Let us give a few examples to show how the goals fit with JSIS policy. Medication to **slow down the rate of loss of function due to, say, a degenerative disease** is eligible (although not necessarily the most expensive ones costing up to and above €200 000

annually). Reconstruction of damaged joints to **improve or restore their function in, say,** disabling rheumatic arthritis is reimbursable; a liver transplant **to compensate for the lost function** of a liver is reimbursable; thousands of reimbursements are paid yearly to **maintain current body and psychological functions**. Medication for the prevention of the **loss of** erectile **function and, more typically, for erectile dysfunction** is reimbursable (whereas a prescription for purely **recreational use** is not).

What is significant is the existence of a cutting point or deselection principles that systematically exclude items that are relevant to disability in particular. The GIPs are designed to exclude persons who have more intensive needs with regard to interventions towards the end of the list.

The cut-off is easiest to see in cases involving compensation for lost function. For example, spectacle lenses are reimbursed, and there are cost waivers for serious but not complete loss of sight as regards lenses. **Beyond that point, the beneficiary is excluded**. Means to compensate for the lost function of sight, such as a white cane, are not compensated (written information from the PMO to a blind EP DSG member). Prostheses reimbursed but appropriate wheelchairs or several mobility aids for different environments (home, street) may not reimbursed (applicants referred to financial aid). Only one aid is typically reimbursed: you e.g., are supposed to use a street wheelchair at home.

9. Stop the Gaps

The Ombudsman could state that while **the UN CRPD is based on a ”no gap” approach to rights, the GIPs typically contains wide gaps.** For a “no gap” policy, **the JSIS should**

- explicitly cover the full scope of measures that target body functions and structures, activities and participation, environmental factors, and personal factors.
- The JSIS should thereby aim at a person achieving and maintaining optimal functioning in interaction with their environment (WHO).
- The reimbursable items should include, for all bodily and mental functions, the full spectrum of interventions from loss of function to maintenance of function.

In the next section, we show that this is currently not the case because **the architecture of rules has been designed to exclude persons from the JSIS** on the grounds of the degree of their disability alone.

Exchange of Views Point by Point

10. Medical and Social are not the Demarcation Line

The quotations are from the minutes of the meeting of 1 June 2017**.** Commission statements are indented, in *italic*, and have quotation marks.

> *"i) The Commission pointed out that the JSIS is a sickness insurance scheme, which covers **medical costs** in accordance with the existing rules (…)."*

The Commission deceptively conflates several issues:

> - what concept of disability underlies "existing rules". What is its provenance, and how, if in any way, are they are interpreted in accordance with the UN CRPD?
> - what concept of the "medical" does the Commission use?
> - how do the above two concepts relate to each other?

It offers **no clarification** on these questions. We will show that the Commission has not followed developments within the medical area concerning disability **for the past few decades** as far as its rules and provisions are concerned.

> *"The Commission, however, takes a holistic approach on disability related health needs by taking into account both the medical (JSIS/Paymaster Office [PMO]) and the social aspects (Directorate-General for Human Resources [DG HR])."*

This is seriously incorrect on several counts. The division between the JSIS and other measures is **not** between the "medical" and "social" aspects. This is obvious from these two examples from the List of Equipment (Annex 1) from the Provisional Guidelines for financial assistance:

- electronic equipment **essential** to education and **communication** for a person who cannot speak, is partially sighted or hard of hearing;
- a text vocalisation scanner for a partially-sighted person;

Six things are notable. First, the scope of persons removed from the JSIS by this example is **very large**, and involves persons with disabilities only: "a person who cannot speak, is partially sighted or hard of hearing." This classification and principle of exclusion from the JSIS is **entirely medical** as it refers to **impairments only**. Second, the functions to be addressed are not "social" but refer to "essential" "communication". Third, all examples involve means to compensate for a lack of bodily function. Fourth, all means of compensation have an equivalent in the JSIS rules for a lower degree of impairment: a hearing aid, corrective lenses, and speech therapy, for example.

Fifth, the Provisional Guidelines fail to address the need for several essential interventions. For example, the costs of sign language interpretation are not mentioned as eligible, even though it is **essential to communication** of persons who cannot speak or hear. Sixth, the list of "electronic equipment" was **drafted before the invention of the personal computer**, and has not been revised since.

This is not holistic. It is policy of **overlapping medical conditions**, where **legitimate JSIS costs** involving a **medically definable** compensation of function loss (hearing, seeing, speaking) are transferred to financial assistance at **far worse terms**. To repeat, this banishment is not based on any distinction between 'social' and 'medical' purposes.

This creates huge gaps within the JSIS, as **functionally justified compensatory** interventions for **hearing, sight, and speech impairments are excluded from reimbursement**. To add **insult to injury**, the Provisional Guides create **more huge gaps**

in financial aid by deliberately not mentioning coverage for essential for communication in the case of those, whose needs are most intensive, such as sign language interpretation.

11. Derogatory and obsolete Language

Supplementary financial aid makes use of a very distinctive concept of disability.

> A person shall be considered **with disabilities** if he/she is suffering from **severe deficiencies, disabilities, or handicaps** resulting from physical impairment, including sensory, mental, or psychological impairment, which **limit or impede integration** or prevent the person from performing an activity or **function considered normal for a human being** (Provisional Guidelines, point 4.1.(PDF)EN).

It should be noted, first, that the expression **not "normal for a human being"** is an exact synonym of **abnormal** in contemporaneous 1980s WHO terminology in cases where the deviation from 'normal' is great. Since the rules refer to "sever" deficiencies, the deviation is great, and abnormality is meant. The Commission, along with all other institutions, **effectively and expressly labels staff with disabilities as abnormal, deficient, and impeded in integration.** Such terms were used to quality homosexuality a mental illness by the WHO until the 1990s, if one needs an idea of their obsoleteness.

