

# BRK-Allianz (Eds.)

Alliance of German Non-Governmental Organizations Regarding the UN Convention on the Rights of Persons with Disabilities

## For Independent Living, Equal Rights, Accessibility and Inclusion!



**First Civil Society Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities in Germany**

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## Preface

The BRK-Allianz was founded in January 2012, with the purpose of participating in the review of the State report on the implementation of the UN CRPD in Germany, and of compiling a parallel report. Altogether, the alliance is comprised of 78 organizations, and thus essentially represents a wide range of disability politics associations in Germany.<sup>1</sup> Most of these organizations emerged from the fields of self-representation of persons with disabilities, disability self-help associations, and social associations.<sup>2</sup> Other members include welfare organizations, expert associations concerned with supporting persons with disabilities, psychiatric experts as well as professional and expert organizations from the educational field, development work, parents' associations and trade unions.

The BRK-Allianz compiled this joint report<sup>3</sup> on the implementation of the UN CRPD in order to lay it before the UN Committee on the Rights of Persons with Disabilities. The associations involved made a strong effort to build their arguments with extensive consideration of all persons with disabilities, and to deliver a well-balanced account of issues to ensure equal participation. For this reason, we refrained from emphasizing specific types of impairments. We do, however, give examples of specific impairments and participation barriers for the purpose of ensuring clarity. We draw examples from as many areas as possible in order to mirror the diversity of associations represented in the Allianz. Since the CRPD regards persons with chronic health issues as disabled persons, we do not distinguish between these groups in this report.

## Legal Notice

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<sup>1</sup> Please refer to the annex for a complete list of the associations involved in the compilation of this report.

<sup>2</sup> Throughout this report, the BRK-Allianz mainly uses the term “persons with disabilities”, in accordance with the language standard set by the UN CRPD.

<sup>3</sup> The arguments and calls for change in the present report correspond with the range of focus areas and the aims of the individual civil society organizations that contributed to the report. All of the involved organizations share the intention of presenting a joint report from a civil society perspective. However, not every assessment and recommendation included in this report is shared by all of the involved organizations.

## Executive summary

**Implementation:** The UN CRPD is deemed to be binding law in the Federal Republic and in the federal states (“Länder”). It establishes a great need for action because a consistent human rights perspective has not yet been adequately implemented in German policy and legislation concerning persons with disabilities. Unfortunately, in their memorandum, the Federal Government relativizes the necessity of implementation in many instances. The Federal Government is considerably less decisive within Germany than they were in the international context prior to the adoption of the Convention.

**National Action Plan:** The Federal Government’s National Action Plan for the implementation of the UN CRPD does not represent a satisfactory implementation of the CRPD goals. It does not hold the Länder and the municipalities responsible, even though Article 24 CRPD for example defines them as the key authorities in charge of inclusion in the education system. Likewise, the actual content of the NAP is disappointing. Although it lists more than 200 individual steps, these steps often lack ambition. Other specifically listed cross-cutting issues, such as migration, remain largely unconsidered in these measures. There is a lack of binding, verifiable goals that the NAP is supposed to achieve. Many of the measures listed in the NAP do not include specific targets and an implementation schedule. As a result, it is not possible to measure the results or monitor the implementation of the CRPD.

**Participation in translation:** The German Federal Government fails to fulfil its obligation to ensure the participation of persons with disabilities by consulting the organizations that represent them. When the CRPD was translated into German, civil society was not involved. As a result, the official **translation** contains considerable mistakes and is unsuitable for the aim of awareness-raising (Art. 8). For example, “inclusion” was translated as “Integration” instead of using the correct term “Inklusion”. Since the persons responsible refused to correct their mistakes, German self-representation organizations found themselves forced to compile a “shadow translation” with the correct terms. In the meantime, the Federal Government started to use the term “Inklusion”, but did not prompt a binding correction of the faulty translation up until this day.

**Participation of civil society - State Report:** While people with disabilities and their associations do participate in many committees and have been invited to numerous conferences, this participation does not qualify as **equal**. The BRK-Allianz holds the opinion that the state does not comply with the CRPD’s participation stipulation, but simply continues to use the current dominant modes of participation. The BRK-Allianz calls for a new conception. The state would need to define how exactly this new type of participation could be implemented in cooperation with civil society. The **State report** was not compiled with close consultation or active involvement of organizations representing disabled persons. In general, the BRK-Allianz is under the impression that the State report does not represent an evaluation of the CRPD’s implementation based on the premises of human rights during the reported period. Instead, the State report seems to serve merely as a representation of the legal situation in the Federal Republic of Germany.

The main deficits and challenges for comprehensive reforms primarily lie in the following areas:

## **1. Concept of reasonable accommodation**

In the CRPD, the notion of “reasonable accommodation” represents an essential tool for ensuring non-discrimination and equal opportunities. However, German law provides for very few “reasonable accommodations”, and those that do exist are not explicitly designated as such. If “reasonable accommodation” is withheld, the German law does not yet provide for any penalties as the denial of reasonable accommodation is not considered as discrimination.

## **2. Accessibility - private sector**

Instead of stipulating a binding legal obligation for private businesses, German law only provides for the possibility to negotiate accessibility target agreements between companies and business associations and disabled persons’ organizations. However, private businesses are not placed under any obligation to do so. Therefore, only a small number of agreements have been negotiated. This did not result in a comprehensive improvement of accessibility. A binding legislation for private businesses is overdue.

## **3. Equal recognition before the law**

While the German guardianship law includes a few references to the principle of “support”, it is still based on the principle of “substituted decision-making”. Consequently, there is a need for additional changes to the law, so that it is possible to implement Art. 12, Para. 3 UN CRPD, which obligates the States parties to make sure that persons with disabilities can access the support they may need in order to exercise their legal capacities (“supported decision-making”).

## **4. Liberty and security of the person - Protecting the integrity of the person**

Several German laws allow for the institutionalization of individuals against their explicit will. Consignments to public institutions are subject to different stipulations in the Länder, and provide for the possibility to institutionalize individuals in order to prevent endangerment to themselves and to others. - Compulsory treatment and forced medication are serious violations of the right to physical integrity. In psychiatric institutions, this norm is violated in many ways in the course of the daily routines. The percentage of compulsory institutionalizations varies considerably between the Länder, as well as between the districts within the Länder. The use of coercion depends on different legal stipulations and procedural laws that are specific to the individual Länder, as well as on the regional care conditions. Up until this day, psychiatric treatments frequently take place without the informed consent of the individual concerned. During treatment, the staff may use threats and violence, which is traumatic for many of those concerned. There are very few measures that provide for out-patient crisis intervention.

## **5. Freedom from exploitation, violence and abuse**

Women with disabilities are two to three times more likely to be victims of sexual violence than women without disabilities. Approximately 74% of these women have been exposed to physical and psychological violence, which is twice the percentage when compared to women without disabilities. Another issue is the structural violence within institutions, such as the lack of single private rooms, bathrooms and toilets that cannot be locked, etc.

## **6. Living independently and being included in the community**

Many persons with disabilities in Germany are not free to choose their place of residence, type of housing and receive the necessary support. They cannot put their right to self-determination into practice for various reasons. For example, persons with disabilities must therefore, to some extent against their declared will, live in in-patient facilities because the necessary assistance and support services as well as nursing services are provided more cost-effectively here than in their own home.

## **7. Inclusive education**

Germany is a long way from inclusive school education. The integration of children with disabilities amounts to 62% in preschools and kindergartens, 34% in primary schools and only 15% in high schools. This places Germany far behind when compared to other international systems.

The education system lacks committed collective action from authorities on the Federal and Länder levels. The Federation does not sufficiently assume its responsibilities. In contrast to other Action Plans, the Federal Government's CRPD National Action Plan entirely disregards the Länder and the municipalities, even though they are given key responsibilities when it comes to education. The Federation and many of the Länder assert that there is hardly any need for action resulting from Art. 24 CRPD with regard to the education system.

Among providing the regulatory framework higher education institutions have to raise awareness to promote positive perceptions towards students with disabilities especially for students with impairments which are not visible (e.g. students with dyslexia and psychological impairments).

## **8. Work and Employment**

In Germany, persons with disabilities are much more often affected by unemployment than other people. The unemployment rate for severely disabled people reached 14.8% in 2011, while the general unemployment rate was 7.9%. - In "sheltered workshops for persons with disabilities" (WfbM) the number of persons with disabilities who are permanently employed increased from 211,246 in 2005 to 248,441 in 2010. This partly results from the lack of job opportunities on the regular labor market. Women remain in WfbM for longer periods of time as compared to men, and they are less likely to transition into the regular labor market.

## **9. Adequate standard of living and social protection**

Disability in Germany also means poverty and discrimination. Programmes enabling participation in community life are means-tested. Persons with disabilities are as a result permanently restricted in their opportunity for economic development and set at a low level throughout their lives.

## **10. Exclusion from the right to vote**

A person for whom a guardian is not only appointed by an interim order to manage *all their affairs* is excluded from the active and passive right to vote in Germany. Persons who have committed an offence in a state of absence of culpability and are housed in a psychiatric hospital are also excluded from the right to vote. This general exclusion of mentally handicapped persons from the right to vote is also discriminatory, as offenders without disabilities may normally vote.

## **A. CRPD Implementation, Action Plan and State Report. General Assessment**

Germany is a signatory party to the UN Convention on the Rights of Persons with Disabilities (Disability Rights Convention, or CRPD) as well as of the Optional Protocol (signed by Germany in 2007, ratified in 2008, and promulgated on March 26, 2009). In June 2011, the German Federal Government adopted a National Action Plan (NAP) for the CRPD implementation. The first State report<sup>4</sup> was published in August 2011, and was presented to the CRPD committee at the time.

The UN CRPD is considered to be binding law in the Länder (the Federal States) and the Federal Republic as a whole. This results in a considerable need for action, as a consistent human rights-based perspective remains widely absent from German disability politics and legislation.

### **I. Content Implementation of the UN Convention on the Rights of Persons with Disabilities (Disability Rights Convention, CRPD)**

Unfortunately, in their memorandum<sup>5</sup> the Federal Government relativizes the necessity of implementation in many instances. For example, they contend that the German legislation on the deprivation of liberty with regard to institutionalization corresponds entirely with CRPD stipulations (Art. 14).<sup>6</sup> Likewise, they maintain that the German education system already includes “manifold compliances” with the CRPD’s Article 24. On the same note, the standing conference of the ministers of education and cultural affairs of the Länder in the Federal Republic of Germany [*Kultusministerkonferenz/KMK*] asserted that the legal situation in Germany essentially corresponds to the standards stipulated in the CRPD.<sup>7</sup> In this respect, the Federal Government is considerably less decisive within Germany than they were in the international context prior to the adoption of the Convention. The BRK-Allianz finds fault with this, and emphasizes the tremendous need for responsive action in accordance with the UN CRPD in Germany.

The appointment of the German Institute for Human Rights [*Deutsches Institut für Menschenrechte*] as the monitoring body, the deployment of a coordination mechanism and the associated committees, and the political intention to draft an action plan, can be considered examples of the structural implementation of the CRPD. However, this is not the case when it comes to content implementation, which has either not been taking place, or remains poorly administered.

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<sup>4</sup> CRPD.C.DEU.1\_en vgl. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>.

<sup>5</sup> Not only the memorandum, but also the first State report of the Federal Government relativizes the necessity of implementation in many instances. See BT-Drs.-Nr. 16/10808.

<sup>6</sup> Draft law of the Federal Government on the UN Convention on the Rights of Persons with Disabilities (December 13, 2006), and on the corresponding Optional Protocol (December 13, 2006), BT-Drs. 16/10808, p. 58: “[...] when looking at core themes in educational politics in the individual federal states of the Federal Republic of Germany, one can see numerous congruencies.”

<sup>7</sup> “Educational and legal aspects of the implementation of the United Nations Convention on the Rights of Persons with Disabilities (December 13, 2006)”, agreement of the Standing Conference of the Ministers of Education and Cultural Affairs of the Länder in the Federal Republic of Germany (KMK) from November 18, 2010, p. 2: “The German legal situation essentially complies with the standards of the Convention.”

## II. National Action Plan (NAP)

The Federal Government's National Action Plan for the implementation of the UN CRPD<sup>8</sup> does not represent a satisfactory implementation of the CRPD goals. It does not hold the Länder and the municipalities responsible, even though Article 24 CRPD for example defines them as the key authorities in charge of inclusion in the education system. However, this would have been entirely possible, as we can see with the example of the action plan "For a child-friendly Germany 2005-2010"<sup>9</sup>, when the Federal Republic, the Länder and the municipalities defined their joint obligations and agreed upon common measures.

Likewise, the actual content of the NAP is disappointing. Although it lists more than 200 individual steps, these steps often lack ambition (such as reissuing an information leaflet on the reconstruction of buildings to fit the needs of senior citizens<sup>10</sup>). Moreover, some of the steps disregard the specific interests of persons with disabilities (patients' rights act/*Patientenrechtegesetz*) or were compiled without considering the CRPD (2008-2011 model scheme for the cooperation between agricultural enterprises and "sheltered workshops"[*Werkstätten für behinderte Menschen/WfbM*]).<sup>11</sup>

Other specifically listed cross-cutting issues, such as migration, remain largely unconsidered in these measures. For example, the plan only lists two campaigns in cooperation with the federal commissioner for migration, refugees and integration [*Beauftragte der Bundesregierung für Migration, Flüchtlinge und Integration*]; however, these campaigns were not specifically initiated to help implement the UN CRPD.<sup>12</sup>

In contrast to the stipulations issued by the German Institute for Human Rights [*Deutsches Institut für Menschenrechte*]<sup>13</sup>, there is a lack of binding, verifiable goals that the NAP is supposed to achieve. The Federal Government displays very little determination; for instance, despite the considerable increase in the unemployment rate among severely disabled persons<sup>14</sup>, the Federal Government confines itself to "raising awareness" among employers and to "support their commitment"<sup>15</sup> when it comes to professional training and employment of disabled persons, instead of defining specific goals for companies with regard to the employment of persons with disabilities. Many of the measures listed in the NAP do not include specific targets and an implementation schedule. As a result, it is not possible to measure the results or monitor the implementation of the CRPD.

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<sup>8</sup> National Action Plan of the federal government with regard to the implementation of the UN CRPD (NAP): "Our path towards an inclusive society", date of publication: September, 2011 (hereafter abbreviated as NAP).

<sup>9</sup> National Action Plan "For a child-friendly Germany 2005-2010", accessible at: <http://www.kindergerechtes-deutschland.de/zur-initiative/nationaler-aktionsplan>.

<sup>10</sup> See NAP, p. 162.

<sup>11</sup> See NAP, p. 128.

<sup>12</sup> See NAP, p. 130 and 179: Continuation of the "Charta der Vielfalt" and "Aktion Zusammen wachsen".

<sup>13</sup> Deutsches Institut für Menschenrechte (ed.): Aktionspläne zur Umsetzung der UN-Behindertenrechtskonvention. Positionen der Monitoring-Stelle. Berlin, September 2010.

<sup>14</sup> In 2009, 167,000 severely disabled persons were unemployed. In 2010, this number increased to 175,000, and in 2011, 180,000 severely disabled persons were unemployed. This is in direct contrast to the general decrease of unemployment in Germany since 2009.

<sup>15</sup> See NAP, p. 129.



### III. Translation Issues – Involvement of Civil Society – State Report

The international CRPD slogan was “Nothing about us without us!” However, the German Federal Government fails to fulfil its obligation to ensure the participation of persons with disabilities by consulting the organizations that represent them (participation stipulation, see esp. Art. 4, Para. 3).

When the CRPD was translated into German, civil society was not involved. As a result, the official **translation**<sup>16</sup> contains considerable mistakes and is unsuitable for the aim of awareness-raising (Art. 8). For example, “inclusion” was translated as “Integration” instead of using the correct term “Inklusion”. The term “living independently” (Art. 19) was translated as “unabhängige Lebensführung”, while “Selbstbestimmt leben” would have been the better option. The notion of “accessibility” (Art. 9) was translated as “Zugänglichkeit”, while the BRK-Allianz regards “Barrierefreiheit” as the appropriate term. Since the persons responsible refused to correct their mistakes, German self-representation organizations found themselves forced to compile a “shadow translation”<sup>17</sup> with the correct terms. In the meantime, the Federal Government started to use the term “Inklusion”, but did not prompt a binding correction of the faulty translation up until this day.

While people with disabilities and their associations do participate in many committees and have been invited to numerous conferences<sup>18</sup>, this participation does not qualify as **equal**. For example, many civil society associations issued statements regarding the NAP, but this did not result in any changes. The associations that cooperate with the German Disability Council [*Deutscher Behindertenrat/DBR*] made precise suggestions about how to promote better participation during the compilation of the NAP.<sup>19</sup> The BRK-Allianz holds the opinion that the state does not comply with the CRPD’s participation stipulation, but simply continues to use the current dominant modes of participation. The BRK-Allianz calls for a new conception. The state would need to define how exactly this new type of participation could be implemented in cooperation with civil society.

The introduction of the first **State report** mentions the “inclusion of civil society [...] under the umbrella of the CRPD” with regard to equal participation. However, in contrast to Art. 35, Para. 4(2) CRPD, the State report was not compiled with close consultation or active involvement of organizations representing disabled persons (Art. 4, Para. 3 CRPD). Civil society was presented with a nearly finished draft of the State report, and was asked to submit their contributions and suggestions for change in written form, within a period of approximately two weeks. In the opinion of the BRK-Allianz, these proceedings do not represent a target-oriented contribution to the State report by civil society. During a hearing of the associations, most suggestions from the civil society regarding the NAP were not taken into consideration. Therefore, most civil society organizations decided to refrain from such statements, and to compile a parallel report instead.<sup>20</sup>

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<sup>16</sup> <http://www.kompre.de/brk/attachments/article/72/BMAS%20-%20Deutsch-abgestimmte%20uebersetzung.pdf>

<sup>17</sup> [http://www.netzwerk-artikel-3.de/attachments/093\\_schattenubersetzung-endgs.pdf](http://www.netzwerk-artikel-3.de/attachments/093_schattenubersetzung-endgs.pdf).

<sup>18</sup> See, for example, the conference “Teilhabe braucht Visionen” at: [http://www.einfach-teilhabe.de/DE/Service/UN\\_BRK/UN\\_BRK\\_Teaser/UN\\_BRK\\_dossier\\_neu.html?nn=1649116&notFirst=true&docId=1649348](http://www.einfach-teilhabe.de/DE/Service/UN_BRK/UN_BRK_Teaser/UN_BRK_dossier_neu.html?nn=1649116&notFirst=true&docId=1649348).

<sup>19</sup> See <http://www.deutscher-behindertenrat.de/mime/00060491D1274941874.pdf> (p. 50-52).

<sup>20</sup> See, for example, the press statement issued by the Deutscher Behindertenrat (DBR) from July 7, 2011.

In general, the BRK-Allianz is under the impression that the State report does not represent an evaluation of the CRPD's implementation based on the premises of human rights during the reported period. Instead, the State report seems to serve merely as a representation of the legal situation in the Federal Republic of Germany, which lacks nuanced data on the life situation and diversity of persons with disabilities. In this respect, the BRK-Allianz considers the present State report to be largely lacking in compliance with the stipulations set out in the OHCHR guidelines.<sup>21</sup>

**The BRK-Allianz calls for the following actions:**

- **The Federal Government shall immediately initiate precise legislative measures leading to the implementation of the UN CRPD in national legislation, as well as a scheme of sanctions in the case of nonexistent implementation.**
- **The official translation shall be changed in due consideration of the “shadow translation”.**
- **The Federal Government shall cooperate with persons with disabilities in order to compile binding standards of participation with regard to all areas of political planning and action, so that consistent participation is ensured.**

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<sup>21</sup> Document CRPD/C/2/3, October 2009.

## B. Implementation of the UN CRPD. Individual Articles

### Article 1 – Purpose

Persons with disabilities encounter numerous types of human rights violations. This is partly caused by implementation deficiencies and by legal regulations that do not yet comply with the CRPD standards. Even the recent definitions of “disability” (§ 2 Social Code [Sozialgesetzbuch] IX – SGB IX, 2001 and in the same wording, § 3 of the German equal opportunities for disabled people act [Behindertengleichstellungsgesetz/BGG], are still based on a medical notion of disability, thus holding the individual impairment responsible for participation barriers.<sup>22</sup> Other German legal codes are even more deficient when it comes to their notion of disability<sup>23</sup> and disregard barriers caused by environmental factors and societal mindsets.

