

Interessenvertretung

“Selbstbestimmt Leben“

in Deutschland e.V. – ISL

Mitglied bei

**„Disabled Peoples´ International”**

**- DPI**

Berlin, September 20th 2015

**Consultation on the topic:**

**The right of persons with disabilities to participate in decision-making**

Submitted by Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. – DPI Germany. DPI Germany is the umbrella organization of the Centers of Independent Living of persons with disabilities in Germany.

1. Please provide information on the legislative and policy framework in place in your country related to the status, establishment, resourcing, and functioning of representative organizations of persons with disabilities at the national, regional and local levels;

In Germany, representative organizations of persons with disabilities are quite diverse. ISL is a disabled peoples´ organization (DPO) meaning that mainly diversely disabled persons themselves work in and manage the organization. In contrast to self-help organizations that focus on specific diagnoses, DPOs do not receive support in functioning/ financing based on legal frameworks. It is the medical insurances that support self-help organizations in case of prevention and rehabilitation[[1]](#footnote-1). DPOs – those who work cross disabilities aiming at inclusion and political participation are not included within this framework, even though their approach includes the human rights perspective and does not focus on alleged deficits. Book 9 of the German Social Code regulates further measures, but political participation or empowerment of disabled persons is a not included prerequisite for support.[[2]](#footnote-2) Concerning awarding financial support out of the compensation fund, organizations can be granted financial support by the “participation board”[[3]](#footnote-3) only in case their project deals with the topic employment. Again, political representation of DPOs is not being funded in general.

Based on a minor inquiry of the party BÜNDNIS 90/DIE GRÜNEN (alliance 90/ The Greens) on sustainable support of political and civil engagement the German Government acknowledged the limited resources of disability related DPOs in Germany. Their reply clearly shows the imbalance when it comes to project funding by the German ministries: DPOs receive less money for complex projects that last for two and a half years; other organizations receive huge funds for “only” hosting several workshops within one and a half years.[[4]](#footnote-4) Another minor inquiry of the party DIE LINKE (the Left) on the implementation of the CRPD in Germany[[5]](#footnote-5) clearly shows the imbalance of the distributions of funds. As a result, traditional welfare organizations or self-help organizations receive larger funds than DPOs. We call this ableism.

Currently the Federal Ministry of Labor and Social Affairs is working on guidelines to include disability issues within policy making processes. Furthermore the government is currently attempting to legally enshrine the funding of political participation of organizations of persons with disabilities.

1. Please provide information on existing legislation and policies aimed at ensuring that persons with disabilities and their representative organizations, including children with disabilities, are consulted and involved in decision-making processes that directly or indirectly concern them

and

**5.** Please explain whether and how persons with disabilities participate in monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities (art. 33, para. 3), and in the nomination of experts to the Committee on the Rights of Persons with Disabilities (art. 34, para. 3);

Germany`s National Action Plan[[6]](#footnote-6) concerning the implementation of the CRPD from 2011 does not focus a lot on participation. Regarding Art 33 of the CRPD it does describe the structural implementation concerning the focal point, the coordinating mechanism including its inclusion board (which is the highest decision making body in which civil society is involved) and its thematic committees.[[7]](#footnote-7) Regarding art. 33 of the CRPD, representatives of Disability-related organizations support/ accompany the Focal Point in its implementation of the National Action Plan via the so called Action Plan Committee that consists of ten members.

This shows the need for taking further measures and setting a standard (that must be developed with disabled persons themselves, so the process itself is participatory) that full participation of organizations can be guaranteed in the future. The German Disability Council (assembles most of the disability related organizations in Germany and can be understood as an Action Alliance) has developed concrete guidelines on participation[[8]](#footnote-8). Unfortunately these have not been recognized so far from the government.

The German civil society – here “CRPD Alliance” also submitted a joint parallel report to the CRPD treaty body. Almost 80 organizations remarked that political participation on eye level is not yet given in Germany and there is the urgent need to work on standards of participation.

1. Please provide information on any consultative body or mechanism established to consult and engage with representative organizations of persons with disabilities, including information about their composition, criteria for membership (nomination, appointment, election, etc.) and functioning;

The CRPD Monitoring Body of the German Human Rights Institute holds consultations of civil society on a regular base.

Within the health care system, The Federal Joint Committee (G-BA) is the highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds in Germany. In accordance with the regulations set forth in the 5th Book of the German Social Code, leading nationwide advocacy groups that represent patient interests or facilitate self-help for people in Germany who are chronically ill or have disabilities are entitled to take part in discussions and submit petitions, but not to vote[[9]](#footnote-9). The Patient Involvement Act sets forth the criteria an organization must fulfill to be recognized by the Federal Ministry of Health (BMG) as a leading nationwide advocacy group.