The definition of disability in the Provisional Guidelines is a verbatim quotation of the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) from **the year 1980**. It was supplanted and became **outdated** with the adoption of the WHO International Classification of Functioning, Disability and Health (ICF) **in May 2001**. The Provisional Guidelines have been revised in or around 2003 which proves that their **obsoleteness is deliberate**.

The contradictions of the restrictive concept of the provisional guidelines with the SR and the UN Convention are numerous. According to the Provisional Guidelines, person with disabilities suffers from "severe" deficiencies, whereas the SR do not; the words "deficiencies", "handicaps", and "disabilities" no longer define disability in the SR; no single

cause, and no single medical cause, such as deficiency, characterises disability in the SR; the concept of abnormality is absent from, and violates, the SR.

By **current standards**, such language is **derogatory**. Publishing such language on e.g., the Intranet or Internet can be considered **cyberbullying**. The EP, for example, quite unacceptably publishes such descriptions of persons with disabilities on the Intranet. We would be very surprised **if the Ombudsman did not take exception to the Provisional Guidelines more sharply in her final conclusions**.

As the UN CRPD Committee has noted, language such as that used in the Provisional Guidelines, can have a direct impact on the enjoyment of rights:

> Negative stereotyping, stigmatization, and prejudices can be **harmful to both the perception of one's dignity and one's perception of being equal in rights**.

Even if the institutions did **interpret** the rules in a UN CRPD manner, which we dispute, the potential beneficiary is likely to be dissuaded by the **untowardness** of the language and attitudes emanating from the rules and other publicly available information.

> *"For this reason, the PMO and the DG HR cooperate fully to deal with requests to reimburse medical and non-medical costs from persons with disabilities."*

Obfuscating language. The issue is whether they do so **successfully** rather than whether they refer persons from one arm of the Commission to another. Absent evidence of success, it is all **hot air.** There is **no such cooperation in the EP to note.**

12. Go Home First

> *"PMO and DG HR work with national authorities (where relevant) and in particular with Belgian authorities in order to help staff members or relatives to benefit from national/Belgian schemes for disabled people."*

Deceptive. The Commission does not "work with" national authorities in the sense of having any say in their workings. The language may refer to things such as the seminars they organise together with national authorities.

The Ombudsman should note that in the Allen case, the Tribunal specifically notes that a beneficiary can **opt out** from a national system on the grounds of being a beneficiary of the JSIS and that, as a result, the "administration has no grounds for pleading against the applicant the argument that she would be able to receive sickness cover in the United Kingdom" or Portugal or, a fortiori, Ireland, where the Commission tried to 'send home' Ms Allen (ECLI:EU:F:2011:162; points 106-108).There is a risk that the Commission still **pursues the flawed strategy of disability *refoulement*** when marketing national assistance, or requiring it, in areas where the JSIS should be the obvious primary, or sole, source of coverage.

As regards Financial Aid, we do **not consider the following requirement equitable**:

> after the disabled person has claimed all possible national aid, which shall be taken into account when calculating the financial support, and submitted documentary evidence of dealings with and any aid granted by national administrations.

The formulation should be weaker: 'if the applicant does receive national aid for the same specific purpose for which aid or assistance is sought, this shall be taken into account'. There should be no obligation to apply for national assistance first, since the process may take months or years, and result in rejection. Note that in the EP, for example, it takes at least half a year to get a Financial Aid decision for even the most mundane items. Having to go a national round first, and then wait for half a year, is an unreasonable delay infor assistance that may be vital to the enjoyment of disability rights.

13. Compliance Assured: Manifestly False Claims

> *"The Commission noted, in response to a specific question, that since the changes to the SR that came into effect in January 2014 aimed at fully complying with the UNCRPD, it did not perceive a need for further significant legislative or regulatory changes to the JSIS."*

This is deceptive and, as such, does **not qualify as a justification**. Neither the Explanatory Memorandum nor the draft proposal for a new SR made any reference to the UN Convention or disability. (The imperative to save money and make sacrifices was the prominent theme.) Hence, the Commission could not have aimed at compliance with the changes to the SR.[2] Further, the Roth-Berendt report on the SR did not propose or aim at full compliance either. It only introduced a reference to the UN CRPD in article 1(d)4 (owing to disability lobbying) which the co-legislators adopted.

> *"The Commission also said that it constantly seeks to interpret and apply all the relevant rules in the area of the JSIS in the light of the Article 1(d) 4 of the SR[3] and the UNCRPD."*

This is deceptive and contradicts the previous claim. A *re*interpretation of the relevant rules should include a procedure to identify which are the relevant rules to (re)interpret, precisely as recommended by the CPAS, and as rejected by the HA. This would be part of a regulatory change process. Since the Commission says that there is no need for "significant" regulatory changes, whatever (re)interpreting is done now must be **insignificant**. Second, interpreting something "in the light" of the UN CPRD can, of course, fall short of compliance, if there is not enough light.

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[2] The Proposal:
http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2011:0890:FIN
The Explanatory Memorandum:
https://www.eumonitor.eu/9353000/1/j4nvhdfdk3hydzq_j9vvik7m1c3gyxp/viv9tnp5amuv
A single reference to the UN Convention was introduced by amendment 20 to the Roth-Behrendt report on the SR, which neither initially nor after the adoption of the amendment aimed at compliance. See
http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2012-0156&language=EN

Further, as will be widely documented here, the obsoleteness of the provisions and the deliberate vagueness of key provisions are dissuasive as such, and make it difficult to challenge decisions. That is sufficient evidence of **the existence of a pattern that destroys the credibility of the claim of any compliant interpretation of rules**.