**The BRK-Allianz calls for the following actions:**

**- A consistent definition of disability must be introduced into all relevant laws, and this definition must consider the CRPD guidelines.**

### Article 2 – Definitions

The State report is based on a narrow notion of **communication**, which only includes sign language, plain or easy-to-read language, and alternative formats for visually impaired persons. In contrast to this, the BRK-Allianz emphasizes a more comprehensive concept of communication, which also includes non-verbal communication, for example. Accessible communication cannot be limited to certain life areas or specific contexts (such as administrative proceedings), but must be available in all aspects of daily life, and is indispensable for an inclusive education and schooling system. Even though the State report underlines the importance of disabled persons’ access to communication, few measures were taken in order to comply with this demand. For example, there is no definition of “plain language”, and there are no standards regarding its utilization. Likewise, there is no legal obligation to use “plain language”. The only legal obligation can be found in the accessible information technology decree [*Barrierefreie-Informationstechnik-Verordnung/BITV 2.0.*]<sup>24</sup>, a law requiring the Federal administration to provide accessible internet content on its homepage including the use of “plain language”.

In the CRPD, the notion of “**reasonable accommodation**”<sup>25</sup> represents an essential tool for ensuring non-discrimination and equal opportunities.<sup>26</sup> The state is obliged to guarantee

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<sup>22</sup> It states here that “persons are disabled if their physical function, intellectual abilities or mental health decidedly differs from the condition that is characteristic for their age group, over a period exceeding six months, and if their participation in social life is therefore impaired.”

<sup>23</sup> For example, § 1(2) of the decree on the promotion of integration [*Eingliederungshilfeverordnung*] according to § 60 SGB XII refers to “persons with considerable cleft lip and palate or spina bidida, or with disfigurements, especially in the face, that can appear as repulsive”.

<sup>24</sup> Accessible information technology decree [*Barrierefreie-Informationstechnik-Verordnung*], September 12, 2011 (BGBl.I., p. 1843).

<sup>25</sup> The following paragraph refers to 1) Deutscher Behindertenrat: Forderungen des Deutschen Behindertenrates für einen Nationalen Aktionsplan zur Umsetzung der UN-Behindertenrechtskonvention. Berlin, May 2010, p. 10/11; 2) Peter Masuch: Die UN-Konvention über

“reasonable accommodation” and can legally pass this responsibility on to private entities. However, German law provides for very few “reasonable accommodations”, and those that do exist are not explicitly designated as such (for example, § 81, SGB IX). Some of these accommodations are insufficient, or their funding is not guaranteed.<sup>27</sup> They are not inherently established by law. If “reasonable accommodation” is withheld, the German law does not yet provide for any penalties (see Art. 5).

In Article 2 of the State report, the Federal Government acknowledges that, “in view of the rising average age of the population and of a future increase in working lives, the significance of **universal design** will increase considerably”.<sup>28</sup> The State report does not specify how the Federal Republic of Germany intends to fulfill its obligation according to Art. 4, Para. 1(f) CRPD, to promote research on and development of universal design (UD), even though UD becomes more and more important in view of demographic change.

#### **The BRK-Allianz calls for the following actions:**

- **The BGG and the Länder laws on equal opportunities for disabled people (*Landesgleichstellungsgesetze/LGG*) must be completed with a clear definition and legal regulations on the use of “plain language”.**
- **In compliance with the CRPD, the notion of “reasonable accommodation” must be established in the Federation and Länder equal opportunities laws. Withholding “reasonable accommodation” must be legally defined and included as discrimination in the general act on equal treatment [*Allgemeines Gleichbehandlungsgesetz/AGG*].**
- **The issue of “universal design/design for all” in combination with “accessibility” requires a specific scheme of measures, and the development of norms and legal regulations (such as they were already implemented in other countries<sup>29</sup>).**

### **Article 3 – General principles**

The Federal Government does not acknowledge the Convention’s principles of “autonomy, non-discrimination and respect for difference” to a satisfactory degree. The issue of **multiple discrimination** is not sufficiently considered. This is true for the areas of “migration/asylum/refugees” combined with the feature “disability”, as well as for lesbians and gay men with disabilities<sup>30</sup> or persons with a need for intense or very specific support.

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die Rechte von Menschen mit Behinderungen vom 13. Dezember 2006. In: Wolfgang Schütte (ed.): Abschied vom Fürsorgerecht. Von der “Eingliederungshilfe für behinderte Menschen” zum Recht auf soziale Teilhabe. LIT Verlag, Berlin 2011, p. 75.

<sup>26</sup> “Reasonable accommodation” is referred to in CRPD Articles 2; 5 (3); 13 (1); 14 (2); 24 (2c, 5); 27 (1i).

<sup>27</sup> For example, persons with hearing or communication impairments do not have a legal right to obtain refunds for communication aids. Hearing impaired persons only have a right to obtain financial support for sign language interpreters or other communication aids in welfare services proceedings, their workplace, and their personal administrative and legal proceedings.

<sup>28</sup> For example, handles that are difficult to operate can be an insurmountable hurdle for people affected with rheumatism, and more generally speaking, for people with a limited grasping function. The same applies to flickering neon lights and their impact on persons with autism, or for intolerance against pollutants or chemicals.

<sup>29</sup> According to the Norwegian plan of action, the principles of UD should be fully implemented by 2025. See [www.universal-design.environment.no/the-plan-of-action](http://www.universal-design.environment.no/the-plan-of-action).

<sup>30</sup> See also the explications in UN CRPD preamble p.2) on national or ethnic origin.

According to the 2009 micro-census, approximately 16 million persons with a migrant background are living in Germany; this corresponds to 19.6% of the population. The official reports (see also the section on Art. 31) do not acknowledge persons with disabilities and a migrant background, and some researchers criticize the lack of sufficient data.<sup>31</sup> Referring only to the statistics on severely disabled persons and the criterion of “non-German citizenship”, the federal statistical office [*Statistisches Bundesamt*] reports a total of 317,935 severely disabled persons; 190,585 are men and 127,350 are women.<sup>32</sup> According to other surveys based on the micro-census and the criterion of “migrant background”, 11% among those persons living in Germany who have an officially recognized disability, also have a migrant background.<sup>33</sup> This corresponds to a total figure of approximately one million.

Persons with disabilities and migrant background experience multiple discriminations due to these two features. Comprehensible information on available support in their native languages is hardly accessible, and the majority of people working in counseling facilities do not receive any intercultural training.<sup>34</sup> On the grounds of real or supposed language deficiencies, a disproportional amount of children with disabilities and migrant background are attending special needs schools (see Art. 24). Upon completion of their schooling, they are often placed in a “sheltered workshop” [*Werkstatt für behinderte Menschen/WfbM*].

Germany is under the obligation to ensure special counseling for particularly **vulnerable refugees**, and to promptly provide them with the support they need.<sup>35</sup> In reality however, families with children who need intense care are placed in so-called reception centers [*Erstaufnahmelaager*], just like any other family. These centers are accommodation facilities for large numbers of people that are not accessible or barrier-free, and provide one single sleeping and “living” room for the entire family. They do not provide grasping-points or other aids in the collective toilets and bathrooms, or nursing beds, special food, and care persons.

Refugees who fall under the law on benefits for asylum seekers [*Asylbewerberleistungsgesetz/AsylbLG*], are not provided with any health insurance coverage during the first 48 months after their arrival. § 4, AsylbLG, states that health care will exclusively be provided to them in the case of acute or pain-causing conditions. In the case of chronic conditions, or physical and mental conditions, care measures are provided if and when they become acute and cause pain. § 6, AsylbLG, only provides other types of medical support if the investigation of an individual case proves that such measures are indispensable in order to maintain the person’s health. The decision about what is an indispensable care measure is left to the representatives who work for the financing agencies. In many cases, these representatives disregard the medical advice that was given. Moreover, it often takes them months to consider requests, even if these requests include a medical expert’s confirmation that prompt action is required.

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<sup>31</sup> See, for example, the second integration indicator report [*Zweiter Integrationsindikatorenbericht*] of the federal commissioner for migration, refugees and integration, December 2011, or the 2009 disability report [*Behindertenbericht*] of the Federal Government, p. 63.

<sup>32</sup> Status: December 2007, see Statistisches Bundesamt (ed.): *Wirtschaft und Statistik 2/2010*, p. 157.

<sup>33</sup> See Wansing/Westphal: *Teilhabeforschung, Disability Studies und Migrationsforschung verbinden*. In: *Orientierung 1/2012*, p. 12 et seq.

<sup>34</sup> See [http://www.bagfw.de/fileadmin/media/Projekte\\_2012/Gemeinsame\\_Erkl%C3%A4rung\\_2012-01-23\\_final.pdf](http://www.bagfw.de/fileadmin/media/Projekte_2012/Gemeinsame_Erkl%C3%A4rung_2012-01-23_final.pdf).

<sup>35</sup> 2003 EU directive (2003/9/EG), Art. 17-20, as well as the UNHCR conclusion on refugees and other persons with disabilities protected and assisted by UNHCR, adopted at the 61<sup>st</sup> session (LXI) held between October 4 and October 8, 2010.

Likewise, § 4 AsylbLG decrees that rehabilitation measures are limited to acute and pain-causing conditions. This means that in most cases, the financing agencies refuse to cover the costs accruing for necessary aids<sup>36</sup>, such as glasses, hearing aids, wheeled walkers, wheelchairs and incontinency care supplies.

Up until now, there are no scientific insights on the situation of **lesbians with disabilities** in Germany. They themselves report that their living situation as lesbians with disabilities is not regarded as normal, that they are excluded from the lesbian scene due to barriers, that sexual identities are not a topic of discussion within the disability movement, and that disability self-help institutions do not provide any information on events that address lesbian women.<sup>37</sup>

People with **extensive care needs**, or deaf-blind persons experience multidimensional impairments. This results in specific barriers preventing them from participating in social life. Consequently, they are in great need of assistance and support, interpretation, plain language, rehabilitation measures and aids in the fields of communication, information, mobility and their organization of everyday life. In many cases, the support provided to persons with disabilities that is supposed to enable them to participate in social life is not sufficiently tailored to their individual specific needs that result from their multidimensional impairments, either in terms of quality or in terms of quantity.

**The BRK-Allianz calls for the following actions:**

- **The UN Convention for the Protection of the Rights of All Migrant Workers and Members of Their Families (UN ICRMW) must be signed and ratified.**
- **The EU directive regarding the reception of disabled refugees must be aligned with the CRPD standards, and the corresponding UNHCR resolution<sup>38</sup> must be implemented.**
- **Surveys on the situation of persons with disabilities and migrant background must be compiled.**
- **Integration programs and services for disabled refugees and migrants, including language classes, must be accessible and barrier-free.**
- **The German law on benefits for asylum seekers must undergo significant changes, so that it ensures equal treatment of all persons with disabilities regarding the social services that they receive.**
- **Disability policy measures, and in general, any measures designed to improve the life situations of lesbians and gay men, must consider the situation of disabled gays and lesbians.**
- **Any measures designed to implement the UN CRPD must sufficiently consider multidimensional discriminations. Among other things, this means that the feature “TBL” [taubblind/deaf blind, or the severely visually and hearing impaired], must be introduced**

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<sup>36</sup> See [http://www.institut-fuer-menschenrechte.de/uploads/tx\\_commerce/aktuell\\_03\\_2012\\_asylbewerberleistungsgesetz.pdf](http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/aktuell_03_2012_asylbewerberleistungsgesetz.pdf).

<sup>37</sup> Gesa Teichert (2007): anders anders. Das Leben als Krüppel-Lesbe in: Bundesministerium für Familie, Senioren, Frauen und Jugend (2007): Einmischen Mitmischen. Informationsbroschüre für behinderte Mädchen und Frauen.

<sup>38</sup> UNHCR ruling on refugees and other persons with disabilities protected and assisted by UNHCR, adopted at the 61<sup>st</sup> session (LXI) from October 4 to October 8, 2010.

in the law on severely disabled persons [*Schwerbehindertenrecht/-gesetz*] and the decree on medical care [*Versorgungsmedizin-Verordnung*].<sup>39</sup>

- The specific needs of particularly vulnerable groups (such as people with multiple disabilities) must be better documented, and efficient support measures such as specific assistance services must be introduced.

## Article 4 – General obligations

In its National Action Plan, the Federal Government does not differentiate between **immediate rights** and obligations that must be implemented step by step (Art. 4, Para. 2 CRPD). In contrast, legal experts consider the right to equal recognition before the law (Art. 12 CRPD), the right to education (Art. 24 CRPD) and the right to health (Art. 25 CRPD) to be immediate rights of German citizens.<sup>40</sup>

In order to comply with the obligation to protect human rights, as is required in the CRPD (see specifically, Art. 4, Para. 1 CRPD), the laws of the Federation and Länder must be assessed with regard to their compatibility with the CRPD standards, and the corresponding adjustments must be made. Up until now, this has not been achieved, and the Federal and Länder action plans do not include such adjustments.

In Germany, numerous laws exist in order to ensure the equal participation of persons with disabilities. However, these laws are not implemented to a satisfying degree. For example, this is the case for the right of beneficiaries to choose which services and goods they want to receive [*Wunsch- und Wahlrecht der Leistungsberechtigten*, § 9, SGB IX], and for the realization of the “Personal Budget” (§ 17, SGB IX). The public authorities argue that the financial means are insufficient with regard to the **implementation of rights**. Several Länder allocate inconsistent compensation sums for disadvantages, such as benefits for the blind or deaf, while other Länder refuse to grant these payments due to their limited financial means. In some cases, out-patient care, such as personal assistance<sup>41</sup> or parental assistance,

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<sup>39</sup> The European Parliament already acknowledged deaf-blindness as a specific disability in 2004. The current political debates in Germany seem to point to a growing desire to establish the feature of “deaf-blindness”. However, up until this day, no concrete steps were taken. See the Bundestag debate (PIProt. 17/17211, November 29, 2013, <http://dipbt.bundestag.de/dip21/btp/17/17211.pdf#P.25887>), as well as the unanimous vote at the 89<sup>th</sup> Conference of Ministers for Labor and Social Affairs on November 28-29, 2013 (agenda item 5.1), [http://www.sachsen-anhalt.de/fileadmin/Elementbibliothek/Bibliothek\\_Politik\\_und\\_Verwaltung/Bibliothek\\_MS/ASMK/Erg\\_ennisse\\_der\\_89\\_Konferenz\\_am\\_28\\_und\\_29\\_11\\_2012.pdf](http://www.sachsen-anhalt.de/fileadmin/Elementbibliothek/Bibliothek_Politik_und_Verwaltung/Bibliothek_MS/ASMK/Erg_ennisse_der_89_Konferenz_am_28_und_29_11_2012.pdf).

<sup>40</sup> Felix Welti: Das Diskriminierungsverbot und die „angemessenen Vorkehrungen“ in der BRK – Stellenwert für die staatliche Verpflichtung zur Umsetzung der in der BRK geregelten Rechte. Rechtsdienst der Lebenshilfe 1/2012, p. 1; Eibe Riedel: Gutachten zur Wirkung der internationalen Konvention über die Rechte von Menschen mit Behinderungen und ihres Fakultativprotokolls auf das deutsche Schulsystem. LAG Gemeinsam Leben, Gemeinsam Lernen NRW, Sozialverband SoVD 2010, p. 32; Peter Masuch: Die UN-Konvention über die Rechte von Menschen mit Behinderungen. In: Wolfgang Schütte (ed.): Abschied vom Fürsorgerecht. Von der „Eingliederungshilfe für behinderte Menschen“ zum Recht auf soziale Teilhabe. LIT Verlag, Berlin 2011, p. 74/75.

<sup>41</sup> [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,29340/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,29340/ticket,g_a_s_t) (accessed on July 8, 2012).

is denied for financial reasons, even though the alternatives are sometimes more expensive.<sup>42</sup>

Disabled persons' associations hold the opinion that the development of the relevant laws is not always monitored with regard to compatibility between the final draft law and the CRPD standards.<sup>43</sup> The same is true for the implementation of the law: According to the German constitution, the CRPD applies to both the Federation and the Länder. However, some court rulings doubt this, and request a transformation process on the Länder level.<sup>44</sup>

All Federal ministries established so-called "focal points" [*Anlaufstellen*] for **disability mainstreaming** (Art. 4, Para. 1(c) CRPD). However, up until now, they still do not have any impact. For example, the Federal Ministry of Health drafted several laws after the CRPD was put into effect in Germany<sup>45</sup>, but never established any accessibility criteria or defined professional training measures for medical staff with regard to persons with disabilities.

As of yet, the Federal Government does not fulfill its obligation to strongly encourage private companies, such as intercity bus providers, to eliminate discrimination on the grounds of disabilities to a satisfying degree (see Art. 4, Para. 1(e) CRPD).<sup>46</sup>

The function of the **federal government commissioner for matters relating to disabled persons** [*Behindertenbeauftragter*] is affiliated with the Federal Ministry of Labour and Social Affairs. Even though the commissioner's responsibilities can be compared to other federal commissioners, this particular commissioner does not hold the status of a minister of state, as does the federal commissioner for migration, refugees and integration, which limits his or her scope of influence.

#### **The BRK-Allianz calls for the following actions:**

- **It must be clarified which CRPD rights are immediate rights. Those norms that are still too vague in order to be implemented<sup>47</sup> must be promptly implemented by means of precise schedules and strategies on the Federal level.**
- **All Federal and Länder laws must be assessed with regard to their compatibility with the CRPD, and adjusted accordingly. The Federal and Länder governments must provide the necessary financial means.**
- **Appropriate measures must be designed in order to monitor the development, application and practical implementation of laws that comply with the CRPD standards:**
- **an expert monitoring commission must be established in order to monitor laws with regard to their CRPD compatibility;**
- **judges must obtain training measures regarding the CRPD;**

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<sup>42</sup> <http://www.elternassistenz.de/doku/marlies-interview.php> (accessed on June 27, 2012).

<sup>43</sup> Even after the CRPD ratification, new laws were adopted that did not adhere to the CRPD standards, such as the care structure act [*Versorgungsstrukturgesetz, 2011*].

<sup>44</sup> Dr. Valentin Aichele: Die UN-Behindertenrechtskonvention in der gerichtlichen Praxis. AnwBl 10/2011, p. 727-730.

<sup>45</sup> Law on public health insurance funding [*GKV-Finanzierungsgesetz, 2010*], law on the reorganization of the pharmaceutical market [*Arzneimittelmarktneuerordnungsgesetz, 2010*], law on the structure of care [*Versorgungsstrukturgesetz, 2011*].

<sup>46</sup> See NAP, p. 129. Instead of establishing legal obligations, the NAP only states that employers should become more aware and consent to hiring persons with disabilities. Likewise, on p. 137, instead of a legal obligation to ensure that medical practices are accessible, it says that there is the intention to "make additional medical practices accessible over the course of the next 10 years".

<sup>47</sup> See rulings such as BverwGE 87, 11 et seq., BverwGE 80, 233 et seq.



- employees of the Federal and Länder administration must receive mandatory disability mainstreaming awareness training;
- the function of the federal government commissioner for matters relating to disabled persons must be strengthened, and his or her affiliation and budgetary means must be assessed and enhanced, if necessary;
- private (service) companies and organizations must be put under a legal obligation to ensure accessibility and reasonable accommodation;
- mandatory participation standards should be defined in a joint effort, and be implemented accordingly.

## Article 5 – Equality and non-discrimination

The German general act on equal treatment [*Allgemeines Gleichbehandlungsgesetz/AGG*] is aimed at protecting people from discrimination. On this note, it lists six protected groups of persons, including people with disabilities.<sup>48</sup> The AGG provides for the Federal anti-discrimination office [*Antidiskriminierungsstelle/ADS*], where those who face discrimination may receive counseling and raise complaints. 24.7% of all queries and counseling sessions at the ADS are made or utilized by persons with disabilities<sup>49</sup>, who thereby represent the biggest group. This clearly illustrates this particular group's need for protection from discrimination.