Close to this, within the German nursing care system, nationwide advocacy groups that represent persons in need for care are entitled to take part in discussions and advise since 2013. This is stated in §118 of the 11th book of the German Social Code[[10]](#footnote-10), but they are not allowed to vote and resources for taking part are not offered. Until now there is a lack of supportive structures and within this field there is no such construct as equivalent to the Federal Joint Committee. For organizations like ours, it means that our involvement happens on a volunteer bases without payment.

1. Please provide information on the efforts undertaken at national, regional and/or local levels to strengthen the capacity of representative organizations of persons with disabilities, in order to facilitate their participation in legislative, policy and other decision-making processes;

There has only been little effort in the past to support organizations like ours. Of course sometimes, as projects on empowerment or political participation are funded, we can push our matters forward to strengthen our capacity, but it is hard since every single project comes to an end at some point after one or two years. A first step of effort would be acknowledging the work of DPOs by setting up a definition of these organizations as the one of the CRPD Committee[[11]](#footnote-11). Until today the word DPO is claimed and used by many actors and distinctions are almost never made.

**6.** Please identify the main challenges faced by the diversity of persons with disabilities in participating in mainstream and disability-specific decision-making processes at the national, regional and local levels, including challenges faced by persons who experience multiple discrimination (e.g., on the basis of disability, age, gender, ethnic origin, geographical location).

In most cases accessibility is not guaranteed, so that diverse barriers are faced by persons with very diverse needs. We find it very disturbing, that participation is not understood correctly in Germany. In many cases politicians think that sending an invitation to a consultation means participation. This is not correct, since organizations want to discuss every topic that is related to disability and human rights, we claim to be truly involved and not just “heard”. This includes receiving information in accessible formats beforehand and after the meeting, this also means respecting us as DPOs as important experts on our topics since we ourselves live with disabilities. We hope that in the future DPOs are valued more and are made visible on all levels. Furthermore it means making a meeting accessible, providing reasonable accommodation if needed and it also means providing proper resources so we can fully use our right to participate on all levels of decision-making.

**7.** Please provide information on the existence of organizations of persons with disabilities in your country, including organizations of children and women with disabilities, as well as their composition and internal decision-making processes and procedures;

Members of the German Disability Council[[12]](#footnote-12) range from independent DPOs, self-help organizations based on type of disability/ illness to Germany´s traditional social associations. A list of the members can be found here: <http://www.deutscher-behindertenrat.de/ID25209>

Unfortunately, there is not a single children organization in Germany. There are only parents´ associations. There is a DPO called `Weibernetz` - a nationwide network from WomenLesbians and girls with disabilities.[[13]](#footnote-13)

**Contact:**

Interessenvertretung Selbstbestimmt Leben in Deutschland, ISL e.V.  
Wiebke Schär  
Tel.: +49(0)30/ 4057 3679  
Fax: +49(0)30/ 4057 3685  
Krantorweg 1  
13503 Berlin - Germany  
E-Mail: [wschaer@isl-ev.de](mailto:wschaer@isl-ev.de)

Internet: www.isl-ev.de

1. 5th book of the German Social Code, §20c Online available at: <http://www.gesetze-im-internet.de/sgb_5/__20c.html> [↑](#footnote-ref-1)
2. 9th book of the German Social Code §13, §29 [↑](#footnote-ref-2)
3. „Beirat für die Teilhabe behinderter Menschen“ as in § 64 of the 9th Book of the German Social Code. See <http://dejure.org/gesetze/SGB_IX/64.html> [↑](#footnote-ref-3)
4. See <http://dip21.bundestag.de/dip21/btd/18/056/1805612.pdf> , page 3. [↑](#footnote-ref-4)
5. See <http://dip21.bundestag.de/dip21/btd/17/145/1714503.pdf> [↑](#footnote-ref-5)
6. Short version in English: <http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a740-short-en.pdf;jsessionid=C8B241D62940A432702452A44B98C8D5?__blob=publicationFile&v=3> [↑](#footnote-ref-6)
7. Further detailed information in english via: <http://www.behindertenbeauftragte.de/SharedDocs/Publikationen/DE/StateCoordinationAgency.pdf?__blob=publicationFile> [↑](#footnote-ref-7)
8. P. 50-52 <http://www.deutscher-behindertenrat.de/mime/00060491D1274941874.pdf> [↑](#footnote-ref-8)
9. <http://dipbt.bundestag.de/doc/btd/15/015/1501525.pdf> [↑](#footnote-ref-9)
10. <http://www.gesetze-im-internet.de/pflebeteiligungsv/BJNR059900013.html> [↑](#footnote-ref-10)
11. see CRPD/C/11/2, Annex II: Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee [↑](#footnote-ref-11)
12. [↑](#footnote-ref-12)
13. <http://www.weibernetz.de/english.html> [↑](#footnote-ref-13)