15. Failed in Epidemiology 101

> *ii) "The rise in the number of complaints starting from 2013 may derive from the fact that applications to renew this decision recognising a "serious illness", following the end of the 5-year period, were unsuccessful due to the change in individual medical circumstances."*

This is **logically impossible and fails basic epidemiological criteria.**

In technical terms, the Commission confuses the first derivative of a variable with the second derivative. If a person's health situation changes, it can be said that the first derivative of the health variable changes: the change can be positive or negative (so that the first derivative is positive or negative). If the **rate of change of a person's rate of change** of health situation changes, the second derivative changes. Here there are more cases. Suppose that the first derivative is positive, and the patient's health improves. That rate of improvement can accelerate, remain unchanged, or decelerate. Here, the second derivative is positive, zero, or negative These are changes in the value of the second derivative. (The rest of the cases are analogous and not discussed here). **The confusion between the two – mistaking the first derivative for the second derivative - invalidates the Commission's argument**.

It is trite for the Commission to point out that cancers go in remission. That has always happened – it is in the nature of cancers that some do so. In other words, the complaints rate has always reflected and been sensitive to the fact that circumstances change. It is only if cancers go into remission **more often than before –** *if the second derivative changes* **-** that one might expect there might be a change in the rate of complaints explicable by changes in medical circumstances**. This, however, is *precisely what the Commission does not argue*.**

Further, the Commission's narrative is highly implausible. Why would someone introduce a complaint if their cancer has gone into remission? An obvious reason, not addressed by the Commission, would be that the costs resulting of having had that cancer remain high and unchanged. Consider a beneficiary who has become seriously disabled because of cancer and the costs of disability remain high. The cancer goes into remission but the costs of serious disability do not change. The obvious reason why the JSIS would refuse to renew 100% reimbursement is the (real or supposed) change in life expectancy given that the cancer is in now remission.

Suppose that the beneficiary introduces a complaint on the grounds that their condition remains "serious" given the consequences of the cancer which have not gone away. It stands to reason that such an application is refused on the grounds that it does not tick all the boxes, in particular the life expectancy box. (The Ombudsman has received information of precisely such a case from our group.)

The explanation with the best empirical support is that the increased rate in complaints results from a change it reimbursement and renewal policy.

More generally, the JSIS has not changed its modus operandi since the Allen case cited above. This is also **evident in the recent decision in FY vs the Council** (CLI:EU:F:2016:83).

16. Forgotten serious Illnesses and Statistics

There are, in addition to the generic clause on "serious illness", provisions concerning specific types of serious illness, health conditions, or other reasons, may also entitle the beneficiary to a so called 100% reimbursement (which can amount to less, according to the PMO) or waivers from reimbursement restrictions. These include pregnancy (p. 16), "insulin dependent diabetes" and other conditions in relation to the buccal cavity (p. 32 et passim), "serious neurological disorders", "serious deafness or neurological disease" of

children (p. 44), ”serious hearing-related illness” (p. 56), ”serious medical condition relating to vision”, ”serious eye disease”, or ”serious disease of the foot”.

Reimbursements upon renewal have changed in these cases, too. One of our members had a full leg prosthesis reimbursed at 100% (precisely). At renewal, the rate was reduced to 85% percent. The member asked: “Did they think that my leg has grown back?”. That shows just how insincere the ‘change in circumstances’ type of explanation is. The loss of a limb does not go “into remission”.

Since the Commission does not report all serious illnesses but only the ‘four box’ illnesses, it **underreports non-renewals** of so called 100% reimbursements. **That is not frank or helpful** in finding a truthful answer to the Ombudsman’s question. This omission of relevant data should count towards finding that the Commission is not answering the Ombudsman’s questions.

17. Benefits of so called 100% reimbursement

Failure to recognise a condition as constituting a ‘generic’ "serious illness affects the percentage of cost reimbursed by the JSIS, the ceiling of the reimbursement, the ceiling of the number of treatments, and other terms of reimbursement, depending on specific situation.” (source GIP p. 6, 41, et passim).” The non-recognition of a ‘specific’ “serious” illness or condition has a similar effect with regard to more narrowly defined items.

The non-recognition of a “serious illness” has, in call cases, a combined effect *on **the affordability and appropriateness of health care*** through the combined **economic** effect of the lower reimbursement rate, the lower reimbursement ceiling, and/or the lower ceiling on the number of treatments reimbursed, compared to its recognition.

We ask the Ombudsman to refer to the consequences of **non-recognition in term of health care interventions in slightly more precise terms**. To repeat, according to the PMO, the **100% reimbursement is apparently not quite precise, as the JSIS may apply some other effective percentage** (as stated at the PMO information session in the EP 30.01.2017).

18. Serious Illness in JSIS is not a Medical Concept

In a nutshell, we **ask the Ombudsman find the criteria of serious illness, as regards the time-frames involved, inconsistent**. If one criterion is met to a large extent, it is rather likely that another criterion cannot be met to a significant extent. She should say **that the problem is not that serious illness does not fit in with the individual circumstances of some persons. Instead, she could say that the problem is that the JSIS does not have an appropriate, clinically validated or even legitimate and non-discriminatory concept of "serious illness" to start with.**

Further, its concept of disability is outdated, mostly evident in discriminatory practices, which only become more aggravated when (a risk) of serious disability is involved. The absence of any guidance makes it comparatively easier for **non-disabled persons to qualify**. The JSIS can change the size and location of the box as it fancies and, we contend, does so to the detriment of persons with disabilities.