The AGG does not provide sufficient legal protection. For example, it still does not recognize the refusal of reasonable accommodations as discrimination. This means that persons with disabilities cannot claim the refusal of reasonable accommodation (such as a nonexistent ramp to a store entrance) as discrimination according to the AGG. Moreover, Germany is obstructing a draft EU directive<sup>50</sup> that would provide precisely this type of protection with regard to accessing goods and services.

Other laws also do not, or not sufficiently, consider the notion of reasonable accommodation.<sup>51</sup> For instance, the updated **decree on workplaces** [*Arbeitsstättenverordnung/AstV*]<sup>52</sup>, which includes regulations on accessibility, is only applicable in those companies that already employ persons with disabilities (see Art. 27). Consequently, companies are afraid to hire persons with disabilities because they fear the costs arising from retrofitting.

In addition to this, the AGG provides rather limited protection from discrimination because those concerned must file their complaint within a very short period of two months.

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<sup>48</sup> The protection from discrimination applies to the categories of race, origin, sex/gender, religion or belief, disability, age and sexual orientation. The question of whether people with chronic health issues are protected by the AGG remains to be solved in German law.

<sup>49</sup> Bundesministerium für Arbeit und Soziales, Übereinkommen der Vereinten Nationen über Rechte von Menschen mit Behinderungen, Erster Staatenbericht der Bundesrepublik Deutschland, August 3, 2011, p. 15.

<sup>50</sup> EU Commission proposal for a directive for the implementation of the principle of equal treatment regardless of religion or belief, disability, age or sexual orientation, July 2, 2008.

<sup>51</sup> In most situations of their daily lives, persons with hearing or communication impairments do not have a legal right to obtain refunds for communication aids. Hearing impaired persons only have a right to financial support for sign language interpreters or other communication aids in social services proceedings, their workplace, and their personal administrative and legal proceedings.

<sup>52</sup> § 15, AstV, version from April 29, 2012.

Moreover, the penalties are soft and those concerned must personally file their complaint. The **anti-discrimination office (ADS)** is also not allowed to support or accompany individuals during their legal proceedings at courts of law. Although the ADS is by definition autonomous, it is nevertheless subject to the authority of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth. In the budgetary year of 2012, the ADS faced a financial cutback of approximately 15%, which makes it even more difficult for the office to fulfill its mandate.

The State report of the Federal Government refers to a project of the Deutsches Institut für Menschenrechte, which trains non-governmental organizations in the process of claiming and filing complaints through the legal means provided by the UN. But since these non-governmental organizations do not receive any funding to engage in this process, this very positive measure is rendered ineffective.

The **federal equal opportunities for disabled people act (BGG)**, which came into law on May 1, 2002, is aimed at eliminating the disadvantages faced by persons with disabilities, and to ensure their equal participation in society. The Länder have their own laws to ensure equal opportunities for people with disabilities (LGG). A key target of these laws is to establish accessibility in the Federation and the Länder.

In the BGG, however, the obligation to ensure accessibility is limited to Federal public law entities. § 5 provides target agreements for private legal parties. Unfortunately, over the past 10 years, it has become obvious that target agreements alone are not sufficient: During this entire period, not more than 25 target agreements were made.<sup>53</sup> Moreover, associations do not yet sufficiently utilize their right to initiate legal proceedings [*Verbandsklagerecht*, § 13] as class action. This might be due to the financial risk that associations take when they take legal measures.<sup>54</sup>

A comprehensive evaluation of the BGG and the LGGs and their compatibility with the UN CRPD remains yet to be accomplished. The Federal Government's National Action Plan scheduled a review of the BGG for 2013.<sup>55</sup>

#### **The BRK-Allianz calls for the following actions:**

- **The refusal to provide reasonable accommodations must be defined in the AGG as an act of discrimination.**
- **It must be ensured that persons with chronic health issues are protected by the AGG.**
- **The Federal Anti-Discrimination Office should obtain the right to file charges, and it should be allocated the necessary budgetary means that it needs to fulfill this task.**
- **The Federal Government should establish a fund for legal proceedings, so that persons with disabilities can exercise their rights and receive support from the relevant associations.**
- **The Federal Government should stop obstructing the process of the new EU directive on equal treatment.**
- **The BGG and the LGGs must be extended and revised so that they can become functional laws with regard to the UN CRPD implementation. This applies to the aims, the notion of**

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<sup>53</sup> See the explications on target agreements, § 9.

<sup>54</sup> See the summary of an event about the 10-year anniversary of the BGG, <http://www.bsk-ev.org/news/4316/10-jahre-bgg/>.

<sup>55</sup> See Nationaler Aktionsplan, p. 180.

disability, the notion of accessibility, and to the entire content of the CRPD, including having an impact on private legal entities and the issue of awareness-raising.<sup>56</sup>

- The legal notion of “reasonable accommodations” must be established within the BGG’s and the LGGs’ prohibition of discrimination.

- The BGG must strengthen the right of associations to initiate legal proceedings as class action. Likewise, it is necessary to look into the possibility of creating legal protection for individuals, and to establish a fund for legal proceedings.

- The BGG must consider the aspect of gender as well as empowerment measures.

## Article 6 – Women with disabilities

Approximately 4 million women with disabilities are currently living in Germany. When one looks at their biographies, it is obvious that they experience multidimensional discrimination in many aspects of their lives (see also the explications in other articles in this report). More often than other women, they live close to the poverty threshold and fear financial hardship. Likewise when compared to other women, they are more likely to live without a partner and without children, their unemployment rate is higher than the average, and they experience two to three times more violence than women without disabilities.<sup>57</sup>

In the State report, the Federal Government declares that there is still no data on the situation of women with disabilities, but that they intend to better examine their situation in the future. The Federal Government’s National Action Plan is more specific about this intention, and states that they plan to consider gender aspects in their leaflet on disability mainstreaming and to review their disability politics reporting. Moreover, they will support **political advocacy for women with disabilities**, through the association “Weibernetz e.V.” However, the funding of this project ends in 2014. Until 2011, funding was allocated to a project that facilitated training measures for women’s affairs officers in “sheltered workshops” and in residential facilities, so that inhabitants and women employed in the “sheltered workshops” could advocate on their own behalf and be provided with a contact person.

Nevertheless, consistent gender-equitable disability politics do not exist in Germany. For example, data collection is not by default gender-specific, which means that existing measures can hardly be assessed with regard to their gender relevance.

Women with disabilities and a migrant background experience even greater disadvantages on the labor market, and have even lower incomes at their disposal. Among all persons with disabilities, they have the lowest education level. Only slightly more than half of them completed some kind of vocational training.<sup>58</sup> In spite of these manifold disadvantages, counseling services that cater to women with disabilities report that they have enormous

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<sup>56</sup> See the monitoring office statement: Vorschläge zur Reform des Behindertengleichstellungsrechts in Bund und Ländern im Lichte der UN-Behindertenrechtskonvention (December 2012), [http://www.institut-fuer-menschenrechte.de/no\\_cache/de/publikationen.html](http://www.institut-fuer-menschenrechte.de/no_cache/de/publikationen.html).

<sup>57</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend (2009): Lebenslagen behinderter Frauen in Deutschland. Auswertung des Mikrozensus 2005; Bundesministerium für Familie, Senioren, Frauen und Jugend (2012): Lebenssituation und Belastungen von Frauen mit Beeinträchtigungen und Behinderungen in Deutschland.

<sup>58</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend (2009): Lebenslagen behinderter Frauen in Deutschland. Auswertung des Mikrozensus 2005.

difficulties reaching this target group. Consequently, disability politics must put a stronger focus on women with disabilities.

**The BRK-Allianz calls for the following actions:**

- **All federal statistics on disability issues must be based on gender-specific data collection and analysis.**
- **The Federation must conceptualize and evaluate all of its measures with due regard to the gender aspect.**
- **There must be a legal obligation to ensure disabled women's advocacy in disability-related institutions, for example by means of a women's affairs commissioner. Likewise, a project must be established to train facilitators, so that these facilitators can again train women's affairs commissioners in institutions.**
- **Specific support must be given to measures that aim at strengthening social participation of persons with disabilities and a migrant background, and measures that work to dismantle the gender bias.**

## **Article 7 – Children with disabilities**

According to **statistical data** from late 2005, 161,555 children with disabilities were living in Germany at that time.<sup>59</sup> However, this figure represents a conservative estimate, since it only includes children who received an identification card for the severely disabled [*Schwerbehindertenausweis*]. The 13<sup>th</sup> Federal Government children and youth report states: "Since there is no legal obligation to report disabilities, the actual number of children and young adults with disabilities is difficult to estimate."<sup>60</sup> The authors of the report think that this lack of data results from "insufficient information and counseling, parental fear and difficulties regarding the relevant forms and applications, ignorance or a lack of awareness about the disability". For the same reasons, children with disabilities and migrant background often do not receive the same support as children with disabilities who do not have a migrant background.<sup>61</sup>

Children with disabilities and their families face considerable problems in Germany. These are partly related to **unclear legal stipulations**, and partly to the **vast number of different agencies**. Services that are at the disposal of families with disabled children are provided by different agencies, and on the basis of legal regulations that are not assessed with regard to their compatibility in many cases. Services for children with disabilities and their families are often not provided in combination with adequate information about, and due consideration of other services, and therefore often cannot sufficiently cater to individual needs. In many cases, adequate services come at the cost of separating the lives of disabled and non-disabled children. This becomes obvious in early intervention measures, in day-care institutions for children, schools and the transition period between school and working life. Children and young adults with disabilities who fall under the AsylbLG are not entitled to participation services.<sup>62</sup>

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<sup>59</sup> See Germany's third and fourth state reports on the Convention on the Rights of Children, p. 64.

<sup>60</sup> 13th Federal Government children and youth report, November 20, 2009, p. 64.

<sup>61</sup> See Spieß, Katharina: Die Wanderarbeiterkonvention der Vereinten Nationen. Ein Instrument zur Stärkung der Rechte von Migrantinnen und Migranten in Deutschland. Deutsches Institut für Menschenrechte, Berlin 2007, p. 59.

<sup>62</sup> See § 1, AsylbLG.

The German social system is characterized by its strictly separated areas and responsibilities. As a result, children with disabilities often do not receive the necessary support, which negatively impacts their potential development. The “**comprehensive early intervention set of measures**” [*Komplexleistung Frühförderung*] that was established in 2001 in SGB IX, was targeted at compensating for these disadvantages. Moreover, the Federal Government relies on general agreements [*Rahmenvereinbarungen*] on the Länder level. Since this does not work in practice, in 2012 the majority of the children in question were still not able to access the necessary services. The BRK-Allianz holds the opinion that the deficiencies with regard to the “Komplexleistung Frühförderung”, which were scientifically proven, must be countered by legal means.<sup>63</sup> However, the Federal Government states in the NAP that it simply intends to “assess” and to “discuss” this issue, and dismisses legal solutions.<sup>64</sup>

The most important agencies for children and young adults with and without disabilities are the social welfare agencies [*Sozialhilfe*] and children and youth social welfare agencies [*Kinder- und Jugendhilfe*]. The integration assistance service [*Eingliederungshilfe*] within the social welfare agencies is in charge of children and adolescents with physical and mental disabilities, and reacts to the specific needs that result from the given impairments. The youth social welfare agencies are responsible for emotionally disabled children and for educational support. The **separation between these responsibilities**, and the different existing notions of “services”, frequently result in a situation where diagnoses are based on the question of who is responsible. This can be quite stressful for children and adolescents, and further impedes understanding their needs. The separation between disabled and non-disabled children’s lives results in a lack of information, both among parents and among youth social welfare agencies. To that effect, youth social welfare agency services rarely reach out to children with disabilities. In its 2010 comment on Germany’s third and fourth State reports on the implementation of the Convention of the Rights of the Child (CRC) (“Ergänzender Bericht”), the National Coalition<sup>65</sup> also criticized this separation of responsibilities, and called for the so-called “big solution” [*große Lösung*], that is, the consolidation of all responsibilities within the same Social Code.<sup>66</sup>

Empirical experience shows that children and adolescents with disabilities face severe challenges when they try to organize their **leisure time** on their own:

- Children and adolescents with disabilities rely on support in their leisure time. The number of transport services and care assistants is insufficient. Moreover, the Social Code does not provide precise definitions of the right, for example, to have the expenses for transport and care covered. Also, different agencies allocate different budgets for these aids.

- Since social associations, and notably sports clubs, are largely based on a notion of “achievement”, they are a significant hurdle for children with disabilities.

- Most organized leisure facilities and activities for (young) persons with disabilities are affiliated with integration assistance [*Eingliederungshilfe*] services and institutions. Notably, so-called integrative offers are donation-based. Moreover, only few leisure and holiday offers take children and adolescents with disabilities into account to begin with.

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<sup>63</sup> See Rechtsdienst der Lebenshilfe 3/2012, p. 108/109.

<sup>64</sup> See NAP, p. 152 et seq.

<sup>65</sup> The “National Coalition” is an alliance comprised of more than 100 German organizations aimed at implementing the UN child rights convention.

<sup>66</sup> National Coalition (NC) für die Umsetzung der Kinderrechte in Deutschland (ed.), *Ergänzender Bericht zum Dritt- und Viertbericht der Bundesrepublik Deutschland*, Berlin 2010, p. 25.

Likewise, adolescents with disabilities are at a disadvantage when it comes to how they experience and explore their **sexual identity**. Compared to their non-disabled peers, they find themselves less frequently to be the object of somebody else's sexual interest and do not experience themselves as attractive to others as adolescents without disabilities might. At the same time, surveys prove that girls and women with disabilities are at a significantly higher risk to become victims of sexual violence.<sup>67</sup>

UN CRC Article 3 demands that all States parties shall consider the **children's best interest**.<sup>68</sup> This also applies to children and adolescents with disabilities. However, still today there is no precise definition of their needs (regarding social participation outside education facilities and their home). Both Anton Bucher's study, "Was Kinder glücklich macht"<sup>69</sup> (What makes children happy), as well as the World Vision surveys directed by Klaus Hurrelmann and Sabine Andresen<sup>70</sup>, came to the conclusion that from the children's perspective, happiness can be defined as satisfaction in three main areas: their home, their education facility (kindergarten and school) and their friends.<sup>71</sup> When looking at the issue of inclusion in Germany, researchers mostly focus on education and care institutions. Surveys that examine the living conditions of children and adolescents in Germany outside these institutions (such as regarding leisure facilities, clubs and associations, media behavior and media skills)<sup>72</sup> do not consider the aspect of disability. Consequently, there is no reliable information or facts and figures.<sup>73</sup>

In order to strengthen children and adolescents with disabilities and to improve their **participation**, the Federal Government states that it plans to launch their initiative, "Strengthening youth" [*Jugend stärken*]<sup>74</sup> and to develop a concept for a children and youth parliament<sup>75</sup> starting in 2013. However, the first program is an unspecific approach that is not conceptually linked to the UN CRPD and that does not explicitly name adolescents with disabilities.<sup>76</sup> It remains to be seen if the establishment of a children and youth parliament will turn out to be helpful in everyday life. In contrast, the Federal Government refuses to include child rights in the German constitution.<sup>77</sup> In their suggestion for a new Article 2a in the constitution, the child rights alliance [*Aktionsbündnis Kinderrechte*] gave a precise

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<sup>67</sup> "Lebenssituation und Belastungen von Frauen mit Beeinträchtigungen und Behinderungen in Deutschland", Universität Bielefeld, 2012.

<sup>68</sup> UN child rights convention, article 3: "1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."

<sup>69</sup> Anton Bucher, Was Kinder glücklich macht? Eine glückspsychologische Studie des ZDF, in Markus Schächter (ed.), Wunschlos glücklich? Konzepte und Rahmenbedingungen einer glücklichen Kindheit, Baden-Baden 2009, p. 44-195.

<sup>70</sup> World Vision Deutschland e.V. (ed.), Kinder in Deutschland. 1. World Vision Kinderstudie, Frankfurt/M. 2007; 2. World Vision Kinderstudie, Frankfurt/M. 2010.

<sup>71</sup> See S. Andresen/K. Hurrelmann, Was bedeutet heute "Glück" für Kinder? In Aus Politik und Zeitgeschichte, 38/2010, p. 6.

<sup>72</sup> In addition to Hurrelmann, see for example, Shell survey, AID:A, Sinus surveys, KIM surveys and others.

<sup>73</sup> This aspect is solely considered in the 13th children and youth survey. Consequently, there is a need for an empirical survey in order to gain insight into the leisure activities and opportunities of children with participation impairments.

<sup>74</sup> See State report, p. 19.

<sup>75</sup> See NAP, p. 153.

<sup>76</sup> See [www.jugend-staerken.de](http://www.jugend-staerken.de).

<sup>77</sup> See Frankfurter Rundschau, November 17 and 18, 2012.

outline of the right to support, protection and participation.<sup>78</sup> In this way, the Federal Government continues to not comply with the recommendations given by the US Committee for the Rights of the Child. In its “Concluding Observations”, the Committee already prompted the Federal Government twice, in 1994 and 2004, to include child rights in the constitution.<sup>79</sup>

**The BRK-Allianz calls for the following actions:**

- **The “comprehensive early intervention set of measures” must be subjected to precise regulations in the Social Code. Therefore, it is necessary to review § 32 SGB IX regarding the authority to issue statutory ordinances [Verordnungsermächtigung] as well as the early intervention measures decree [Frühförderungsverordnung]. Moreover, the Länder governments must compile precise framework agreements between the responsible Länder ministries, the service agencies and the associations of the service providers.**
- **The lists of services covered by the early intervention program must include cooperation with daycare facilities for children.**
- **The early intervention decree and the Länder framework agreements must include the following points: a concise, comprehensible definition of the “comprehensive early intervention set of measures”; the content, range and quality of the services; regulations on lump-sum payments, cost sharing (funding plans) and proceedings; the provision of easy-to-access and low-threshold services; the establishment of a conflict resolution scheme in order to avoid blockades when service agreements are about to be made.**
- **Services for all children and adolescents with and without disabilities must be consolidated into one single services law and one services agency. The consolidation of services within SGB VIII must not result in a decline of services and their funding.**
- **Children and youth social welfare schemes must consider children and adolescents with disabilities in their leisure programs. This is an essential part of inclusive child and youth social welfare planning. Every offer provided by youth social welfare must be assessed with regard to inclusion and its adequacy for children and adolescents with disabilities.**
- **Since inclusion also means participation during leisure time, leisure activities and facilities must be shaped according to social accessibility for children from the relevant age groups. The goal should be that children can share their activities and experiences. In this way, the social trend towards an erosion of solidarity should be countered.<sup>80</sup> At the same time, children and adolescents with disabilities must have the opportunity to have new experiences within their peer group, even if they are living in rural areas.**
- **There is a need for quantitative studies that examine the living conditions, including leisure opportunities and activities, of children and adolescents with disabilities. In this way, it will be possible to gain insights regarding better support and inclusive services and offerings.**
- **The constitution of the Federal Republic of Germany must include child rights.**

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<sup>78</sup> [http://www.kinderrechte-ins-grundgesetz.de/fileadmin/content\\_media/projekte/Themen/Kinderrechte/Formulierungsvorschlag\\_KR\\_ins\\_GG-2012-11-14-js.pdf](http://www.kinderrechte-ins-grundgesetz.de/fileadmin/content_media/projekte/Themen/Kinderrechte/Formulierungsvorschlag_KR_ins_GG-2012-11-14-js.pdf).

<sup>79</sup> vgl. [http://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Pakte\\_Konventionen/CRC/crc\\_state\\_report\\_germany\\_1\\_1994\\_cobs\\_1995\\_de.pdf](http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/CRC/crc_state_report_germany_1_1994_cobs_1995_de.pdf).

<sup>80</sup> “What are the mindsets of tomorrow’s adults? Sinus Survey 2012: More pressure to perform, deeper gaps between social classes. Some diagnose a new trend to maintain distance to social others, a decrease of solidarity. Many youths, the study states, made derogative statements about unemployment services beneficiaries and adolescents with migrant backgrounds, even if they sometimes chose coded wordings such as ‚Well, somebody has to say that ...‘” See Spiegel online, March 28, 2012.