19. Recommend Models 1: National Recognition

> *"iii) The patient has to submit to the PMO a detailed medical report assessing his/her medical situation by his/her personal doctor. There **is no specific model** or type of form to be used for this purpose."*

We ask the **Ombudsman to recommend accepting, for the purposes of determining eligibility for serious illness, of attestations or certificates of "serious disability"** (or equivalent) given by, or issued in compliance with, **national health systems**, or any actor with such powers under national health regulations. Since the Commission admits that it has no fixed notion of serious disability linked to "serious illness", it can **easily start interpreting the GIPs in the manner we propose here**.

The Commission clearly puts great trust in national disability services, "together with" whom it works. If a person gets assistance from a national system because of, say, serious illness, the Commission deducts that assistance from whatever it can. Surely it

must accept that a person is seriously disabled, when a national system attests to it, when it comes to “serious illness” and the JSIS: in for a penny, in for a pound.

To do otherwise would be to direct persons with disabilities towards national systems in bad faith. Given its answers, **it is not open for the Commission to argue that national administrations do not have the high standards that the Commission expects of and attributes to the JSIS**.

20. Lower JSIS Coverage can skew Recruitment

Systematically lower coverage by the JSIS in case of disability, including serious disability, dissuades persons with disabilities or with family members with disabilities who are entitled to a higher protection of health in their country of origin from working in the EU institutions. The EU institutions are likely, by maintaining an overly restrictive, idiosyncratic and intractable sickness insurance system compared to EU member states, to create a barrier to equality in employment as well**. It is justified to presume that the systematic discrepancy can lead to both direct and indirect discrimination**.

21. Recommend Consensus Standards of the WHO

There should be a model that is independent of national systems. In all cases, the **JSIS should encourage the use the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) and, where feason;e, its “core sets”.** This would encourage the use of ”a common framework to understand and describe functioning and disability. To make the ICF more applicable for everyday use, WHO and the ICF Research Branch (www.icf-research-branch.org) created a process for developing core sets of ICF categories or "ICF Core Sets". ICF Core Sets facilitate the description of functioning, for example in clinical practice, by providing lists of essential categories that are relevant for specific health conditions and health care contexts. These ICF categories were selected from the entire ICF following a scientific process (https://www.icf-core-sets.org).

It should also give advice to beneficiaries on **the possibility of using the WHO Disability Assessment Schedule 2.0**, which is a generic assessment instrument for health and disability. ”It is used across all diseases, including mental, neurological and addictive disorders.”

> *“Under a different heading and in a separate context, the Commission's GIPs provide assessment schedules for physical and mental impairments. (…) These forms are specific to assessing the possible reimbursement of the cost of a permanent or long-term residence in a paramedical establishment.”*

The Ombudsman could use **stronger language** to describe her problem with these forms, given their **unpleasant, outdated** and **clinically unsound notion of disability.**

> *“The "Medical certificate for the assessment of a disability" (…)”*

The same reference to ICF and the WHODAS 2.0 are in place as above. The form is out of date. The EP medical service would like to revise the form on the lines of WHODAS 2.0 in cooperation with the EP DSG.

> *“As noted in point 2(a) of the Conclusion of the Heads of Administration N°177/87, reference is made to the European Assessment Schedule for Physical and Mental Impairments.”*

The assessment schedule is *expressis verbis* restricted to the consequences of physical trauma and (motor vehicle) accidents. The Ombudsman should refer to ECJ case law, in particular the Jette Ring case. It is not acceptable to reduce the scope of disability to a limited set of causes such as congenital disability and accidents (Jette Ring, point 40). To further reduce the causes from accidents in general to (motor vehicle) accident trauma specifically, as the European rating scale does, is no longer a lawful way to implement the SR as regards the evaluation and recognition of disability. A **reference to Jette Ring** (point 40) would be in place.

22. Autism involves shortened Life Expectancy

> *"The Commission stressed that each case is assessed on its own merits. It gave the example of a PMO decision which recognised the existence of "serious illness" in the case of a* ***child with autism, while there was no shortened life expectancy****."*

Self-incriminating. In fact, there is strong and accumulating evidence that autism spectrum disorders (ASDs) are related to a reduced life-expectancy across the spectrum, as we will explain. It is make-believe to deny, against scientific evidence, that the link does not exist.

In a high standard study involving 27 122 persons with ASD and 2 672 185 persons in the well-matched control group, Hirvikoski et alia (2016)[3] found that

> Cause-specific analyses showed **elevated mortality in ASD for almost all analysed diagnostic categories**. Mortality and patterns for cause-specific mortality were partly moderated by gender and general intellectual ability. (…) **Premature mortality was markedly increased in ASD owing to a multitude of medical conditions**.

Individuals with ASD had a 2.56-fold increased odds of mortality compared with matched general population controls:

> Individuals in the control group died at a mean age of 70.20 years (s.d. = 24.16, median = 80), whereas **the corresponding figure for the entire ASD group was 53.87 years** (s.d. = 24.78, median = 55), **for low-functioning ASD 39.50 years** (s.d. = 21.55, median = 40) **and high-functioning ASD**

[3] Tatja Hirvikoski, Ellenor Mittendorfer Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte. The British Journal of Psychiatry Mar 2016, 208 (3) 232-238; **DOI:** 10.1192/bjp.bp.114.160192 http://bjp.rcpsych.org/content/208/3/232

> **58.39 years** (s.d. = 24.01, median = 63) respectively. The time period between registered ASD diagnosis and death (regardless of cause of death) was on average 5.30 years (s.d. = 4.85) for low-functioning ASD and 3.79 years (s.d. = 4.17) for the high-functioning ASD group.

That the Commission maintains, in public, that ASD does not generally meet the Commission's reduced life expectancy criteria is tragicomic. For **the Ombudsman to give credence to its claims here would be very unfortunate**. It would reduce the chances of **rights holders with an ASD** to claim 100% reimbursement. She could ask h**ow many false decisions has the JSIS made with regards to ASDs on the untrue grounds – as we now know - that it does not involve a shortened life expectancy.**

We do, of course, ask for the GIPs to state that reduced life-expectancy should not be sufficient criteria or serious illness. But she should draw attention to the Commission's track record, as affirmed by the ECJ and their answer above, to misuse and abuse the criterion.

23. Learn to Sum Things up

> *"iv) The Ombudsman inquiry team asked whether the criteria set out by the Commission to recognise a "serious illness" risk being disproportionately disadvantageous (or disproportionately difficult to satisfy) for persons with disabilities.* ***By way of reply, the Commission noted that the four criteria used to recognise a "serious illness" are inter-dependent****."*

They are obviously not interdependent in any clinically justified, evidence-based, scientific, or logically coherent way, as the Commission's answers will also show. First, several contradictory requirements are placed with regard to the expected duration of the condition. The "need for aggressive diagnostic and/or therapeutic procedures" can last for a very short time, for example to diagnose and/or avert an acute risk of death. This risk may involve a binary outcome: imminent death or recovery. Conceptually and medically

speaking, such situations need not involve any risk of or degree of disability to be extremely serious.

The same needs can also persist a very long time in the case of a ”drawn-out” illness. The presence of a serious disability is definitely of an indeterminate and typically, very long duration, and is different from a ”drawn-out” illness, which, by definition, can come to an end and be ’healed’. Nevertheless, the same need for ”aggressive” interventions may persist. Lastly, the relevant time frame for a ”risk” of a serious disability is rather indeterminate.

In sum, these conditions cannot by any standards be considered conceptually interdependent and coming together in the concept of a ”serious” illness. To recap, **a ”serious illness” cannot, at the same time, risk being short term (fatal), medium term (”drawn-out”), and permanent (as in permanent disability) and require aggressive measures in the short run only, the medium run only, and for the duration of a ’standard’ expected life time as may be the case with a serious disability**.

Second, there is a wide scientific consensus that expected life-time and disability are not interdependent in the way that the Commission asserts. It is for such reasons that the WHO, and the scientific community, have taken to analysing health policy in terms of years lost to disability (YLDs) and Disability-Adjusted Life Years (DALYs), and other measures that are sensitive to the quality of life. This measure holds that **reduced life expectancy (years of lost life) and years lost to disability are independent additive variables**. While there are other legitimate ways to measure the value of health interventions, the wide, if not uncritical, acceptance of DALYs shows that the concept of “serious illness” adopted by the JSIS, which holds that disability and life expectancy are interdependent (and not additive) variables, shows that **the Commission’s concept of “serious illness” would find no backing in the relevant scientific community**.

The Ombudsman should recommend that the JSIS operationalise its decisions by using measures of health care needs where additional life years with disability are a not a reason *per se* to reduce coverage. Disability should be addressed as such. **Measures to improve life expectancy (or reduce it, in the case of euthanasia), should be**

addressed separately in the criteria for serious illness, and reimbursements in general.

24. Bigger Boxes for the Non-disabled

> *"The four criteria, which serve as guidelines to assess each case in a holistic way, are not applied in any kind of automatic fashion. The Commission's GIPs are therefore interpreted in the light of the UNCRPD."*

This is nonsense. For reasons stated above, it is obvious that JSIS cannot and does not apply an 'all boxes ticked' approach or make automatic decisions. **It is fairly obvious that it classifies avoidable imminent fatalities as serious illnesses, even if there is little or no risk of serious disability.** Otherwise, it would not be **spending close 30% of its reimbursements on serious illness**. There are not enough persons with serious disabilities who would qualify for 100% reimbursement to account for such high spending. It those with **a real or incorrectly imputed risk** of serious disability who, by all accounts, must be receiving the bulk of the money.

To reach UN CRPD compliance, the **'not all boxes ticked' approach should be applied in a non-discriminatory fashion**. The Commission's answer proves that this is not the case.

The criteria are **stacked against persons with serious long-term health needs**: the absence of a shortened life expectancy is easy for the JSIS to argue, since the burden of proof is placed on persons to show that their life expectancy is shortened. The autism spectrum disorder (ASD) case is proof of that. The **Commission could not be bothered to check** what the epidemiological literature actually says about ASDs.

On the whole, there is little or no statistical data, where uniform, clinically relevant types of serious disability are discrete variables, for which life expectancy data exists. **In cases, where such data exists, such as ASDs, Down's syndrome, spinal injuries, or mental health problems, we know that the JSIS by office has abused, and continues to**

abuse, as well as crassly ignore, mortality data. We see it doing so with regard to ASDs in this inquiry.

Moreover, the criterion is stacked against persons, in the case of whom it is difficult to say whether and how a medical intervention changes their life expectancy. This is very often the case of children. Such a bias is extremely serious, since children are exceptionally vulnerable and their rights should need to be protected strongly and as a matter of priority, as the ECJ, too, has recently made clear to the JSIS ((F-76/15, FY vs the Council).

The further problem arises from the fact that since GIPs are contradictory as regards the time duration it is impossible to draw clear guidance from them. The applicant would not understand what the rules are about**.** The absence of an adequate concept of disability in the GIPs may also be detrimental to persons with disabilities by enabling an unjustifiably more favourable treatment of persons without disabilities.