## Article 8 – Awareness-raising

The BRK-Allianz approves of the fact that the Federal Ministry of Labour and Social Affairs [*Bundesministerium für Arbeit und Soziales/BMAS*] launched the **campaign**, “There’s a remedy against disabling others” [*Behindern ist heilbar*], two years after they ratified the CRPD.<sup>81</sup> Since the dominant notion of disability is still very much informed by a medical perspective in Germany, there is an urgent need for campaigns and other awareness-raising activities. Persons with disabilities are regarded as deficient and in need of help.<sup>82</sup> The notions of “disability”, “suffering” and “pity” are often intertwined, and most prenatal measures are aimed at avoiding “disability”. The German discourse on society’s view of disabilities largely disregards the theoretical approach of “ableism”<sup>83</sup> that was introduced in the context of Disability Studies. Within the administration and in the public sphere, a notion of “disability” based on human rights remains practically nonexistent.

The German **media landscape** is quite diverse, and characterized by the coexistence of private and public providers. Their coverage of issues regarding disabilities is sophisticated and good individual case reports are frequently broadcast. However, this is not the default case. Mostly, their representations of disabilities are informed by stereotypes and prejudices, such as “in spite of his disability”, “tied to her wheelchair”, “suffering from”, and so on.<sup>84</sup>

Starting in 1995, the German Criminal Code [*Strafgesetzbuch/StGB*] prohibited abortions that are justified by the disability of the embryo (abolishment of the so-called embryonic indication according to § 218a, Para. 2(1) StGB-alt). Nevertheless, in Germany the **society’s perspective on disabilities** is still heavily influenced by prenatal diagnostics (PND) and pre-implantation diagnostics (PID). PND is aimed at helping future parents decide whether to have an abortion if the results make a disability seem likely. From this perspective, medical conditions and disabilities are considered ailments that can and should be avoided. This is an existential insult, and discriminatory towards persons with disabilities. These approaches are aligned with a “medical notion” of disabilities that locates the causes of a disability within an individual person and her/his physical and mental dispositions. Some members of the BRK-Allianz consider both PND and PID to be violations of CRPD Article 8b, which requires the abolishment of “[...] harmful practices relating to persons with disabilities”. PID should instead focus on the detection of medical conditions, so that they can be treated.

When talking about promoting public awareness, the State report solely focuses on more familiar disabilities and widespread conditions such as dementia. However, numerous **rare conditions** and disabilities exist and for the most part remain unnoticed, even though approximately four million people in Germany are affected by more than 5,000 different rare conditions.<sup>85</sup>

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<sup>81</sup> vgl. [www.behindern-ist-heilbar.de](http://www.behindern-ist-heilbar.de).

<sup>82</sup> The “Menschen mit Behinderungen” leaflet published by federal agency for civic education [*Bundeszentrale für politische Bildung/BPB*] provides a good overview of the current societal perspectives: <http://www.bpb.de/apuz/27782/menschen-mit-behinderungen>.

<sup>83</sup> The word “ableism”, from “ability” and “-ism” can be compared to notions such as racism or sexism. See Rebekka Maskos’ input, : [http://www.zedis.uni-hamburg.de/wp-content/uploads/maskos\\_14122011.pdf](http://www.zedis.uni-hamburg.de/wp-content/uploads/maskos_14122011.pdf)

<sup>84</sup> See [www.leidmedien.de](http://www.leidmedien.de)

<sup>85</sup> A condition is considered “rare” if up to 5 out of every 10,000 persons are concerned. See Allianz chronischer seltener Erkrankungen, [www.achse-online.de](http://www.achse-online.de).



The BRK-Allianz calls for the following actions:

- The Federal Government must develop schemes for comprehensive human rights education<sup>86</sup> within the administration and the public sphere, in cooperation with disabled people's organizations. This must be accompanied by an image campaign.
- Journalists, editors and media executives must be provided with sustainable training and awareness programs that comply with the CRPD standards.
- The supervisory committees of public media institutions must appoint experts with disabilities.
- It is necessary to review the laws pertaining to pregnancy and maternity, as well as the law on predictive genetic diagnostics. Moreover, the Federal Government must abandon any federal funding of PND that is aimed at genetic selection.
- The new legal regulations for the permission of PID in defined circumstances as well as the stipulations on its procedural implementation must comply with the CRPD standards.
- Awareness-raising must also be promoted when it comes to the participation of persons with rare conditions or disabilities, and medical experts in these fields must be provided with training programs.

## Article 9 – Accessibility

**A comprehensive notion of accessibility:** In the official German translation of the UN CRPD as well as in their first State report, the Federal Government refers to “approachability” [*Zugänglichkeit*] instead of “accessibility” [*Barrierefreiheit*] with regard to Article 9 (see also introduction). However, as stated in § 4 BGG, “accessibility” is a more comprehensive notion, since it does not only include “approachability”, but also usability. According to this definition, all “constructed facilities and places [...] must be accessible and usable for disabled persons just like for all other persons, that is, without any special difficulties and, as a matter of principle, without support from others”. This definition must be considered to be a legal stipulation that must be substantiated in other regulations, determinations of standards and contractual agreements.

While the definition of accessibility is quite sophisticated when it comes to persons with physical and sensory disabilities, and has found its way into technical standards, this development is at a very early stage regarding persons with cognitive impairments. Due to the insufficient knowledge on this issue, there is a great need for basic research and proven insights about this group. This applies, for example, to “plain language”/“Easyread” and adequate orientation systems.

Accessibility is also a matter of different possible participation barriers for different people. For example, persons with mental impairments who need to seek out a public agency in order to apply for a service, might perceive a fixed time limit as a considerable barrier. If they do not show up for their appointments, they risk losing their benefits.<sup>87</sup>

Likewise, when it comes to emergency situations, the concerns of many people with disabilities are not acknowledged. Not only is the “two senses rule” [*Zwei-Sinne-Prinzip*]

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<sup>86</sup> See texts and materials at <http://www.institut-fuer-menschenrechte.de/de/menschenrechtsbildung.html>

<sup>87</sup> For example, according to §§ 31, Para. 1(1) and 3(31) SGB II regarding the allocation of services and the corresponding integration contracts as defined in § 15 SGB II.

not put into practice in the areas of construction and technology, but persons with sensory impairments, such as hearing or visual disabilities, are also not acknowledged sufficiently or on equal ground when it comes to planning schemes for emergency situations.

**Construction and housing:** In most buildings that are accessible to the public, such as administration buildings, schools and hospitals, accessibility has only been taken into account if they were comprehensively remodeled, or constructed within the last ten years. At that time, the Länder introduced the relevant provisions into their construction regulations. However, the accessibility stipulation is limited to those areas that are frequented by the general public. Likewise, the requests of persons with sensory disabilities were not sufficiently taken into account. In general, these stipulations only regulate matters of accessibility, but not of the usability and findability<sup>88</sup> of the services that are offered in these buildings. There are hardly any regulations with regard to this aspect.

Buildings that are open to the public, and that are mainly used by private service agencies, are often not accessible, even if they were newly constructed within recent years. The main cause of this is insufficient or nonexistent monitoring by construction supervision authorities. Many existing buildings are exempt from accessibility remodeling measures, since they were constructed prior to the establishment of the current construction regulations (they fall under the scope of the so-called "Bestandsschutz", i.e. buildings constructed before a defined date are then protected), and are largely inaccessible to persons with disabilities.

Currently, the Länder construction regulations are undergoing review.<sup>89</sup> The Länder commissioners for matters relating to persons with disabilities articulated sharp criticism towards the planned changes to the regulations. Among other things, they requested that accessibility must become a binding obligation and that its implementation must become more effective.<sup>90</sup> Likewise, accessibility must not be limited to public visitor areas, but extended to internal user areas. For example, this applies to schools and hospitals with regard to those areas that are used by students and patients. The BRK-Allianz finds fault with the fact that the concerns of persons with sensory disabilities remain hardly acknowledged today.

There are no reliable figures on accessible apartments in Germany. The estimate is approximately 500,000. The predicted demand for accessible flats will be around 2-2.5 million in 2025.<sup>91</sup> When looking at these figures, it is incomprehensible that the Federal Government cancelled their involvement in the program for remodeling flats which was to compensate for the disadvantages experienced by senior citizens, "Altersgerechtes Umbauen", in 2011. The program is managed by the Kreditanstalt für Wiederaufbau (KfW), a Federal and Länder public banking institution. There is still an urgent need to promote and

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<sup>88</sup> See the leaflet, "Barrierefrei- und jeder weiß wo es lang geht!" [www.pro-retina.de/dateien/kontraste-der-pro-retina-deutschland.pdf](http://www.pro-retina.de/dateien/kontraste-der-pro-retina-deutschland.pdf).

<sup>89</sup> On the review of the standard construction regulation [*Musterbauordnung*], see the resolution of the 123<sup>th</sup> construction ministry conference, September 20/21, 2012, <http://www.is-argebau.de/IndexSearch.aspx?method=get&File=b8a84yy3y8b984808abb4yb8y9ya8ayyb9y884b94ya2a0a14849a3aba4494b80b8y0nfmfvavql0smkxrr4dmmkiof>.

<sup>90</sup> See Berlin resolution of the federal commissioner for matters relating to persons with disabilities, June 3, 2011, [http://www.masf.brandenburg.de/sixcms/media.php/4055/Dresdner\\_%20Erkl%C3%A4rung\\_Endfassung.pdf](http://www.masf.brandenburg.de/sixcms/media.php/4055/Dresdner_%20Erkl%C3%A4rung_Endfassung.pdf).

<sup>91</sup> [http://www.bundestag.de/presse/hib/2012\\_05/2012\\_230/06.html](http://www.bundestag.de/presse/hib/2012_05/2012_230/06.html).

fund accessible (and social) housing and the removal of barriers by means of remodeling measures.

**Transportation – general aspects:** Undeniably, the BGG allowed for improvements in public transportation, railway traffic and the accessible design of public space in recent years. However, it must be stated that for the most part, it was the needs of persons with physical impairments (wheelchair users) that were taken into account (see above). Frequently, the staff of the public transportation agencies is not provided with sufficient training that would enable them to acquire social and communicative skills. Usually, transportation companies only offer a telephone information service to their clients, while hearing disabled people need additional communication facilities, such as email or fax.

**Railway traffic:** Travelers with disabilities are put at a disadvantage on a daily basis. Only 50% of the 5,400 German railway stations are accessible and usable. Moreover, railway companies deploy trains that cannot carry passengers with wheelchairs<sup>92</sup> or, for example, have a toilet for disabled persons that is out of order and cannot be used. Visual contrasts to facilitate orientation are nonexistent.<sup>93</sup> Some railway stations are not staffed at all, leaving nobody present to help disabled travelers get on and off the trains. Also, travelers with disabilities repeatedly report that the railway station staff discriminated against them.<sup>94</sup>

The second Deutsche Bahn AG program for the implementation of accessibility was presented to the public in April 2012.<sup>95</sup> It lists three points of disagreement between Deutsche Bahn and representatives from disabled persons' organizations:

\* Deutsche Bahn AG placed itself under the obligation to create accessibility when comprehensive reconstruction measures are carried out in railway stations that are frequented by more than 1,000 travelers per day. The representatives from disabled persons' organizations consider this to be a systemic infringement, since comprehensive remodeling measures in the public sphere always entail the obligation to create accessibility, regardless of the number of users.

\* Usually, disabled travelers can only make use of the Deutsche Bahn mobility service between 6 a.m. and 10 p.m., and sometimes within an even shorter period of time. This is an unacceptable site of discrimination when compared to other travelers.

\* Information is not always presented in compliance with the two senses rule. This means that railway users with sensory disabilities are frequently discriminated against.

**Air travel:** In 2008, the EU established their air travel regulations<sup>96</sup> [*Flugverordnung*] that aimed at enabling persons with disabilities to participate in discrimination-free air travel.

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<sup>92</sup> [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30168/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30168/ticket,g_a_s_t).

<sup>93</sup> Verbesserung von Visuellen Informationen im öffentlichen Raum, Kontrast, Helligkeit, Farbe und Form. Herausgeber Bundesministerium für Gesundheit 1996, [http://www.pro-retina.de/dateien/ea\\_handbuch\\_fuer\\_planer\\_und\\_praktiker.pdf](http://www.pro-retina.de/dateien/ea_handbuch_fuer_planer_und_praktiker.pdf)

<sup>94</sup> [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30237/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30237/ticket,g_a_s_t).

<sup>95</sup> See [http://www.deutschebahn.com/de/presse/presseinformationen/pi\\_k/2454512/h20120427.html](http://www.deutschebahn.com/de/presse/presseinformationen/pi_k/2454512/h20120427.html), [http://www.bahn.de/p/view/mdb/bahnintern/services/mobilitaet\\_service/barrierefrei\\_-\\_neu/mdb\\_85159\\_2\\_\\_programm\\_der\\_db\\_stand\\_20-06-2012\\_.pdf](http://www.bahn.de/p/view/mdb/bahnintern/services/mobilitaet_service/barrierefrei_-_neu/mdb_85159_2__programm_der_db_stand_20-06-2012_.pdf)

However, considerable deficiencies remain.<sup>97</sup> In spite of several improvements when it comes to support provided in air travel, persons with disabilities encounter severe problems when they use air travel companies and airport services. In particular, the airplanes themselves lack accessibility. Many persons with disabilities, especially wheelchair users, cannot use the onboard toilets. Likewise, people with visual and hearing impairments face considerable difficulties, for example, when it comes to assistance animals that travel with them, or incomprehensible loudspeaker announcements at the airport or in the plane. Again and again, disabled travelers are denied their flights due to the fact that supposedly too many disabled guests are onboard<sup>98</sup>, or because they travel unaccompanied. More barriers are encountered due to non-accessible onboard information and movies, insufficient acoustic information on flight magazines provided through the audio channels, and nonexistent audio-descriptions of movies.

**Internet and user interfaces:** The internet is becoming more and more important for information, social networking and communication, and the purchase of goods and services. If internet pages were designed in an accessible way, this development could improve participation opportunities for persons with disabilities. With BITV2.0, Germany set model legal standards with regard to the design of the Federal administration websites.<sup>99</sup> However, these standards are not valid outside the administration, and are often ignored. Likewise, IT user interfaces contain accessibility barriers. Numerous software, mobile apps and digital signatures are not subjected to any legally binding accessibility standards. Many public services as well as job positions therefore remain inaccessible for persons with disabilities. For example, De-Mail<sup>100</sup>, a platform for future IT-based communication between citizens and authorities or courts, is as inaccessible as the corresponding functions of electronic ID documents.<sup>101</sup>

Life-long learning is a very important matter for all of us. However, the currently available accessible learning and teaching material is not sufficient, and prevents persons with disabilities from using it to a satisfying degree. The same is true for insufficient accessibility with regard to buildings and communication facilities, for example, in community colleges [*Volkshochschulen*]. Up until this day, very few internet and e-learning services are accessible. Schooling laws provide for homeschooling, instead of accessible online schooling and learning platforms that are used by the entire class.

**Target agreements:** Instead of stipulating a binding legal obligation for private businesses, § 5 BGG (2002) only provides for the possibility to negotiate accessibility target agreements between companies and business associations and disabled persons' organizations. However, private businesses are not placed under any obligation to do so. Therefore, only a small number of agreements have been negotiated.<sup>102</sup> This did not result in a comprehensive improvement of accessibility.

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<sup>96</sup> Regulation (EC) No. 1107/2006 of the Parliament and of the Council of July 5, 2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air.

<sup>97</sup> See the project report with regard to the preparation of target agreements for air travel, <http://www.isl-ev.de/de/aktuelles/projekte/680-zielvereinbarungen-zur-barrierefreiheit.html>.

<sup>98</sup> Air Berlin's refusal to transport a passenger created a public outcry, see <http://de.ria.ru/society/20121013/264698433.html>.

<sup>99</sup> See [http://www.gesetze-im-internet.de/bitv\\_2\\_0/](http://www.gesetze-im-internet.de/bitv_2_0/).

<sup>100</sup> Law from April 28, 2011, BGBl. I, p. 666.

<sup>101</sup> Law on ID documents and electronic proof of identity, June 18, 2009, BGBl. I, p. 1346.

<sup>102</sup> Over a period of ten years, only 25 target agreements have been negotiated. See the target agreement register at <http://www.bmas.de/DE/Themen/Teilhabe-behinderter-Menschen/Zielvereinbarungen/Zielvereinbarungsregister/inhalt.html>.

Starting in 2009, the Federal Government has been promoting the federal accessibility competence center<sup>103</sup> [*Bundeskompetenzzentrum Barrierefreiheit/BKB*], which is facilitated by disabled persons' organizations. One of its aims is to push target agreements. The BKB has proven to be a skillful point of contact for disabled persons' organizations when it comes to accessibility issues. It coordinates the work of various disabled persons' associations, and has consolidated different demands made by different groups of persons with disabilities. Consequently, it became an important element of standardizing accessibility that caters to people with all possible kinds of disabilities. Moreover, it has compiled fundamental data and knowledge about accessibility, provided training and is active in the field of public relations. Nevertheless, the Federal Government had considerably reduced their funding for the BKB by late 2012.

Since the free market itself rarely promotes and creates accessibility, additional legal regulations are necessary. If decisions about public funding and contract bidding were consistently based on accessibility standards, a strong impulse would be given to the accessible goods and services market; and the impacts of this impulse would reach far beyond the public administration. An expert accessibility institution, such as the current BKB, is also absolutely indispensable in order to expedite the creation of accessibility in a systematic and target-oriented way. Likewise, it is absolutely necessary to fund disabled persons' associations, so that they can truly fulfill their representational duties when it comes to accessibility issues.

**Education:** Accessibility is rarely featured as obligatory subject matter within established vocational training, further education and study courses. The lack of basic knowledge about accessibility and universal design is noticeable wherever one looks.

**The BRK-Allianz calls for the following actions:**

- **The current legal regulations, particularly in the Federal and Länder equal opportunities laws, must be evaluated and reviewed in order to implement the accessibility requests as defined in the UN CRPD within strictly defined time periods and on all levels (Federation, Länder and municipalities). Different demands with regard to accessibility must be taken into account, and in particular, the needs of persons with mental disorders must be considered. Complaints offices, monitoring and penalty options must be expanded. Moreover, there is a need for incentive schemes.**
- **Public transportation agencies and public space must be remodeled according to accessibility needs (plain language signage, pictograms, luminance contrasts, symbol labeling, compliance with the two senses rule).**
- **Deutsche Bahn AG and other railway companies must be put under an obligation to**
  - \* **only deploy trains that can also be used by travelers with disabilities;**
  - \* **up-skill their staff regarding a human rights perspective on disabilities;**
  - \* **make all information accessible according to the two senses rule;**
  - \* **create accessibility in the context of all new construction and comprehensive remodeling measures.**
- **The mobility service must be compelled to ensure support to travelers with disabilities in all railway stations and at all times.**
- **Accessible design inside airplanes must be subjected to international binding standards.**
- **Accessible emergency management, a review of emergency management schemes, unhindered access to the European-wide emergency number 112 as well as to the national**

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<sup>103</sup> [www.barrierefreiheit.de](http://www.barrierefreiheit.de).

emergency number 110 in all Länder must be legally regulated with regard to persons with cognitive impairments, hearing and speech impaired persons.

- There must be contract biddings for participatory research projects in order to extend fundamental knowledge about accessibility. In particular, criteria regarding persons with cognitive disabilities must be compiled.
- Professional training and further education curricula for the relevant professions must be completed according to accessibility and universal design standards.
- A permanent accessibility expert institution, such as the BKB, must be established.
- The allocation of public funds must be strictly based on the compliance with accessibility.
- Private legal entities that provide facilities and services to the public must be legally obliged to ensure accessibility.
- Draft laws for electronic administration proceedings and electronic legal transactions must contain precise regulations pertaining to accessibility. Accessible De-Mail services, electronic ID documents and electronic payment services must be obligatory and decreed. Moreover, the BITV2.0 decree must be introduced beyond the Federal institutions, and become valid in the Länder and municipalities, by means of the LGGs.