The rules should also make it clear that in **cases where a reduced life expectancy is initially present, a higher reimbursement can well be continued, even the prognosis of life expectancy improves, should the seriousness of the illness or disability warrant it according to the 'not all boxes ticked' approach**.

25. Suggestions on Life-expectancy and Serious Disability Criteria

Here are some of our suggestions for the Ombudsman summarised:

- shortened life expectancy should be considered a **non-necessary, independent** and non-cumulative criterion of a serious health condition.
- ICF and ICF "core sets" should be mentioned as a consensus framework, WHODAS 2.0 should be mentioned as an option,
- additionally, nationally recognised serious disability should be automatically recognised

- as regards the component of serious disability, each of the criteria of the impact of disability in WHODAS 2.0 is linear and additive, and the same pattern should hold in the assessment by the JSIS.
- the long, even difficult-to-determine life-expectancy of a person, especially that of a child or a person with serious disability, **should not be a disadvantage** in obtaining higher reimbursement.
- The Commission should be asked to keep, and periodically publish, statistics of the **handling of cases involving identifiable as well as recognised and non-recognised disability, and respective reimbursement decisions (denied/granted, reason) using e.g., the ICF-10 level,**
- **Even if reduced life-expectancy has been a criterion of a decision, its renewal should not be automatically be conditional on the continued presence of the criterion. The evolution of the state of health should be decisive.**
- It should adopt a statistical methodology, and ICF and other relevant coding, for case handlers to keep such statistics.

26. Commission contradicts itself Sentence by Sentence

> *"By way of conclusion, while the Commission will always take account of all four criteria (in this sense the criteria are "cumulative"), there is no threshold for each criterion viewed in isolation from the other three criteria."*

It should not take the four criteria cumulative, and the thresholds should be viewed in isolation.

> *"If a person meets one criterion to a very large extent, this may compensate for the fact that the person does not meet another criterion to a significant extent."*

Contradicts the previous claim. This one is a **non**-cumulative notion of serious illness, **where each condition is effectively considered in isolation**, and then summed up. The **inability of the Commission to use standard - even elementary - medical language flatly contradicts their claim that the JSIS is, per force, medical**.

> *“The Commission noted that the existing criteria are "vague / general" on purpose. They allow the necessary flexibility for PMO to deal with a wide and very diverse range of cases.”*

Self-contradictory tinfoil hat stuff. If the Commission argues that its approach is medical, it should not defend “vague” concepts where the health, welfare, and rights of beneficiaries are involved.

Both ICF core sets and WHODAS 2.0 are designed to cover a “wide and very diverse range of cases” in a clinically valid **non-vague** manner. It is true that validity does not mean that they cover all of (serious) disability according the WHO. But WHO work is a rational and defensible consensus starting point in this area.

> *“More specific criteria would limit this possibility.”*

Logically unsound. The Commission has just effectively argued for (non-cumulative) additive criteria. Even a child would understand that introducing more (non-cumulative) additive criteria allows for more things to be taken into account (better fit, higher validity). This increases, instead of limiting, the scope for flexibly by better covering aspects of serious disability from the outset.

The **Ombudsman could state that there is a wide discrepancy between the goals cited by the Commission in its reply, on the one hand, and those of the UN CRPD as well the WHO global disability action plan 2014-2021**: better health for all people with disability (WHO, 2015), on the other hand. The WHO action plan is ”directed at improving the health, functioning and well-being of people with disability” “in line with” the UN CRPD.[4]

The Commission’s reply identifies no obstacles, refers to no human rights, and presents no goals for improving the health situation of persons with disabilities.

[4] http://apps.who.int/iris/handle/10665/199544

27. Safety Net misrepresented

> *"The Commission also referred to Article 72(3) SR which provides for special reimbursement in case of heavy expenditure. It provides a safety-net where the total expenditure not reimbursed for any period of twelve months exceeds half the officials' basic monthly salary or pension."*

Materially misleading and deceptive. The clause is discretionary so there is no fixed net there for anyone to jump into. Payments "shall be allowed" but there is no requirement to make them. The Commission has provided no data concerning persons eligible, and payments made. A beneficiary cannot base their health care decisions on the assumption that such a payment will, in the end, be made.

A person who **cannot afford to pay for care in the first place cannot**, of course, benefit from a safety net, even if it did exist.

The **Ombudsman should also draw attention to the asymmetry** that exists because there is a category of "costs deemed excessive by comparison with normal costs in the country where the costs have been incurred" but not an effective category of reimbursements **or level of care deemed insufficient** (Joint Rules Article 20(2)). In most EU countries, the health care system provides cost free or strongly subsidised health care to persons with disabilities on the grounds of their disability. This may well entitle to more the 100% reimbursement under the GIPs, given its restrictions.

The same care, if available on the free market, may well be deemed "excessive by comparison with normal costs in the country where the costs have been incurred", if the normal costs are heavily subsidised and lower. Further, if one's costs are not reimbursed because found excessive in the first place, there is no safety net and *ex post* top up.

28. Discrimination in recruitment

Article 23 the Joint Rules of the JSIS allows the institutions to **exclude a temporary official or contract agent from reimbursement from ”certain” expenses by the JSIS.** The rules set no limits to the causes, conditions, or types of expense from which the person can be excluded from. Disability is, indeed, an acceptable reason for the institutions to exclude a person, because the person may start to receive reimbursements after two years if ” the sickness or invalidity has not reappeared or given rise to unusual sequelae in the course of the said period.” **The clause is discriminatory and ought to be revised.**

The EP DSG suggests that the Ombudsman further asks, why contract staff who are excluded from certain benefits of the JSIS upon recruitment on the grounds of disability (or other grounds) still pay the same JSIS contribution?