## Article 10 – Right to life

In Germany, an abortion is often carried out after a fetus is diagnosed with a disability. On the basis of the so-called medical indication, an abortion is not punishable by law even after the 12<sup>th</sup> week of pregnancy if the delivery is considered a danger to the mother's physical or mental well-being. This regulation, which is frequently applied in the case of a disability diagnosis, allows for the termination of the pregnancy up to its very last day. In order to avoid the possibility of a live birth after the 20<sup>th</sup> week of pregnancy, ecboolic medication is usually combined with an injection of potassium chloride into the heart of the fetus.<sup>104</sup> In Germany, 2,891 abortions based on a medical indication were conducted after the 12<sup>th</sup> week of pregnancy in 2011, and 480 among these were carried out after the 22<sup>nd</sup> week.<sup>105</sup> Altogether, 3.2% of all abortions took place after a medical indication. Media reports and scientific surveys indicate that the majority of parents decide to have an abortion if the fetus is, for example, diagnosed with trisomy 21.<sup>106</sup>

**The BRK-Allianz calls for the following actions:**

- Independent and accessible counseling centers for pregnant women and their relatives and/or partners must be introduced all over the country, and they must include advisors with disabilities, in order to ensure a greater freedom of choice for those who seek advice.
- Families with disabled children must be provided with effective support.
- Awareness-raising measures must be conducted in order to inform people about life with disabled children.
- Medical physicians and other health professionals must be provided with awareness training with regard to the issue of living with disabilities in our society, so that they can

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<sup>104</sup> Wirth, Gesine (2006): Strafrechtliche und rechtsethische Probleme der Spätabtreibung, p. 55 et seq., <http://publikationen.ub.uni-frankfurt.de/frontdoor/index/index/docId/4593>.

<sup>105</sup> Statistisches Bundesamt, Fachserie 12, Reihe 3, 2011.

<sup>106</sup> See Bundeszentrale für gesundheitliche Aufklärung (2006): Schwangerschaftserleben und Pränataldiagnostik. Repräsentative Befragung Schwangerer zum Thema Pränataldiagnostik, p. 31; Josef Römelt (2009): Christliche Ethik in moderner Gesellschaft. Band 2: Lebensbereiche [Grundlagen Theologie]. Kapitel 3, Punkt 2.3.4.

provide sophisticated counseling. This issue should be an essential part of medical study courses at universities.

## Article 11 – Situations of risk and humanitarian emergencies

The UN CRPD places Germany under the obligation to ensure the safety and the protection of people in situations of risk and humanitarian emergencies. Consequently, the Ministry of Foreign Affairs included persons with disabilities as a particularly endangered group in their work scheme in 2010.<sup>107</sup> Nevertheless the Ministry only allocated very modest funds to corresponding projects.<sup>108</sup> Apart from some individual measures, the concerns of disabled persons are not incorporated into humanitarian aid; specific projects or inclusive approaches are nonexistent. The field of disaster relief is characterized by similar funding policies. The Ministry of Foreign Affairs does not recognize disability as an important cross-cutting issue on a strategic level or when it comes to the implementation of measures.

The same is true for the transitional aid provided by the Federal Ministry for Economic Cooperation and Development [*Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung/BMZ*], which is meant to bridge the gap between humanitarian aid and development cooperation.<sup>109</sup> Only few of the recently funded projects specifically targeted or included persons with disabilities. The considerable deficiencies of the Ministries' viewpoints became apparent in the comprehensive evaluation of German humanitarian aid provided between 2005 and 2009, which was presented in December 2011.<sup>110</sup> Persons with disabilities are not once mentioned in the entire report.<sup>111</sup>

**The BRK-Allianz calls for the following actions:**

- **All humanitarian aid and disaster risk reduction and disaster preparedness measures must be shaped according to the standards of inclusion and accessibility. The two senses rule must be acknowledged.**
- **The future “humanitarian aid strategy” must explicitly acknowledge “disability” as a funding criterion. Specific measures must be promoted in order to ensure the fulfillment of basic needs (protection, safety, food, water etc.) as well as of specific needs (aids and other articles, medical care, specific medication and so on).**
- **Specific and inclusive approaches that promote accessibility with regard to all measures for persons with disabilities must be ensured in the field of transitional aid.**

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<sup>107</sup> This can be found in the “Konzept zur Förderung von Vorhaben der Humanitären Hilfe”.

<sup>108</sup> For example, small funds were allocated to humanitarian projects in the context of the humanitarian landmine and explosive ordnance clearance. In 2010, 5 projects in the context of the so-called victim relief [*Opferfürsorge*] received funds of 500,000 EUR.

<sup>109</sup> Up until this day, the funds of the “Entwicklungsorientierte Not- und Übergangshilfe” are managed by the BMZ. The funds management for food aid will be transferred from ENÜH to the Ministry of Foreign Affairs. By means of the “Entwicklungsfördernde strukturbildende Übergangshilfe” (ESÜH), the BMZ will mainly support projects in the cooperation countries of the German developmental assistance.

<sup>110</sup> <http://www.auswaertiges-amt.de/cae/servlet/contentblob/344844/publicationFile/54405/Bericht2006-2009.pdf>.

<sup>111</sup> There is not even a reference in the chapter on cross-cutting issues.

## Article 12 – Equal recognition before the law

Germany facilitates legal guardianship for persons who need assistance in order to exercise their legal capacity (§ 1896 et seq. BGB). According to the guardianship law, the legal guardian is bound to promote the wishes, the subjective well-being and the rehabilitation of the person under legal guardianship (§ 1901, Para. 2-4 BGB). At the same time, the legal guardian represents the person under guardianship before and beyond the court, and within the scope of her or his duties and responsibilities (§ 1902 BGB).

According to the Federal Government<sup>112</sup>, the German guardianship law “is in conformity with the Convention”, and there is “no need for legislative action”. The appropriate means (Art. 12, Para. 4 CRPD) are ensured through a “strict principle of necessity”. However, the BRK-Allianz would like to point out that the number of legal guardianships is constantly increasing (1,200,000 cases in late 2005; 1,300,000 in early 2010).<sup>113</sup> The “principle of necessity” is increasingly violated on a regular basis, since many persons do not have an alternative to legal guardianship: there is no easy-to-access, low-threshold system to help persons make their decisions.<sup>114</sup> While the German guardianship law includes a few references to the principle of “support”, it is still based on the principle of “substituted decision-making” [*ersetzen* *Entscheidung*]. Consequently, there is a need for additional changes to the law, so that it is possible to implement Art. 12, Para. 3 UN CRPD, which obligates the States parties to make sure that persons with disabilities can access the support they may need in order to exercise their legal capacities (“supported decision-making” [*unterstützende Entscheidung*]).

Every guardianship includes some form of encroachment upon the right to self-determination. Rather than the actual adult individual seeking representation, it is the guardianship court that entitles the legal guardian to represent the individual concerned. As a rule, a guardianship decree automatically results in the transfer of the right to representation. While it is possible to issue an alternative representation agreement [*Vollmacht*] instead of falling back on legal guardianship, this is only legal if a person is considered to be contractually capable. However, contractual capacity requires a degree of intellectual and communication skills that persons with intellectual impairments are usually not thought to have. On this note, legal guardianship does not distinguish between persons in a vigilant coma and people with intellectual or psychosocial problems. The German legal

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<sup>112</sup> First State report of the Federal Republic of Germany, concluded by the Parliament on August 3, 2011, p. 34 and 35.

<sup>113</sup> Source: Bundesamt für Justiz, analysis: Deinert, [http://www.bdb-ev.de/220\\_Basisinformationen.php-3Fakten.pdf](http://www.bdb-ev.de/220_Basisinformationen.php-3Fakten.pdf). The increased demand must be considered in light of the fact that dementia and mental conditions are on the rise, while potential support systems within families are becoming less frequent and reliable. At the same time, the social welfare scheme was transformed according to the paradigm of the “activating welfare state”, and linked to high expectations regarding the beneficiaries’ involvement. Support services, such as budget assistance in the context of the Personal Budget as defined in § 17 SGB IX, or regional care management offices [*Pflegestützpunkte*] according to § 92c SGB IX, could potentially serve as guidelines when navigating the highly segmented German care system, but their implementation was deficient. On the issue of budget assistance, see [http://www.forsea.de/projekte/Gesetzesreformen/040522\\_pb\\_ass.shtml](http://www.forsea.de/projekte/Gesetzesreformen/040522_pb_ass.shtml); on care management offices, see Deutscher Bundestag (Drucksache 17/9203): Kleine Anfrage der SPD-Fraktion vom 28. 3. 2012 zum Ausbau der Pflegeinfrastruktur durch Pflegestützpunkte und Pflegeberatung.

<sup>114</sup> For example, the Swedish Skåne region established this type of system and therein the *Personligt Ombud* (PO) program. See [www.po-skane.org](http://www.po-skane.org); see World Bank & WHO (2011): World report on disability, p. 138.



system does not provide for an easily accessible, low-threshold representation authorization, such as the Canadian “Representation Agreement”.<sup>115</sup>

The stipulations regarding contractual incapacity in the German civil law are based on the assumption that persons can be permanently in a state of “pathological mental disturbance, which prevents free exercise of will”. These persons are largely excluded from participating in legal relations, and their declarations of intent are null and void (§ 104 et seq. BGB), apart from the exceptions defined in § 105a BGB. In the Federal Government’s opinion<sup>116</sup>, these stipulations comply with the CRPD.

However, this conflicts with the notion of “capacity” according to Art. 12, Para. 2 and 3 UN CRPD, which requires that a person’s capacity to articulate her or his intent, must be assessed individually in each case, and that the necessary support must be provided in order to help them exercise their legal capacity. Characterizing a person as permanently contractually incapacitated is not compatible with the UN CRPD.

#### **The BRK-Allianz calls for the following actions:**

- **The German guardianship law must be amended according to the concept of “supported decision-making”. Persons with disabilities must be provided with assistance for supported decision-making, without intervening in their right to self-determination.**
- **There is a need for model projects that are scientifically supervised, with the aim of testing new schemes for supported decision-making that are not based on a mandate for legal representation. These model projects must make use of accessible communication means.**
- **With regard to supporting persons with disabilities who want to exercise their legal capacities, mandatory quality criteria must be compiled and established.**
- **The stipulations regarding contractual incapacity must be adjusted on the basis of Art. 12 UN CRPD. In particular, § 104, Para. 2 BGB requires a fundamental review. It must be acknowledged that persons with progressing brain damage are in need of special protection.**
- **Support as defined in Art. 12, Para. 3 and 4 UN CRPD must be established in the German (social) code, and it must be defined as a separate entitlement to the relevant services. This is necessary in order to ensure compliance with Art. 12, Para. 4 UN CRPD, which demands that the principle of necessity is acknowledged.**

### **Article 13 – Access to justice**

Persons with disabilities do not have equal access to justice. The current law stipulates that a person is only entitled to participate in legal proceedings if he or she is considered contractually capable.<sup>117</sup> Persons who are not contractually capable, including many intellectually disabled persons or persons with mental conditions, are denied their right to take legal action, and their declarations of intent are null and void (§ 105 BGB). Moreover, persons are generally not permitted to take legal action if requirement for consent

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<sup>115</sup> UN 2007: From exclusion to equality, p. 90.

<sup>116</sup> 1<sup>st</sup> State report, p. 32-33.

<sup>117</sup> See § 52 civil procedure rules [*Zivilprozessordnung/ZPO*], § 71 social courts act [*Sozialgerichtsgesetz*].

[*Einwilligungsvorbehalt*] was decreed (§ 1903 BGB) or if the person is represented by a legal guardian during the trial (§ 53 ZPO).

Legal aid does not cover expenses that result from disabilities, such as assistance, interpretation or travel costs. Persons with disabilities who receive social welfare benefits are usually not able to cover these expenses on their own.

Barrier-free access to justice and accessible communication are not always ensured. For example, trials are sometimes conducted in rooms that are located in the involved authorities' buildings. This can convey the impression that the administration is not clearly separated from the legal system. Currently, a draft law is being compiled in Germany with regard to electronic communication with the legal system [*E-Justice*]. This draft law does not contain the necessary stipulations on accessibility. Hence, it will likely endanger accessibility improvements with regard to the administration and the legal system will change for the worse, for both citizens as well as legal staff with disabilities.

**The BRK-Allianz calls for the following actions:**

- **The stipulations regarding the right to participate in legal proceedings must be changed according to Art. 12 CRPD.**
- **Court buildings and court proceedings must be accessible. It is imperative that legal staff receive comprehensive accessibility awareness training.**
- **Legal aid must cover expenses for necessary assistance, interpretation and travel.**
- **Draft laws regarding electronic communication with the legal system must be completed by precise regulations with regard to accessibility.**

## **Article 14 – Liberty and security of the person**

Several German laws allow for the institutionalization of individuals against their explicit will. Consignments to public institutions are subject to different stipulations in the Länder, and provide for the possibility to institutionalize individuals in order to prevent endangerment to themselves and to others. According to the BGB civil right stipulations with regard to institutionalizations, it is lawful to institutionalize persons in order to protect them from harming themselves. In 2005, there were 193,373 cases of compulsory institutionalization in Germany, and 236,377 cases in 2009. The overall figures have been on a continuous rise since 1992.<sup>118</sup>

In both the State report<sup>119</sup> and the NAP<sup>120</sup>, the Federal Government refers to the current legal situation. These documents mention very few improvements to be made, namely, a greater number of visiting committees in order to examine the situation of persons who were institutionalized. In addition, they state that more independent complaints offices must be established. Moreover, they mention that the federal joint committee on medical affairs [*Gemeinsamer Bundesausschuss*] was prompted to compile quality management indicators with regard to medical care for persons with mental conditions. With these

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<sup>118</sup> Source: Federal Ministry of Justice, Special Survey on Legal Proceedings according to the Guardianship Law [*Verfahren nach dem Betreuungsgesetz*] 1998 – 2005.

<sup>119</sup> 1<sup>st</sup> State report, p. 35.

<sup>120</sup> NAP, p. 93.

statements, the Federal Government misjudges both the questionable legal situation in Germany and the everyday reality of the legal system.

Some associations of persons who have been hospitalized state that the institutionalization of a mentally ill person is per se incompatible with the UN CRPD. Instead, they demand that in all cases, the same law enforcement statutes must be valid for all people. Other associations, including associations of persons with disabilities, hold the opinion that compulsory institutionalization can be a last resort if it is absolutely necessary, and only in order to ensure that the person is protected from harming her-/himself or others. They declare that this decision must be individually weighed against another essential legal interest, namely, the health of the individual. .

However, in reality many instances of institutionalization result from a lack of other therapeutic or social support, or from another institution's inability to handle a specific situation or person. Also, agencies are often not willing to provide their services in a timely manner or in a way that is adequate for the individual case, which can result in institutionalization. Institutionalization proceedings often include the following essential deficiencies:

- \* Medical reports and other statements issued by consultants often do not fulfill the necessary quality criteria.
- \* The appointment of case guardians does not always ensure effective legal protection.
- \* Hearings are often scheduled at a time when a person is already treated with drugs, and therefore not only impaired by his or her mental condition, but also by the early effects and side-effects of the drugs they are required to take.
- \* Likewise, the judges' actual decision-making is in need of improvement.

Consequently, several aspects of the law must be changed in order to guarantee that the means employed are de facto adequate in all of these cases, so that those concerned enjoy effective legal protection.

We agree with the Federal Government's opinion that independent complaints offices must be established. However, these offices are not included in the recently adopted law on patients' rights [*Patientenrechtgesetz*].<sup>121</sup> In this way, the Federal Government does not act in compliance with their own State report.

#### **The BRK-Allianz calls for the following actions:**

- **The law pertaining to institutionalization on the basis of the guardianship law must be fundamentally reviewed. The existence of a disability cannot justify any deprivation of liberty. Moreover, the preconditions as defined in Art. 14 UN CRPD must be fulfilled.**
- **The Länder laws with regard to institutionalization<sup>122</sup> must be fundamentally adjusted so that they comply with UN CRPD Art. 14.**
- **In every case of involuntary institutionalization, the institutionalized person must be entitled to a lawyer free of charge.**
- **Court decisions regarding a person's institutionalization must be ruled promptly. The court must hear the disabled person who is to be institutionalized before he or she is treated with neuroleptic drugs, in order to make sure that the court acquires an undistorted, individual impression of that person. Other important legal interests, such as**

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<sup>121</sup> BT-Drs. 17/10488 and 17/11710.

<sup>122</sup> For example, the laws on mentally ill persons [*Psychisch-Kranken-Gesetze/PsychKGs*].

**the protection of the individual concerned, the right to treatment, and the protection of other people, must be carefully weighed up against each other.**

**- In order to ensure this, it is mandatory that the court examines any psychosocial or medical support that could or should be offered or provided to the person in question, in order to avoid institutionalization. Social services agencies must be obliged to cooperate in these proceedings.**

**- A documentation system must be established with regard to both the Länder and the municipal court districts, in order to collect data on the number of institutionalized persons, the legal grounds for the institutionalization, and the issued period of the institutionalization. This documentation must present the data in a comprehensive way, and the data should be anonymous. Research on legal facts with regard to institutionalization must be set in place, and conducted in a consistent manner.**

**- In order to implement these demands, a comprehensive support system must be built that is based on the concerned individual's voluntary agreement.**

## **Article 15 – Freedom from torture or cruel, inhuman or degrading treatment or punishment**

German law categorically prohibits research involving people who are “unable to give their consent” if this research is to be utilized by or in the interest of third parties. The German law on medicinal products [*Arzneimittelgesetz/AMG*] allows for drug research with minors if the research is necessary and the risks and exposures are minimal. Moreover, the parents as well as the minor must consent, if the latter is possible. It is prohibited to conduct such research with intellectually disabled children and adolescents. The permission for strictly defined research activities with minors that will be utilized by third parties is justified by the lack of medication tested and approved for children and adolescents. However, some have criticized that the current specifications on “persons who are unable to give consent” might result in a general annulment or weakening of the prohibition.

It is mandatory that the legal regulations regarding genetic research are reviewed as soon as possible. This type of research frequently includes persons who were described as “unable to consent” prior to the adoption of the UN CRPD. The law on genetic diagnostics only applies to diagnostic proceedings, but disregards the issue of research. The urgent necessity of clarification becomes apparent when looking at the completed research project “MR Net”, which investigated the genetic causes of so-called “mental retardation”.<sup>123</sup> This project was conducted without any consideration of internationally accepted standards regarding vulnerable groups of people. In their motivation statement, the researchers referred to the social benefits of their project, since the phenomenon of “mental retardation”, in their words, represents a considerable cost factor. Despite the fact that the protection needs of the “investigated” group were not sufficiently acknowledged, this research project was funded by the Federal Ministry of Education and Research [*Bundesministerium für Bildung und Forschung/BMBF*]. This serves as a clear example for the urgent need for legal clarification.

In 2011, the UN committee that monitors the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), argued in favor of intersexual

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<sup>123</sup> See <http://www.german-mrnet.de/>.

persons, stating that Art. 16 CAT has been violated with regard to this group of people.<sup>124</sup> In the “Concluding Observations of the Committee against Torture” from November 2011, the committee issued four recommendations to Germany in item 20.<sup>125</sup> The Federal Republic of Germany did not act upon these recommendations. Still today, the rights of intersexual persons who were made severely disabled were never enforced.<sup>126 127</sup>

**The BRK-Allianz calls for the following actions:**

- **The free and informed personal consent of the test person, given after the best possible medical explanation, must be the indispensable precondition of research involving human beings. The prohibition of third-party interest research on human beings who do not consent to the procedure must not be overridden by other stipulations. The Federal Government must commit Germany to the establishment and maintenance of these standards on a national and European level, and in this way, must prevent these standards from being weakened in the context of EU legal regulations, since these EU regulations would be legally binding for the Federal Republic of Germany.**
- **The use of the notion of “inability to consent” [*Einwilligungsunfähigkeit*] is not compatible with the UN CRPD notion of “capacity” as defined in Art. 12, Para. 2. A political debate on the UN CRPD “capacity” notion and the German notion “inability to consent” is urgently necessary. (The criticism regarding the so-called “inability to consent” also applies to health professionals who enforce treatments, see Art. 17 UN CRPD.)**
- **The Federal Government must implement the recommendations issued in 2011 by the UN Committee against Torture in favor of intersexual persons. This includes the obtainment of informed consent, the investigation of the medical procedures that were carried out, financial compensation as the circumstances require, training of medical professionals, and information for parents on the consequences of medical procedures.**
- **Castrations and medical procedures without informed consent of the concerned person must be prohibited.<sup>128</sup>**

## **Article 16 – Freedom from exploitation, violence and abuse**

Persons with disabilities are particularly affected by right-wing extremist violence, and in general, violence based on prejudices.<sup>129</sup> Newspapers frequently report these types of abuse. Likewise, the child abuse roundtable<sup>130</sup> [*Runder Tisch Kindesmissbrauch*], held between April 2010 and November 2011, uncovered the fact that persons with disabilities

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<sup>124</sup> [http://www2.ohchr.org/english/bodies/cat/docs/ngos/IMF\\_Germany\\_CAT47.pdf](http://www2.ohchr.org/english/bodies/cat/docs/ngos/IMF_Germany_CAT47.pdf) (Shadow report on intersexuality).

<sup>125</sup> See item 20 at [http://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Pakte\\_Konventionen/CAT/cat\\_state\\_report\\_germany\\_5\\_2009\\_cobs\\_2011\\_de.pdf](http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/CAT/cat_state_report_germany_5_2009_cobs_2011_de.pdf).

<sup>126</sup> <http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf> => German Ethics Council (Deutscher Ethikrat), Stellungnahme Intersexualität, 2012, and the press statement: <http://www.ethikrat.org/files/press-release-2012-01.pdf>

<sup>127</sup> [http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5\\_en.pdf](http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf) (Concluding observations 2011, Intersex people).

<sup>128</sup> Stellungnahme des Deutschen Ethikrates zur Situation Intersexueller Menschen (2012).

<sup>129</sup> Berliner Forum Gewaltprävention, see [http://www.berlin.de/imperia/md/content/lb-lkbgg/bfg/nummer16/21\\_schmidt.pdf?start&ts=1182169235&file=21\\_schmidt.pdf](http://www.berlin.de/imperia/md/content/lb-lkbgg/bfg/nummer16/21_schmidt.pdf?start&ts=1182169235&file=21_schmidt.pdf).

<sup>130</sup> <http://www.rundertisch-kindesmissbrauch.de/>.

are a particularly vulnerable group. For example, the final report<sup>131</sup> emphasized that there are not enough counseling services for persons with disabilities.

While reliable data exists with regard to violence against girls and women with disabilities (see below), as of yet, hardly any research has been conducted on boys and men with disabilities who are exposed to violence. One Austrian survey<sup>132</sup> from 1997 is based on the analysis of 117 interviews with disabled men who live in institutions. The results show that more than 25% among the interviewees had experienced sexual violence.

According to a statement<sup>133</sup> published by the federal coordination office [*Staatliche Koordinierungsstelle* (Art. 33 UN CRPD)] in September 2012, research is currently being carried out with regard to disabled boys' and men's exposure to violence. However, none of the interviewees are men who live in institutions.

In recent years, the Federal Government carried out and implemented several measures targeted at the prevention of and the struggle against **violence against women and girls with disabilities**. Non-governmental organizations approve of these steps (for example, the action plan II for the struggle against violence against women). However, the NAP has not provided for any further anti-violence measures since 2012.

The Federal Government commissioned a representative survey on the living conditions of women with disabilities. The results were presented in 2012 and show that women with disabilities are two to three times more likely to be victims of sexual violence than women without disabilities (that is, more than half of the population of women with disabilities is exposed to sexual violence). Approximately 74% of these women have been exposed to physical and psychological violence, which is twice the percentage when compared to women without disabilities. Another issue is the structural violence within institutions, such as the lack of single private rooms, bathrooms and toilets that cannot be locked, etc.<sup>134</sup>

One effective way to protect individuals from violence is through self-confidence and self-defense training. The German rehabilitation law, which came into effect in 2001, stipulated the creation of training programs that are aimed at strengthening self-confidence in the context of rehabilitation sports. Unfortunately, in contrast to what the State report says, no such programs and classes have been provided. In this way, women and girls with disabilities cannot exercise their right to self-defense training. According to the statements of the German national paralympic committee [*Deutscher Behindertensportverband*], which is in charge of providing this service, the first nine female trainers qualified in 2012, and up until this day they are the first and only persons to provide such classes in Germany.<sup>135</sup>

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<sup>131</sup> [http://www.rundertisch-](http://www.rundertisch-kindesmissbrauch.de/documents/111130AbschlussberichtRTKM111213.pdf)

[kindesmissbrauch.de/documents/111130AbschlussberichtRTKM111213.pdf](http://www.rundertisch-kindesmissbrauch.de/documents/111130AbschlussberichtRTKM111213.pdf).

<sup>132</sup> Bundesministerium für Frauenangelegenheiten und Verbraucherschutz, compiled by Aiha Zemp, Erika Pircher, Heinz Schoibl: Sexualisierte Gewalt im behinderten Alltag. Jungen und Männer mit Behinderung als Opfer und Täter, Salzburg 1997.

<sup>133</sup> „Frauen und Mädchen mit Behinderung besser vor Gewalt schützen“, see [http://www.awo-informationsservice.org/index.php?eID=tx\\_nawsecuredl&u=0&file=uploads/media/PositionspapierGewalt\\_-\\_Staatliche\\_Koordinierungsstelle\\_14092012.pdf&t=1350656197&hash=e75b0b3c898da0b73758cb32f492cc9becf4046](http://www.awo-informationsservice.org/index.php?eID=tx_nawsecuredl&u=0&file=uploads/media/PositionspapierGewalt_-_Staatliche_Koordinierungsstelle_14092012.pdf&t=1350656197&hash=e75b0b3c898da0b73758cb32f492cc9becf4046).

<sup>134</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend (2012): Lebenssituation und Belastungen von Frauen mit Beeinträchtigungen und Behinderungen in Deutschland (see also [http://www.uni-bielefeld.de/IFF/for/zentrale\\_ergebnisse\\_kurzfassung.pdf](http://www.uni-bielefeld.de/IFF/for/zentrale_ergebnisse_kurzfassung.pdf)).

<sup>135</sup> <http://www.dbs-npc.de/nachrichten-dbs/items/praxiseinstieg-fuer-uebungsleiterinnen-1692.html>.

The Federal Government's State report points to the special penal provisions that are aimed at protecting persons with disabilities from sexual abuse. However, the German law provides different penalties for sexual assaults. The minimum penalty for sexual assault of persons who are "able to resist" is one year, while the sexual assault of persons who are said to be "unable to resist" results in a minimal penalty of only six months.

The State report also emphasizes the large number of women's shelters and counseling centers for women who have been exposed to violence (altogether, 860). However, only a small number of these protection and support institutions are barrier-free.<sup>136</sup>

In addition, the law on protection against violence [*Gewaltschutzgesetz*] does not sufficiently protect women with disabilities. For example, if a domestic partner who provides care to a disabled person exerts domestic violence and is expelled from the shared home, there is no clear legal regulation which guarantees that expenses for an alternative care person are covered promptly and without having to go through a complicated procedure. Also, the law on protection against violence is not applicable to institutions within the field of agencies and services for persons with disabilities, since it is not possible to expel the offender if she or he is living in the same institution.

**Violence in the context of care** exists on many different levels. These include the shaming of the care recipient, supplying insufficient nutrition, neglecting hygienic needs, violence during the administration of drugs, verbal attacks and physical assault. Although extreme cases, such as those in which a care recipient was bound or physically tied down, are frequently made known to the general public, less obvious cases, such as verbal humiliation or insults, also qualify as violence.

In Germany in late 2009, 2.34 million persons, the majority of whom are women, were in need of care as defined in the long-term care insurance law [*Pflegeversicherungsgesetz*, SGB XI]. More than two thirds of the care recipients lived in their own home, and again, most of them were women. Also, 75% of full in-patient care recipients in institutions are women.<sup>137</sup>

Deficiencies in patient care are mainly revealed in nursing homes, but also in other sites of malpractice. In its 3<sup>rd</sup> care quality report (2012),<sup>138</sup> the medical services of the umbrella organization for the health insurance companies [*Medizinischer Dienst/MDS*] stated that the quality of care had improved when compared to earlier reports (2005 and 2007), but that considerable deficiencies continue to exist. For example, there is a large number of cases where persons in need of extensive care, and specifically patients with dementia, are tied down, or confined to closed wards.<sup>139</sup> Regarding these care deficiencies, the UN Human Rights Committee went as far as to refer to the prohibition of torture, inhuman or degrading treatment or punishment in their concluding observations<sup>140</sup> concerning the 6<sup>th</sup> German

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<sup>136</sup> Regarding outpatient counseling, according to a recent and still unpublished survey conducted by the federal association of women's counseling centers and women's emergency hotlines [*Bundesverband Frauenberatungsstellen und Frauennotrufe/bff*], 220 women's counseling centers and emergency hotlines, 20% of these are wheelchair accessible. Less than 10% of them provide tactile and optical design elements and information in Braille and DGS.

<sup>137</sup> Pflegestatistik 2008, Pflege im Rahmen der Pflegeversicherung – Deutschlandergebnisse, Statistisches Bundesamt, Wiesbaden 2011.

<sup>138</sup> 3. Bericht des MDS nach § 114a Abs. 6 SGB XI, Qualität in der ambulanten und stationären Pflege, Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS), Köln 2012.

<sup>139</sup> Deutsches Institut für Menschenrechte, Pressemitteilung anlässlich der Veröffentlichung der Abschließenden Bemerkungen des UN-Menschenrechtsausschusses, November 1, 2012.

<sup>140</sup> <http://www2.ohchr.org/english/bodies/hrc/docs/co/CCPR-C-DEU-CO-6.doc>

State report on the CCPR [*Zivilpakt*]. These deplorable conditions exist both in out-patient and in in-patient care situations.

Improvements were made regarding the supply with food and drink as well as the treatment of patients with dementia. In contrast, there is a lot of room for improvement when it comes to avoiding bedsores and inadequate medication.<sup>141</sup>

Food and drink supply: Deficiencies were detected in 5% of the residents in care facilities. 79.5% of the people concerned are assisted during the intake of food. In institutions where this support was systematically omitted, the inspectors discovered that the residents experienced an average weight loss of 34%.

Bedsore: Almost half of the examined residents (46.9%) were at risk of developing decubitus.<sup>142</sup> Compared to the 2007 report, there is no improvement regarding decubitus prevention.

Medication: 95% of residential facility in-patients need support in handling their medication. Approximately 18% of them are treated with drugs that are not appropriately documented or stored. With almost half of the patients with potential pain, the care staff did not conduct any pain assessment procedure. 6% of those patients who were prescribed pain therapy by doctors were denied their pain medication.<sup>143</sup>

With regard to senior citizens', and in particular, older women's exposure to violence, it is important to keep the war experiences of older generations in mind. Mass rape traumatized many women, many of whom never had the opportunity to process their experiences. In old age, these memories can resurface due to the care situation or other incidences. Mistakenly, these women's reactions are often diagnosed to be a symptom of dementia. Hence, they are not provided with adequate support.<sup>144</sup>

For many years, NGOs have been requesting that patients be entitled to same-sex care staff in order to protect female care receivers from violence exerted by men. Nevertheless, this demand was established in the reviewed long-term care insurance law with the wording "where possible".<sup>145</sup>

#### **The BRK-Allianz calls for the following actions:**

**- Counseling services for persons with disabilities who are or were exposed to violence must be accessible. Funding must be allocated for better accessibility in women's shelters and expert counseling centers for women who have experienced violence. This includes covering the expenses for interpretation, for example, into and from German Sign Language [*Deutsche Gebärdensprache/DGS*].**

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<sup>141</sup> 3. Bericht des MDS.

<sup>142</sup> In 59.3% of these cases, necessary prevention was employed, such as position changes or the use of medical aids. However, the inspectors detected neglect in 40.7% of the cases.

<sup>143</sup> *Ärzte Zeitung "Pflegerheime: Schmerztherapie mit Defiziten"*, April 24, 2012.

<sup>144</sup> Daten, Fakten, Berichte zur Lebenssituation älterer Menschen, Sigrid Arnade, in: Einmischen Mitmischen, Informationsbroschüre für behinderte Mädchen und Frauen, Bundesministerium für Familie, Senioren, Frauen und Jugend (ed.), Berlin 2007.

<sup>145</sup> § 2 Social Code XI: "If care recipients express the wish for a same-sex care person, this wish should be acknowledged where possible."



- Research must be conducted on exposure to violence regarding boys and men with disabilities, and it must include boys and men who live in institutions.
- A comprehensive network of self-confidence training programs for women and girls with disabilities must be set in place, as defined in the rehabilitation law.
- Penalties for sexual assault must be standardized, regardless of the question of whether the victim is or is not considered able to resist.
- The right to same-sex care must be established.
- The law on protection against violence must be reviewed so that it ensures the protection of women and men with disabilities who were or are exposed to violence, who are in need of care or assistance and/or live in institutions for disabled persons.
- Professionals in law enforcement, the legal system, the medical system, forensic medicine, caregivers, educational staff etc., must be trained on how to handle and interact with women and men with disabilities who were or are exposed to violence.
- Agencies that finance institutions in the field of services for the disabled must decree mandatory measures for violence prevention and intervention, and they must consider the specific living conditions of transsexual and intersexual persons.
- Care standards must be defined, implemented and effectively monitored in order to ensure that malpractice in both inpatient and outpatient care will be eliminated and avoided in the future.
- In order to diminish care deficiencies, caregivers must be provided with human rights training.

## **Article 17 – Protecting the integrity of the person**

Compulsory treatment and forced medication are serious violations of the right to physical integrity. These practices can only be justified in a specific situation, where the patient is unable to autonomously act upon her/his fundamental rights and therefore cannot give her/his consent, and if the infringement is conducted in the best interest of her/his equally fundamental right to life, physical integrity and liberty.

In psychiatric institutions, this norm is violated in many ways in the course of the daily routines. It is estimated that approximately 10% of all in-patients are exposed to compulsory treatments<sup>146</sup>, and that 2%-8% of all in-patients are exposed to forced medication.<sup>147</sup> The percentage of compulsory institutionalizations varies considerably between the Länder, as well as between the districts within the Länder.<sup>148</sup> The use of coercion depends on different legal stipulations and procedural laws that are specific to the individual Länder, as well as on the regional care conditions.

Up until this day, psychiatric treatments frequently take place without the informed consent of the individual concerned. During treatment, the staff may use threats and violence, which is traumatic for many of those concerned. There are very few measures that provide for outpatient crisis intervention.

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<sup>146</sup> R. Ketelsen, M. Driessen, C. Zechert (2007): Kooperationsmodell zwischen psychiatrischen Kliniken mit dem Ziel der Qualitätssicherung bei Zwangsmaßnahmen. In: Psychiatrische Praxis, Supplement 2, 35: p. 208-211.

<sup>147</sup> Steinert T, Kallert TW (2006) Medikamentöse Zwangsbehandlung in der Psychiatrie. In: Psychiatrische Praxis 33: p. 160-169.

<sup>148</sup> See BT-Drs. 17/10712.

The German federal constitutional court [*Bundesverfassungsgericht/BVfG*] ruled that the current psychiatric laws [*Psychiatriegesetze*] of two of the Länder are unconstitutional.<sup>149</sup> Both laws allow for unconstitutional compulsory treatment measures. In the context of the guardianship law, coercive institutionalization is only lawful in order to allow for medical treatments (§ 1906, Para. 1(2) BGB).<sup>150</sup>

**The BRK-Allianz calls for the following actions:**

- **The guardianship law (§ 1906, Para. 1(2) BGB) as well as all Länder laws regarding mentally ill persons, institutionalization and hospitalization in psychiatric and forensic facilities, must be amended in accordance with the stipulations of the German high courts and the CRPD. This must include the following provisions:**
- **In emergency situations, it is mandatory to carry out and document de-escalation crisis intervention measures.**
- **Psychiatric institutions must systematically provide information about the possibility to issue legally binding advance health care directives and treatment agreements.**
- **Any medical evaluation that is required prior to a compulsory treatment must be issued by an external expert. More specifically, this expert must not work in the institution where the person concerned is assigned. The estimate must include a separate section with explications on the adequacy, type and duration of the compulsory treatment.**
- **Before somebody is committed to an institution and receives compulsory treatment, it shall be always mandatory to make a serious and verifiable effort to obtain the consent of a disabled patient in a way that is based on trust.**
- **Any attempts to obtain somebody's consent to treatment, as well as any actual compulsory treatment conducted, must be subject to exhaustive documentation.**
- **If somebody is placed in restraints, it is indispensable to provide a nurse aid on permanent watch that is controlled on an hourly basis by a medical physician. The necessary human resources must be provided.**
- **Independent psychiatric complaint offices must be set in place.**
- **Psychiatric institutions shall be obliged to conduct systematic qualification measures for de-escalation strategies.**
- **Suicide and/or death caused by the administration of psychotropic drugs must be systematically investigated. The link between compulsory treatments and the individual on-site patient care conditions must also be examined.**

## **Article 18 – Liberty of movement and nationality**

Due to the fact that the German asylum procedure law [*Asylverfahrensgesetz*] prohibits individuals from entering other Länder or municipalities (the so-called "*Residenzpflicht*"), **asylum seekers with disabilities** are not entitled to choose their place of residence. (In some of the Länder, this law does not apply.) This type of restriction is currently being debated<sup>151</sup>, and was already criticized in the 2011 shadow report compiled by the Alliance for economic, social and cultural rights in Germany [*WSK-Allianz*]. They write: "In addition, in case of

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<sup>149</sup> Decision of the BVerfG from March 23, 2011 – 2 BvR 882/09 Rheinland Pfalz, decision of the BVerfG from October 12, 2011 – 2 BvR 633/11 Baden Württemberg.

<sup>150</sup> In the meantime, the federal court of justice [*Bundesgerichtshof/BGH*] ruled in two resolutions from June 20, 2012, that the guardianship law does not represent a sufficient basis for compulsory treatments.

<sup>151</sup> See <http://www.tagesspiegel.de/politik/asylpolitik-der-lange-marsch-der-fluechtlinge/7173520.html>.

illness/disability/care dependency and traumatization of the refugee or his/her relatives, the necessary regular contact with and support of family members, often living hundreds of kilometres away in another place in Germany, is obstructed and prevented.”<sup>152</sup>

Technically, persons with disabilities can leave Germany without encountering any legal problems, but in reality, individuals who rely on **care or assistance outside Germany** will likely nevertheless face problems. This becomes apparent with the example of a young man who wanted to study abroad in the U.S.<sup>153</sup> The Austrian shadow report mentions similar problems.<sup>154</sup> While German citizens are entitled to receive their German care allowance [*Pflegehilfe*] within the European Union, the European Court of Justice ruled that care devices and products [*Pflegehilfsmittel*] or benefits in kind [*Sachleistungen*] will not be covered.<sup>155</sup>

Contrary to the Federal Government’s claims in the State report, the current civil status law [*Personenstandsrecht*] actually provides for many disadvantages, namely with regard to intersexual children. § 21, Para. 1(3) PStG requires that the child’s gender be certified in order for the child to be recorded in the civil registry [*Personenstandsregister*]. In reality, this means that either the male or the female gender must be assigned to the child, which results in the inherent discrimination of intersex children.

#### **The BRK-Allianz calls for the following actions:**

- **The residency obligation [*Residenzpflicht*] in the asylum procedure law must be abolished.**
- **States must sign bilateral agreements in order to regulate the covering of assistance costs abroad.**

### **Article 19 – Living independently<sup>156</sup> and being included in the community**

In recent years, the German welfare state has become more and more aligned with the principle of the “activating welfare state”.<sup>157</sup> The allocation of socio-political benefits has also become increasingly dependent upon certain conditions, and beneficiaries must

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<sup>152</sup> See [http://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Pakte\\_Konventionen/ICESCR/icescr\\_state\\_report\\_germany\\_5\\_2008\\_parallel\\_Alliance\\_de.pdf](http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/ICESCR/icescr_state_report_germany_5_2008_parallel_Alliance_de.pdf), p. 16.

<sup>153</sup> See [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,16085/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,16085/ticket,g_a_s_t)

<sup>154</sup> See „Bericht zur Umsetzung der UN-Konvention über die Rechte von Menschen mit Behinderungen in Österreich“, Wien 2010, p. 72.

<sup>155</sup> See <http://curia.europa.eu/juris/document/document.jsf?text=&docid=124987&pageIndex=0&doclang=D&mode=lst&dir=&occ=first&part=1&cid=152354>.

<sup>156</sup> See the introduction of this report on the faulty official translation of “living independently” as “unabhängige Lebensführung” instead of the correct term “selbstbestimmt leben”.