29. Lack of Guidance creates Legal Uncertainty

> ***“****v) (…) In the context of an Article 90(2) complaint the complainant may provide all documents, which he/she considers important to support his/her claim (including medical opinions/reports issued by doctors of the complainant's choice).”*

Disingenuous. The Commission has already admitted that the concept of serious illness is deliberately “vague” and that no guidance on the concept of disability is offered in order to maximise the flexibility of the JSIS. The applicant has no tangible administrative guidance on what is **“important” according to the JSIS**. **This is a recipe for arbitrary, unjust and unlawful decisions**, for which the JSIS has an increasing notoriety.

> *“a Medical Officer, who re-analyses the file and issues a reasoned opinion ("avis circonstancié").”*

We refer to the EC DSG comments on the whole.

30. Systemic Issues need System to become issue

> *"If required, the specific case may be presented to the Medical Council[4], e.g. where the individual case is particularly difficult or where it may (potentially) concern a greater number of cases ("systemic issue")."*

Vexatious. What would be a systemic issue? Are ASDs one? Perhaps, but the Commission is wrong about ASDs and mortality, so a "systemic" decision here would just do more damage. Perhaps there has been one but how do we know. **This is below the minimal standards of transparency required from a public administration.**

More generally, without a logically consistent and medically valid concept of serious illness, a risible notion of "flexibility", and vague criteria, of which the Commission cannot even say if they are cumulative or not, the very idea a "greater number of cases" or "systemic issue" makes little or no sense. If the Commission has an idea of a "system" or what constitutes a "greater number of cases", surely it should make this information public, and part of the GIPs, or 'soft rules', so as to act like an orderly and regulated administration. **Incompetence should weeded out**.

> *"Where the point at issue is of a medical nature, the Management Committee may seek expert medical advice before giving its opinion."*

We refer to the EC DSG answer.

31. Reasonable Accommodation

> *"Besides the JSIS medical reimbursement, there are three other types of benefit outside the JSIS for persons with disabilities:"*
>
> *"iii) reasonable accommodation"*

The Commission's answer asserts that "other available forms of support such as those mentioned above as well **as the reasonable accommodation provided by the**

institutions in their capacity as employers **serve to compensate disadvantages resulting from other aspects of a disability".**

The idea of **disability as a disadvantage** and, in particular, the setting of the limits of disability actions at "compensation" for disability, are clearly at odds with the UN CRPD with regard to, for example, reasonable accommodation.

The UN Handbook for Parliamentarian's on the UN CRPD points out that

> The Convention stipulates that a failure to afford a person "reasonable accommodation" amounts to discrimination on the basis of disability. Consequently, any legislative definition of discrimination should include the denial of reasonable accommodation as an act of discrimination. Specific reference should be made to the definition of "reasonable accommodation" that appears in article 2 of the Convention.

Conversely, any definition of RA should state that denying it is an act of discrimination. It is notable that the Commission does not state as much in its answers. Neither does the Commission's Diversity Communication state this, although it does refer to the proposed Equal Treatment Directive, which does so (if someone bothers to follow the links).

> ***"****In case iii) the Medical Service may be asked to provide its opinion but the question is solely what reasonable accommodation must be provided by the Commission as employer in the work environment (special IT software, adapted furniture….) in accordance with Article 1d(4) of the SR."*

First, the process is **overly medicalised**. There should be **a RA board or comparable with representation of staff with disabilities**. Second, the **scope is also too limited** in relation to the UN CRPD, as the obligation to provide RA extends beyond the employment nexus i.e., the Commission as employer.

Third, as regards what is **reasonable**, the Commission's examples are very modest and limited and avoid, in a **dissuasive manner**, the inevitable **hard cases** such as **personal assistance, sign language interpreters, interpreters for deaf-blind**, as well as

notorious bottlenecks such as modifying the EPSO competitions, of which two of our members have complained to the Ombudsman, and a third visually impaired member complained directly to the EPSO for obvious failure to provide RA or design non-discriminatory tasks (to no avail).

The **Ombudsman should remind** the Commission that as a large organisation with a very large budget, **it is expected that it shall not find the harder cases to be a burden**.

As the UN Handbook notes on RA:

> In the case of employment, this might involve physical changes to premises, acquiring or modifying equipment, **providing a reader or interpreter** or appropriate training or supervision, **adapting testing or assessment procedures**, altering standard working hours, or allocating some of the duties of a position to another person.
>
> *"**Reasonable accommodation** may concern e.g. the adaptation of office equipment or flexible working arrangements. Reasonable accommodation is always provided for on a case-by-case basis."*

Misleading. **The Ombudsman should ask for** a **policy for reasonable** accommodation, under which individualised decisions are made. That is different from making case-to-case decisions in the absence of a policy.

The language of the answer on RA is that of **the Employment Equality Directive** which the Commission knows to be outdated in this regard.

> *"Social integration is the most important aspect of the **social aid scheme;"***

Deceptive. The UN CRPD aims at **full integration** and **enjoyment of rights**. First, the Commission does not pursue a human rights based policy in contradiction to the Convention. Second, the social aid scheme aims merely at a degree of **compensation** and facilitation instead of full enjoyment of rights. The Provisional Guidelines for Financial Aid illustrate the problem. An application

shall include a detailed assessment by the person concerned or his/her representative of **the measures necessary to offset the effects of the disability and facilitate social integration**.