<sup>157</sup> One example of this are the so-called Hartz IV laws that established the principle of “promote and challenge” [*“Fördern und Fordern”*]. These laws allowed the granting of tax-funded unemployment benefits to be tied to the condition that the concerned individuals must be proactive in trying to overcome their need for support.

thereby display a higher degree of motivation, responsibility and self-organization in order to receive social services. These sociopolitical goals, namely the “activation” and “self-sufficiency” of the beneficiaries, came along with a rising amount of restrictions attached to the allocation of services, and more and more services must be contended for in court.<sup>158</sup> This development comes at a disadvantage for people who do not have sufficient access to resources (information, social networks, education, financial means etc.), or for those who are impaired by health conditions or disabilities.

The German social code and its administrative implementation are characterized by a traditional notion of welfare [*Fürsorgegedanke*] and by tight public budgets. Different service agencies disagree on the question of who is responsible for what; there are controversies about service standards; the proceedings are bureaucratic; services are subjected to restrictions that often do not comply with an individual’s right to the necessary services, all of which frequently leads to cutbacks. The application procedures are in themselves often complicated, which represents a big hurdle especially for persons with cognitive impairments.

There is a great need for a dense network of services that is based on the beneficiaries’ **living and social environment**, such as assistance for communication, mobility and participation, or independent counseling, all of which are essential for people with disabilities who want to live independently. As a result, it is often impossible for individuals to freely choose their place of residence. In contrast to the stipulations in the “UN Guidelines”<sup>159</sup>, the State report remains silent on this issue. The authors do not explain to which extent such offers actually exist or are to be created in order to comply with UN CRPD Art. 19. However, if disabled persons are not provided with adequately available assistance, they are likely to become dependent on public institutions or on relatives and other personal contacts, who are then in charge of compensating for the lack of paid assistance.<sup>160</sup>

Particularly persons in need of extensive support are often pushed towards moving into a residential facility for financial reasons, instead of being enabled to live the life that they would like to live, namely, in their own apartment with assistance.<sup>161</sup> In this way, these individuals do not have a **free choice of their place of residence** as CRPD Art. 19 stipulates. Agencies only cover expenses for out-patient social services if this service does not entail “disproportionate additional costs” when compared to a “reasonable” [*zumutbar*] in-patient option (such as living in a care facility; see clause on additional costs [*Mehrkostenvorbehalt*], § 13, Para. 1(3) SGB XII). The agencies determine what is “disproportionate” and what is “reasonable”. In this sense, the clause on additional costs violates the right to freely choose the place of residence, and therefore goes against the UN CRPD. The monitoring office

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<sup>158</sup> The flood tide of lawsuits against Hartz IV related decisions at the federal social court [*Bundessozialgericht/BSG*] is not coming to a stop. In 2010, 32,000 lawsuits were filed in this context; almost half of them were at least partly successful.

<sup>159</sup> Committee for the Rights of Persons with Disabilities: Guidelines on the treaty-specific document to be submitted by States parties under Article 35, Paragraph 1, of the Convention on the Rights of Persons with Disabilities, United Nations, Geneva 2009 (CRPD/C/2/3).

<sup>160</sup> For example, this is frequently the case with deaf-blind persons, since there is not enough staff trained to provide deaf-blind assistance.

<sup>161</sup> See for example, [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,25110/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,25110/ticket,g_a_s_t).

[Monitoring-Stelle] also stated that the authorities should not have the right to refuse applications for living with out-patient support and assistance.<sup>162</sup>

The lack of information, counseling and support, the ensuing fears of insufficient care outside of institutions and the fear of, or lack of strength for tedious (legal) disputes, all contribute to the fact that disabled persons are often pushed to live in in-patient residential care facilities. If persons with disabilities, and specifically persons who need extensive support, use their freedom of choice to decide that they want to live in an institution, it is important to make sure that the spatial layout as well as the staff fulfill the needs of the inhabitants.

Resource cutbacks over the past years have already resulted in a considerable decrease of care quality. This is no longer acceptable. In-patient residency cannot be reduced to a mere provision of basic care.

Regarding in-patient residential facilities within institutions from the field of services for the disabled, long-term care insurance providers [*Pflegekassen*] only pay a restricted lump sum, namely 256 EUR/month, in order to compensate for care benefits in kind [*Pflegesachleistungen*, § 43a SGB XI]. Hence, persons with disabilities who need care services are denied the very benefit entitlements that they acquired through their own financial contributions, simply because they chose to live in an in-patient facility.

The **Personal Budget** option has the potential to make it easier for persons with disabilities to live independently. This is especially true when it comes to obtaining services from different agencies. However, these agencies misuse the Personal Budget frequently in order to save expenses. In contrast to the legal stipulations, it thus becomes necessary to fight for individual benefits and services in budget conferences. In any case, budgets that are connected to more than one single agency are an exception to the rule. Out of all Personal Budgets, only 1% is linked to more than one single agency.<sup>163</sup> Independently from the issue of Personal Budgets, the procedures for the determination of an individual's needs and requirements are complicated, and strongly characterized by the pressure to make financial cutbacks; this is especially true when it comes to extensive or specific needs.<sup>164</sup>

While the State report assigns many words of praise to Personal Budgets<sup>165</sup>, numerous problems arise during their actual implementation that remain unmentioned. It is very complicated to determine an individual's needs and to manage claimed services accounts, but Personal Budgets do not include any funds that are specifically targeted to help solve these issues. Therefore, notably persons with cognitive impairments are actually often unable to make use of the Personal Budget.

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<sup>162</sup> Monitoring-Stelle zur UN-Behindertenrechtskonvention: Die UN-Behindertenrechtskonvention: ihre Bedeutung für Ämter, Gerichte und staatliche Stellen. Deutsches Institut für Menschenrechte, Positionen Nr. 6, Berlin 2012.

<sup>163</sup> Source: Prognos AG (2012): Umsetzung und Akzeptanz des Persönlichen Budgets. Endbericht (Entwurf), 15.11.2012 (unveröffentl. Bericht, p. 7).

<sup>164</sup> This applies for example to deaf-blind persons.

<sup>165</sup> According to the BMAS statement from October 2012, approximately 20,000 persons with disabilities make use of the Personal Budget in Germany. See [http://www.budget.paritaet.org/index.php?eID=tx\\_nawsecuredl&u=0&file=fileadmin/budget/budgettag\\_2012/Pressemat/Pressemitteilung\\_des\\_BMAS\\_26\\_10\\_.pdf&t=1352053617&hash=9bc07222459a1fda2c8658257ba0aeb8d47e18a](http://www.budget.paritaet.org/index.php?eID=tx_nawsecuredl&u=0&file=fileadmin/budget/budgettag_2012/Pressemat/Pressemitteilung_des_BMAS_26_10_.pdf&t=1352053617&hash=9bc07222459a1fda2c8658257ba0aeb8d47e18a).

**Integration assistance services** [*Eingliederungshilfeleistungen*] fall within the scope of SGB XII. Hence, the principle of individual needs [*Bedürftigkeitsprinzip*] from the social benefits law applies to these services. This means that persons with disabilities must initially contribute their own earned income and assets if they want to claim participation services. In many cases, spouses, parents and/or children are also obliged to provide financial support. Moreover, it is often extremely complicated to determine which type of benefit should be claimed in individual cases<sup>166</sup> (see also Art. 28).

**The BRK-Allianz calls for the following actions:**

- **Participation benefits for persons with disabilities must be regulated in an independent and specific services law [*Leistungsgesetz*] that is separated from the social welfare laws. Participation services must be granted to persons with disabilities entirely independently from their income and assets.**
- **Living and social environments must be provided with a dense network of inclusive schemes that allow for independent living and self-determined participation in society. This includes residential facilities, personal assistance programs and other services, independent counseling and information services as well as their funding. Specific needs of certain groups, such as deaf-blind or autistic people, must be acknowledged.**
- **The clause on additional costs [*Mehrkostenvorbehalt*] according to SGB XII, § 13, Para. 1(3) must be removed.**
- **The restriction for care benefits in kind [*Pflegesachleistungen*], as defined in § 43a SGB XI, must be abolished.**

## **Article 20 – Personal Mobility**

The personal mobility of disabled people<sup>167</sup> is one of the essential preconditions of autonomous, equal participation. The local public transport services [*Öffentlicher Personennahverkehr/ÖPNV*] must ensure such mobility (see our comment on Art. 9 in this report)<sup>168</sup>. Likewise, the provision of local easily accessible transport services, up-to-date and low-cost aids and remedies, a comprehensive accessible design of public space, the availability of (human, animal, and technical) assistance and the use of assistive technology must be guaranteed. However, many personal mobility aids are de jure and de facto subjected to means testing of the person's income and assets, and therefore considerably discriminate against persons with disabilities and put them at a disadvantage.

**Transport services** for persons with disabilities who cannot use ÖPNV are virtually nonexistent outside major cities. Therefore, persons with disabilities who live in rural areas are exposed to particularly severe mobility constraints. The utilization of such transport services by the persons concerned is limited to a defined number of trips that are funded by

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<sup>166</sup> Some examples of this are the relation between integration assistance [*Eingliederungshilfe*] and care support [*Hilfe zur Pflege*], as well as the relation between care benefits [*Pflegegeld*] and the blind and deaf benefits [*Blindengeld and Gehörlosengeld*] that are granted by the Länder. This leads to controversies about responsibilities, tedious lawsuits and periods of time during which only a part of the financial aids that a person is entitled to, is de facto granted.

<sup>167</sup> Deaf-blind persons (that is, people with a dual sensory disability) are exposed to considerable restrictions in their personal mobility on a daily basis. Their interests – to be accompanied by an assistant and receive communication assistance – remain unacknowledged de jure and de facto.

<sup>168</sup> The State report comments exhaustively on ÖPNV in article 20. We do not intend to repeat this faulty classification, and commented on ÖPNV in the section on Article 9.

public means, and to a restricted period of time during which these services are available. Transport services are a voluntary social service offered by the agencies, and are therefore frequently subject to negotiations and debates with regard to minimizing costs and spending.

Persons with disabilities can apply for a subsidy for purchasing a car and paying for alterations on the vehicle to fit the needs of their disability. If persons with disabilities are reliant on a car in order to pursue vocational training or gainful employment, this **motor vehicle funding assistance** [*Kfz-Hilfen*] is granted easily in most cases.<sup>169</sup> With regard to all other persons with disabilities, the social welfare agencies might theoretically grant them financial aid but in reality these subsidies are usually denied. This represents a particular hardship to mothers with disabilities who depend on a car but do not have gainful employment.<sup>170</sup>

The provision of **remedies and aids** that fulfill a person's needs is also vital for personal mobility. The unclear distribution of responsibilities between many different potential benefits agencies leads to problems in this context.<sup>171</sup> More problems arise because the agencies are only obliged to provide benefits that compensate for so-called basic needs [*Grundbedürfnisse*]. In this scheme, the distance that a non-disabled person can walk on foot serves as the basis for the calculation of an individual's range of mobility. However in rural areas, these definitions cannot be applied to the real living conditions.<sup>172</sup> Consequently, the costs for a replacement wheelchair are currently only compensated for in exceptional cases.<sup>173</sup> This results in severe hardships in individual cases.

#### **The BRK-Allianz calls for the following actions:**

- **Transport services must be set in place and maintained with regular public funding, especially in rural areas.**
- **The personal mobility of disabled people must be ensured through public funds with regard to their gainful employment, but also when it comes to their participation in the community and society.**
- **The provision of remedies and aids, including the utilization of assistance support and the corresponding technology, must be guaranteed and based upon the individual's needs.**

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<sup>169</sup> The details are regulated in the motor vehicle assistance regulations [*Kraftfahrzeughilfverordnung*], see <http://www.gesetze-im-internet.de/bundesrecht/kfzhv/gesamt.pdf>.

<sup>170</sup> Statement on the issue of parenthood for persons with disabilities, compiled by the expert committee "Freiheits- und Schutzrechte, Frauen, Partnerschaft, Familie, Bioethik" of the inclusion advisory board [*Inklusionsbeirat*] within the coordination mechanism [*Koordinierungsmechanismus*].

<sup>171</sup> Gesundheit für Menschen mit Behinderung. Zwischen Ansprüchen der UN-Konvention, Kostendämpfung und Wirklichkeit. "Teilhabe braucht Gesundheit". Tagungsreihe 2010-2011, hrsg. vom Beauftragten der Bundesregierung für die Belange behinderter Menschen, Berlin, p. 269.

<sup>172</sup> Felix Welti: Hilfsmittel zum Behinderungsausgleich: Rechtlicher Rahmen und Reformbedarf. *Rehabilitation* 2010; 49: p. 37-45.

<sup>173</sup> See <http://www.rehadat.de/rehadat/Reha.KHS?State=341&Db=4&Dok=0&OptDisp=false&Index=-1&Reset=0&SUC=&AKT=L+8+KR+310/08&SORT=R09&cbMark=1&rOutput=1&cb0=true&cb5=true&cb1=true&cb6=true&cb2=true&cb7=true&cb3=true&cb8=true&cb4=true&cb9=true>.

## Article 21 – Freedom of expression and opinion, and access to information

Access to information is an essential precondition for ensuring that persons with disabilities are able to lay claim to their rights as defined in CRPD Art. 21, and to form their own opinions. In contrast to other countries, it is not mandatory in Germany to broadcast TV programs with subtitles and audio descriptions. Currently, only 19% of all TV programs are subtitled in Germany.<sup>174</sup> The percentage of programs with audio description or sign language interpretation is below 1%. Therefore, the **accessibility of radio and TV** is not ensured. The new national broadcast agreement [*Rundfunkänderungsstaatsvertrag*] represents an additional accessibility hurdle.<sup>175</sup> Prior to the agreement, many persons with disabilities were exempt from paying radio and TV licensing fees. This was intended to compensate for the fact that they are not equally able to attend events outside of the home as compared to non-disabled people. This disadvantage compensation does not exist anymore. This is explained by the assertion that the money is used for improving accessibility. However, accessible TV programs must be financed by society as a whole. The costs must not be placed upon persons with disabilities.

Currently, a draft law is in the process of being compiled with regard to electronic administration procedures.<sup>176</sup> Unfortunately, it does not embody the necessary regulations on accessibility. Consequently, there is a risk that persons with disabilities' accessibility to administration agencies will become more complicated.

In the opinion of the Federal Government, the internet platform [www.einfach-teilhabe.de](http://www.einfach-teilhabe.de) will be an essential means of ensuring better participation for persons with disabilities in the context of the E-Government strategy. Unfortunately, almost all information provided on this website is limited to disability-related issues, programs and events.

**The BRK-Allianz calls for the following actions:**

- **In order to improve accessibility in television, accessible alternative formats must be ensured, and audio description, subtitles and sign language interpretation must all be equally available.**
- **A short-term “TV measures” plan must be compiled in order to work out a strategy for the interim period prior to the standard provision with accessible formats.**

## Article 22 – Respect for privacy

Due to the fact that persons with disabilities must apply for financial aid or benefits in kind, especially those as defined in SGB XII, they must disclose a great deal of personal,

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<sup>174</sup> Comparative subtitle statistic of the Deutsche Gesellschaft der Hörgeschädigten – Selbsthilfe und Fachverbände e.V., accessible at:

[http://sign-dialog.de/files/Dokumenten/201204\\_UT\\_Statistik.pdf](http://sign-dialog.de/files/Dokumenten/201204_UT_Statistik.pdf).

<sup>175</sup> The 15<sup>th</sup> national broadcast agreement [*Rundfunkänderungsstaatsvertrag*] came into effect on January 1, 2013. Accessible at [http://www.rundfunkbeitrag.de/service/infomaterialien-und-formulare/Fuenfzehnter\\_Rundfunkaenderungstaatsvertrag.pdf](http://www.rundfunkbeitrag.de/service/infomaterialien-und-formulare/Fuenfzehnter_Rundfunkaenderungstaatsvertrag.pdf).

<sup>176</sup> See

[http://www.bmi.bund.de/SharedDocs/Downloads/DE/Gesetzestexte/Entwuerfe/Entwurf\\_EGovG.pdf?\\_\\_blob=publicationFile](http://www.bmi.bund.de/SharedDocs/Downloads/DE/Gesetzestexte/Entwuerfe/Entwurf_EGovG.pdf?__blob=publicationFile).



confidential and often intimate information. The persons concerned frequently perceive this as an unnecessary, even inappropriate requirement.

The authorities or agencies in charge not only request the comprehensive disclosure of personal income and assets, but they also demand an exhaustive catalog of spouses' and relatives' income and assets. The same applies to changes with regard to the living situation, civil status and so on. Recipients of care benefits in kind [*Pflegesachleistungen*], as defined in SGB XI, must agree to the compilation of a care documentation record [*Pflegedokumentation*]. This file mainly contains health information, but also large amounts of intimate and personal details.

In the case of some "participation plans" [*Teilhabepläne*] that must be compiled and filled out with regard to "individual goals", the persons concerned are expected to explain why they have not achieved their goals. This might reinforce their perception of being "transparent citizens", who cannot make their own decisions and do not have any privacy.

The BRK-Allianz is aware of the fact that it is important to collect the necessary data in order to define individual requirements and provide transparent quality monitoring. Nevertheless, it is essential to respect the privacy and data protection rights of persons with disabilities, and to prevent the collection of any data that are not absolutely necessary. In our view, there is not enough awareness of this problem. This becomes obvious in the State report, where it says that the privacy of persons with disabilities is sufficiently protected in the constitution and ordinary laws.

**The BRK-Allianz calls for the following actions:**

- **Data collection must be restricted to indispensable data. The privacy and data protection rights of persons with disabilities must be better emphasized and respected.**
- **The determination an individual's needs must be conducted with due consideration of disabled persons' privacy and the privacy of their relatives and partners.**

## **Article 23 – Respect for home and the family**

Currently, approximately 390,000 families<sup>177</sup> in Germany consist of mothers or fathers with disabilities living together with minors. This figure does not include parents with chronic conditions who do not have an official ID for the severely disabled.

Due to their functional impairments, but also due to the multiple social barriers, **parents with disabilities** depend on support when it comes to exercising their parental roles. This includes supported parenting [*pädagogische Begleitung, begleitete Elternschaft*] as well as parental assistance [*Assistenzdienstleistung, Elternassistenz*]. According to Art. 23 CRPD, the Federal Republic of Germany is obliged to guarantee this type of assistance. Up until this day, the German social codes do not contain any explicit entitlement to parental assistance or to supported parenting<sup>178</sup>, and claims must be brought to court. As a result, it may occur

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<sup>177</sup> According to the 2010 statistical yearbook (figures as of December 31, 2010), Statistisches Bundesamt 2010, p. 234 and Lebenslagen behinderter Frauen in Deutschland - Auswertung des Mikrozensus 2005, BMFSFJ 2009, p. 57.

<sup>178</sup> Parental assistance [*Elternassistenz*] supports parents with disabilities in the fulfillment of their parenting responsibilities according to their own beliefs and instructions. In contrast, supported

that parents with disabilities are deprived of their custody, rather than being granted the necessary support.<sup>179</sup> It is not unusual for the youth welfare offices to make a rash judgment and declare that the best interest of children with disabled parents is in danger.<sup>180</sup>

In the State report, the Federal Government describes the practical difficulties with regard to granting aid to parents with disabilities. However, the authors do not see any need for legislative action.<sup>181</sup> Parents with disabilities do not share this opinion<sup>182</sup>: if they apply for support (parental assistance, supported parenting, aids, motor vehicle aids), they often realize that the youth welfare and welfare offices push the applications back and forth between themselves or declare that they are “not in charge”, without actually assessing the request. Even though courts already acknowledged the right to parental assistance to be an element of integration assistance<sup>183</sup>, parental assistance continues to be refused, or is only granted after long disputes. Even some employees of youth welfare offices state that legislative clarification is necessary.<sup>184</sup>

Parents with a disability who also have a migrant background are exposed to particularly severe disadvantages when it comes to applying for support. There is not sufficient access to the necessary support. There is also a lack of appropriate counseling services.