32. Thresholds and Addition

> *"To benefit from **the social scheme** (for adults and children), a person needs to have a physical disability of at least 30% or a mental disability of at least 20%."*

The criterion is arguably not consistent with the Jette ruling. Consider a person who has a disability of 48 percent, which is very high, consisting of 29% of physical disability and 19% mental disability. The person can be denied aid on these grounds. We just had a case where 30% + 20% was not considered not to be equal to 50%, so we are not kidding. We managed to overturn the decision but most staff would not.

> *"The entitlement to reimbursement under that scheme is linked to the family income, meaning that there are specific thresholds."*

We refer to the EC DSG answer as to income and needs. The current rules make e.g., support for essential tools for communication dependent of family income, which is not compatible with affordable assistive technology (UN CRPD), given **the very high costs** of items that may be needed.

> *"As regards the **doubling of the dependent child allowance**, a degree of disability of at least 50% is needed in order for the allowance to be automatically doubled. In cases where the disability is below 50% but at least 30% in the case of a physical disability or 20% in other cases, the allowance will be doubled if the costs incurred are higher than the amount of the allowance."*

We refer to the EC DSG answer. As noted above, even some EU medical officers are unable to add 30 and 20 to get 50. The overall notion is unsound.

> *"the social aid scheme"*
> *"ii) the doubling of the dependent child allowance"*

We refer to the EC DSG's answer.

33. Information? Not more of this, please

> *"Persons with disabilities should have clear information on the non-medical benefits they might be entitled to receive. For this purpose, a special website is currently being developed covering all different forms of support."*

Self-serving and obfuscating. The Commission freely admits that it has not taken "all appropriate steps to ensure that reasonable accommodation is provided (Article 5(3)." There are other steps missing as well. **The Commission has just argued that JSIS information should be unclear to provide for flexibility.** Why should **only 'non-medical' information be clear?**

Further, if this website will contain the kind of **deceptive and evasive information given to the Ombudsman, it will not promote the enjoyment of rights under the UN CRPD.**

> *"Moreover, the request forms to be filled out by applicants for these benefits have been made more user-friendly in cooperation with representatives of persons with disabled family members."*

We refer to the answer of the EC group as to the degree of – i.e., the lack of - their participation. We note, and they would not disagree, that **the accessibility of the forms has not been aimed at or achieved**.

34. Refer to WHO APL explicitly

> *"vii)* ***There is no exhaustive JSIS list of assistive devices and therapies that can be reimbursed****. There are, however, three categories: devices explicitly covered by the JSIS (such as manual wheelchairs), devices explicitly excluded from JSIS reimbursement (****such as cars****); some items might be eligible for reimbursement under the social scheme, and a "grey zone" of devices that might be reimbursed (such as electric wheelchairs) depending on a case-by-case assessment. In these cases, the Medical Council is asked for an opinion."*

This complete mess is nothing but maladministration. Systemic issues have already been covered, some examples need to be added. The total **ban on reimbursing cars** by the JSIS is **disproportionate and unnecessary**. **Some heavy-duty wheelchairs may have to be registered as cars** under national law, so the ban on cars is simply **anti-disabled** (personal communication of a seriously disabled trainee, whose customised wheelchair had to be registered as a car in her country of origin). This ban alone means **she would spend a large fraction of her yearly income** for something that she absolutely needs to have reimbursed.

It is **ridiculous** that **the Medical Board** has to give its opinion on e.g., an electric wheelchair. First, the need will be obvious: the contraindications for a manual wheelchair are extremely well known. Second, the need is also obviously immediate, whereas the process is deliberately slowed down. Second, there is **a huge literature on the uselessness, in many circumstances, of manual wheelchairs,** which is the default option.

> *"The absence of a detailed list allows for more flexibility, which is necessary in dealing with disability related health needs."*

Why and how? Differential treatment of persons with disabilities should be justified, necessary and proportionate. The Commission makes no effort to answer the question. Flexibility only seems to mean **more flexible and more frequent denial of aid**. A non-exclusive list gives legal certainty and improves **flexibility beyond the baseline**.

We ask the Ombudsman to refer to the WHO APL in her final document. "The APL is designed to support WHO Member States to fulfil their commitment to improve access to assistive products as mandated by the United Nations Convention on the Rights of Persons with Disabilities (CRPD)." Otherwise, nothing will happen.

35. Inter-institutional Issues - inter-institutional Representation

> *"viii) Staff with disabilities, through their representative associations, will be involved in any decision-making process which concerns them (in accordance with the Diversity Communication that was adopted on 19 July 2017)."*
>
> *"The Commission highlighted that until recently no association of disabled staff formally existed."*

The Commission should also provide **time and capacity-building assistance for organizations of persons with disabilities to participate effectively in the governance of the JSIS**.

The **EDF exists and should be heard**, too. **The EP Disability Support** Group is more than a decade old and **should be mentioned and heard.**

The Diversity Communication does not cover the EP, and the Commission seems to distance itself from us.

Yet, the JSIS and the GIPs are inter-institutional, and representation should be as well.

36. Threats are not nice

> *"A different approach would entail a total reform of the system, meaning that the JSIS would have to be transformed from a sickness insurance scheme to a social security scheme covering both medical and non-medical aspects of*

disability. Such a reform would have major implications and would not necessarily benefit persons with disabilities."

This is misguided, as noted above. A total reformation of the way – which cannot possibly called a system – in which the Commission addresses or, rather, fails to address, its obligations under the UN CRPD, is required. As a first step, **a sound system should be put in place**.

It is **unfortunate** for the Commission to intimate at the end of a **thoroughly insincere** document that it has **the best interests of persons with disabilities in mind while threatening them with a worse outcome, should an effort to meet their needs in a way requested by them be made.** It does **not augur well** for the consultation of persons with disabilities, including children, and their representative organisations.