Between 2002 and 2009, an annual average of 100 **sterilizations** of “persons who were unable to consent” were permitted in Germany.<sup>185</sup> This is possible because legal guardians can voice a substituted consent to sterilization if the person in question is “unable to consent”. § 1905 BGB determines the conditions under which the sterilization of somebody who is “unable to consent” is permitted. This regulation is not compatible with CRPD Art. 23, Para. 1(c) that guarantees persons with disabilities the right to retain their fertility. Likewise, the UN expert committee on the CRPD emphasized that sterilization is inadmissible “without the full and informed consent of the patient”,<sup>186</sup> in their conclusions on the Spanish State report in October 2011.

#### **The BRK-Allianz calls for the following actions:**

- **The right to parental assistance and supported parenting must be clearly established on the Federal level.**
- **Information on planned parenthood, pregnancy, prenatal diagnostics, birth, parental education and parenting, as well as adoption, must be provided in counseling centers, medical offices, hospitals and other relevant places in an accessible and intercultural way.**
- **Long-term separation of children from their parents is only permissible if the child’s interests are clearly at risk. In order to prevent a separation, it is necessary to provide the**

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parenting [*begleitete Elternschaft*] focuses on supporting the parenting skills of parents with disabilities who cannot fully exert their parental responsibilities.

<sup>179</sup> See also <http://www.elternassistenz.de/004.php>.

<sup>180</sup> Statement of the expert committee “Freiheits- und Schutzrechte”.

<sup>181</sup> First German State report on the CRPD, p. 51.

<sup>182</sup> <http://www.elternassistenz.de/004.php>.

<sup>183</sup> Verwaltungsgericht Minden, decision from June 25, 2010 - 6 K 1776/09; LSG Nordrhein-Westfalen, decision from February 23, 2012. Az. L 9 SO 26/11 (decision is not yet legally put into effect, revision at the BSG, reference number B 8 SO 12/12 R is pending).

<sup>184</sup> According to the Netzwerk behinderter Frauen Berlin e.V.

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[http://www.bmj.de/SharedDocs/Downloads/DE/pdfs/Betreuungsgesetz\\_Verfahren.pdf?\\_\\_blob=publicationFile](http://www.bmj.de/SharedDocs/Downloads/DE/pdfs/Betreuungsgesetz_Verfahren.pdf?__blob=publicationFile).

<sup>186</sup> See CRPD/ESP/CO/1 lf.Nr. 37 and 38.

**currently existing parenting support, as well as to develop alternative long-term parental options, such as legal guardianship for children of disabled persons.**

- **The human right of persons with disabilities to plan and start a family must be acknowledged in vocational training and further education programs for medical, legal and educational experts. Parents in search of counseling must be provided with prompt information on the right to parental assistance, supported parenting and other aids. The corresponding programs that cater to their needs must be created.**
- **§ 1905 BGB (sterilization of persons who are “unable to provide consent”) must be changed in a way that sterilization that goes against the will of the person concerned is inadmissible.**

## **Article 24 – Education**

As defined in CRPD Art. 24, an inclusive education system must ensure comprehensive access to the general education system, starting from preschool and elementary school and continuing on through high school, university, vocational training and lifelong learning. This includes the utilization of all reasonable accommodations, an accessible design of the facilities as well as high-quality, individualized measures to promote learning in due consideration of aspects that support both habilitation and rehabilitation. The German education system is a long way from reaching these standards. The integration of children with disabilities amounts to 62% in preschools and kindergartens, 34% in primary schools and only 15% in high schools.<sup>187</sup> This places Germany far behind when compared to other international systems.

The education system lacks committed collective action from authorities on the Federal and Länder levels. The Federation does not sufficiently assume its responsibilities. In contrast to other Action Plans<sup>188</sup>, the Federal Government’s CRPD National Action Plan entirely disregards the Länder and the municipalities, even though they are given key responsibilities when it comes to education. The Federation and many of the Länder assert that there is hardly any need for action resulting from Art. 24 CRPD with regard to the education system.<sup>189 190</sup> In addition, CRPD Art. 24 was incorrectly translated ; “inclusive” was translated

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<sup>187</sup> Survey “Gemeinsam lernen. Inklusion leben. Status quo und Herausforderungen inklusiver Bildung in Deutschland” Prof. em. Dr. Klaus Klemm, survey commissioned by the Bertelsmannstiftung, 2010, p. 9, accessible at:

[http://www.bertelsmann-stiftung.de/cps/rde/xbcr/SID-78AA2DEA-109CF3E8/bst/xcms\\_bst\\_dms\\_34589\\_34590\\_2.jpg](http://www.bertelsmann-stiftung.de/cps/rde/xbcr/SID-78AA2DEA-109CF3E8/bst/xcms_bst_dms_34589_34590_2.jpg).

<sup>188</sup> National Action Plan “For a child-friendly Germany 2005-2010”, accessible at:

<http://www.kindergerechtes-deutschland.de/zur-initiative/nationaler-aktionsplan/>.

<sup>189</sup> Draft law by the Federal Government on the UN CRPD and on the Optional Protocol (BT-Drs. 16/10808, p. 58): “[...] in the education politics of the individual Länder within the Federal Republic of Germany, manifold areas of agreement are visible.” Likewise, the faulty German translation of Art. 24 CRPD has still not been corrected. Also, the Federal Government continues to insist on the incorrect statement made in the memorandum, namely that Art. 24 CRPD only reflects the current integrative approach of the German schooling system (“lassen vielfältige Übereinstimmungen erkennen“, BT-Drs. 16/10808, p. 58). This is in clear contrast to the resolution adopted by the German Bundestag (BT-Drs. 16/ 11234).

<sup>190</sup> The KMK produced a similar statement during their conference, “Pädagogische und rechtliche Aspekte der Umsetzung des Übereinkommens der Vereinten Nationen vom 13.12.2006 über die Rechte von Menschen mit Behinderungen”, resolution of November 18, 2010, p. 2: “The legal situation in Germany essentially complies with the CRPD stipulations.”

as “integrativ”<sup>191</sup> (see introduction of this report). The German education system is only partly integrative, and it is certainly not inclusive. Moreover, the authorities ignore the international legal debate with regard to the extent to which Art. 24 CRPD allows persons with disabilities to claim immediate rights, and especially their right to access regular education institutions (Art. 24, Para. 2(2) CRPD). The Federal Government and the Länder even question these rights.<sup>192</sup>

The debate on inclusion cannot be reduced to the mere right to having access. Instead, it must also insist on a high quality education system. In most current cases, the allocation of individual aids (reasonable accommodations) in the area of education is subjected to the same preconditions that must be fulfilled in order to receive social benefits. This allocation is tied to certain restrictions and isolated from other social welfare provisions, and is not primarily aimed at creating the best possible learning environment. Again and again, persons with disabilities are forced to fight for reasonable accommodations in court. The right to bilingual education as well as bilingual education programs for people with hearing impairments is not consistently implemented. Altogether, general education schemes are still not sufficiently aligned with the standards of accessibility and comprehensive needs. This applies to the layout of buildings, pedagogy and didactics, as well as learning and teaching materials. Additional barriers result from the restrictive copyright law. Moreover, all elements of the education system suffer from the lack of ongoing and systematic qualification measures for the staff.

A nationwide, independent, accessible and holistic education counseling system provided by independent experts and persons belonging to the peer group of those in search of consultation does not exist. Associations that offer this type of counseling rarely receive any funds. Instead, counseling is frequently provided by special institutions [*Sondereinrichtungen*] or other actors in the education system. This impedes self-determined participation in education.

In our opinion, the public debate on inclusive education lacks appreciation and acknowledgement of diversity within education processes. The German education system is highly selective and gives rise to injustice at the expense of socially disadvantaged people, persons with migration backgrounds and persons with disabilities. The critique that Vernor Muñoz, the UN special rapporteur on education, articulated in 2006<sup>193</sup>, is still accurate. In the current debate, “inclusion” is not sufficiently regarded as a benchmark of high quality education. Inclusion must be imperative throughout the entire educational biography of all human beings.

## 1. Kindergarten and preschool

According to SGB VIII, every child is legally entitled to a quality upbringing, education and **care in a day-care institution** or in private day-care starting on their 3<sup>rd</sup> birthday. As of August 1, 2013, this right will apply to children starting on their 1<sup>st</sup> birthday. Children with and without disabilities shall be immersed in learning environments “together in groups”,<sup>194</sup>

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<sup>191</sup> Ibid p. 23: “[...] the States parties guarantee an integrative education system on all levels”.

<sup>192</sup> See ibid p. 2: “Subjective legal entitlements only exist where the legislator has already implemented the law.”

<sup>193</sup> Report of the Special Rapporteur on the right to education, Vernor Muñoz – mission to Germany 2006, “Implementation of the UN resolution 60/251”, Human Rights Council, March 15, 2006 (Addendum, section IV: Education Challenges).

<sup>194</sup> SGB VIII, § 22a, Para. 4.

if this is compatible with their assistance requirements. SGB IX also regulates the “shared care of disabled and non-disabled children”.<sup>195</sup> Barriers must be dismantled, and the providers of child day care institutions must make the necessary arrangements.

Children with disabilities and disadvantages are from birth on entitled to aids provided by the **early intervention system**.<sup>196</sup> However, early intervention measures are not consistently included in child day care, even though the law prompts welfare and youth welfare agencies to cooperate. The different responsibilities and funding regulations are a hindrance for inclusion (see also Art. 7).

Even though the percentage of **special needs daycare institutions for children** was as low as 0.6%, namely 299 institutions, out of all child daycare institutions in 2011, children with disabilities are still singled out.<sup>197</sup> In Bavaria, children are cared for in “school preparation institutions” and in Baden-Württemberg, in “school kindergartens” that are affiliated with special needs schools. Funding is based on deficiencies and medical diagnoses, not on participation needs. Instead of providing “reasonable accommodations” inside the institutions and structures (Art. 2 CRPD) and dismantling barriers, these children and their parents are forced to organize the necessary resources on their own.

While the current early intervention system does provide important resources and skills, it is still not an adequate means for promoting inclusive education and childcare, because it is primarily based on medical diagnostics.

Currently 92% of all children between 3 and 6 years attend a day-care institution. The percentage of children under 3 years is as low as 37%.<sup>198</sup> This also represents a disadvantage for disabled children. In addition, the “home care allowance” [*Betreuungsgeld*] that the Federal Government introduced in August 2013, will discourage families even more from enabling their (disabled or non-disabled) children to participate in meaningful, collective daycare activities.

Moreover, only 32% of all daycare facilities for children are inclusive. Accommodation is hindered by funding problems with regard to the necessary individual aids. Due to the imbalanced ratio between children and staff, inclusion schemes are difficult to implement. Even in integrative institutions, children with (severe) disabilities are sometimes singled out and put into their own special group.

The **care situation with regard to children under 3 years** is absolutely unsatisfactory. This group is disregarded in the current government plan for the expansion of the preschool system. There is both a lack of educational concepts and the necessary human resources. 80,000 children are attending day-care facilities, and only 1.3% of them have disabilities.<sup>199</sup> In the age group of 3 to 6 year old children<sup>200</sup>, 21,200 are attending a day-care institution

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<sup>195</sup> SGB IX, § 19, Para. 3.

<sup>196</sup> See SGB VIII and SGB XII.

<sup>197</sup> Statistisches Bundesamt: Kinder und tätige Personen in Tageseinrichtungen und in öffentlich geförderter Kindertagespflege am 01.03.2011, Statistisches Bundesamt, Wiesbaden 2011.

<sup>198</sup> BMFSFJ: Dritter Zwischenbericht zur Evaluation des Kinderförderungsgesetzes, Berichtsjahr 2011, May 2012.

<sup>199</sup> 901 out of a total of 79,720 children have one or more disabilities.

<sup>200</sup> 546 out of a total of 21,184 children have one or more disabilities.

and a mere 2.6% of them are disabled.<sup>201</sup> Children from plurilingual families are not sufficiently supported with regard to their language skills. The same is true for children with communication disabilities who for example rely on Sign Language. The severe lack of qualified personnel raises considerable doubts about the pedagogic quality of day-care facilities for children. This increases skepticism and an aversion to inclusion schemes.

Close cooperation between preschool childcare and elementary schools is essential, but such cooperation is not consistently present. Preschool education has the potential to be a model example and motor of inclusion. However, in order for this to be possible, early intervention must function as a timely consulting opportunity for families that is aimed at building inclusion. Moreover, youth welfare schemes must push inclusion programs that consider the living environments of adolescents.

## 2. Primary school through high school

Regarding the implementation of the CRPD in German schools, there is a particularly great need for action and a lot of difficulties, due to the fact that the Federation and the 16 Länder are obliged by international law to implement the Convention's stipulations together (Art. 4, Para. 5). The German education system still primarily considers heterogeneity among students to be a problem, and seeks to create homogenous learning groups. This results in a highly segregated school system. After completing elementary school, the students are divided and placed into set educational tracks within segregated school types. These school types differ considerably from one another as well as between the different Länder.<sup>202</sup> These systems always include high schools [*Gymnasium*], which enforce a particularly strict selection process.<sup>203</sup> Furthermore, there is a broad landscape of special needs schools [*Sonderschulen*]<sup>204</sup> that divides students according to as many as nine special needs pedagogical criteria (learning, behavior, speech, auditory, visual, intellectual and physical disability, autism, medical conditions).

The **legal situation** in Germany does not comply with Art. 24 CRPD. It is true that all Länder schooling laws envisage the possibility<sup>205</sup> of inclusive learning groups that include both students with and without disabilities.<sup>206</sup> Nevertheless, students with disabilities are not legally guaranteed access to mainstream schools<sup>207</sup>; in spite of legislative changes brought

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<sup>201</sup> Our own calculation, based on Bertelsmann Stiftung data: Ländermonitor. Frühkindliche Bildungssysteme (Status: June 2012); Statistisches Bundesamt: Kinder und tätige Personen in Tageseinrichtungen und in öffentlich geförderter Kindertagespflege am 01.03.2011, Statistisches Bundesamt, Wiesbaden 2011.

<sup>202</sup> The different secondary school models offer different school diplomas: the lower secondary school diploma [*Hauptschulabschluss*], the secondary school diploma [*Realschulabschluss*], and some of them offer the high school diploma [*Abitur*].

<sup>203</sup> In the following sections, we refer to these schools with the term "regular school".

<sup>204</sup> In the meantime, the Länder replaced the term "special (needs) school" [*Sonderschule*] with the term "advancement school" [*Förderschule*], without actually changing the system. This is why we decided to use the term "special (needs) school".

<sup>205</sup> In German education law, the term "students with disabilities" [*Schüler\*innen mit Behinderungen*] designates "students with a need for special pedagogic support" [*Schüler\*innen mit sonderpädagogischem Förderbedarf*]. In order to simplify the following pages, we use the term "students with disabilities".

<sup>206</sup> See NAP, p. 45

<sup>207</sup> The term "regular school" is used in order to emphasize the difference between "special (needs) schools" and all other schools. "Regular schools" comprise all types of general education schools with

about in 2009, almost all of the Länder laws stipulate that students can exercise this right only under the condition that specific human resources, organizational and material preconditions are fulfilled.<sup>208</sup> In some of the Länder, it is even legitimate to send students to special schools against their parents' will.<sup>209</sup> In this way, students with disabilities in mainstream schools do not have the right to claim comprehensive reasonable accommodations, compensation for disadvantages and accessible teaching and learning materials.

Recently in some Länder, parents were asked to choose between regular and special needs schools.<sup>210</sup> The BRK-Allianz finds fault with the fact that in this way, some Länder consider the **parental right to choose** to represent a de facto implementation of the CRPD. We deplore the fact that politicians misuse the parental right to choose in order to question the fundamental right to an inclusive education in a mainstream school that is close to the student's place of residence. Since mainstream schools are insufficiently equipped, parents are pushed towards a decision in favor of a special needs school<sup>211</sup>; moreover, politicians refer to the parental right to choose in order to maintain the widespread special needs school system. Maintaining the special needs school system further binds resources that could otherwise be used to create an inclusive education system.

In the 2010 and 2011 statements with regard to CRPD Art. 24<sup>212</sup>, the **standing conference of the ministers of education and cultural affairs of the Länder** [*Kultusministerkonferenz/KMK*] ignores the need for action.<sup>213</sup> They assert that the German legal situation already complies with the CRPD, and that the CRPD does not establish legal entitlements for individuals.<sup>214</sup> Furthermore, they prioritize the plurality of institutions that provide advancement measures, and the preservation of special needs schools. According to the KMK, the structural selection within the segregated schooling system does not contradict an inclusive school system. Hence, the KMK considerably weakens the disabled students' right to inclusive education within regular schools, and therefore does not comply with Art. 24 CRPD.

Likewise, **jurisdiction** impedes inclusive education in Germany. A fundamental court decision handed down by the Hesse administrative court [*Verwaltungsgerichtshof Hessen*]<sup>215</sup> in 2009, questioned the validity of the CRPD in Germany altogether, and denied that students with disabilities can derive any rights and entitlements from Art. 24 CRPD. This decision was often

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the exception of special (needs) schools. In this way, the word does not correspond to the secondary type of school called "regular school" in Thuringen, but greatly exceeds it.

<sup>208</sup> See Hesse schooling law [*Hessisches Schulgesetz*], § 49 Para. 2(1), November 21, 2011, GBl. I; p. 679.

<sup>209</sup> See Lower Saxony schooling law [*Niedersächsisches Schulgesetz*], March 23, 2012, GVBl. p. 83, § 59 Para. 5.

<sup>210</sup> Some of the associations represented in the BRK hold the opinion that the CRPD only grants the right to opt for inclusive schooling in the case of children with sensory impairments..

<sup>211</sup> Statement from the Berlin schooling authority [*Berliner Schulbehörde*] in the Land social court Berlin-Brandenburg 2011: "Just like the other two schools that were asked, the principal should have refused to admit the child, due to the lack of human resources. Where all regular schools decline, a special needs school is simply the only option."

<sup>212</sup> KMK statement, November 18, 2010.

<sup>213</sup> KMK resolution from October 20, 2011, "Inklusive Bildung von Kindern und Jugendlichen mit Behinderung in Schulen".

<sup>214</sup> KMK statement, p. 2.

<sup>215</sup> Hesse administration court, decision from November 12, 2009, Aktenzeichen: 7 B 2763/09.

referred to by other courts<sup>216</sup>, and makes it more difficult for parents to file a lawsuit after being refused the option of inclusive education in a school close to their home. Also, this can be used as grounds to deny rights deriving from Art. 24 CRPD. Along with the monitoring office and many organizations from civil society, we strongly disagree with this court decision, which ignores obligations that derive from international law. It is in contradiction to numerous official legal statements.<sup>217</sup> The legal situation must be clarified.

### **Integration: the current situation**

Even though the Länder schooling laws allow for integrative schooling for students with disabilities, in reality this option is not “frequently preferred”, in contrast to the statements made by the Federal Government.<sup>218</sup> In 2010, only 29% of all students with disabilities were able to attend a mainstream school in Germany.<sup>219</sup> The integration quotas vary considerably between the different Länder; they range from 6% to more than 40%<sup>220</sup>, and the highest quota is found in primary schools. The integration quota in secondary schools differs widely between the school types: it amounts to 39% in lower secondary education schools [*Hauptschule*], but only to 5% in high schools [*Gymnasium*].<sup>221</sup>

There are more and more private schools. This development partly led to further social exclusion, because they attract a certain type of student. In this way, other schools are increasingly perceived as institutions for “left-behind” students [*Restschule*]. On the other hand, “free schools” all over Germany serve as model examples of inclusion, and many of them are more progressive and more flexible than state schools.

The overwhelming majority of students with disabilities continue to attend special needs schools in Germany. In 2010, 75% left school without obtaining any diploma.<sup>222</sup> Inclusion requires high quality standards; it cannot be reduced to the highest possible quota of students who obtain a school qualification. In spite of rising integration numbers, the number of special needs school students has not decreased significantly, due to the fact that more and more students are diagnosed with the need to obtain special needs advancement resources. In 2010, this was the case for 487,000 students, which corresponds to 6.4% of all students.<sup>223</sup> “Measured against all other EU states, [...] Germany has the highest percentage of students who receive special needs education” (Bundesbildungsbericht 2010).<sup>224</sup>

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<sup>216</sup> See, for example, Lower Saxony high administration court, decision from September 16, 2010, Aktenzeichen: 2 ME 278/10.

<sup>217</sup> Prof. Dr. Eibe Riedel. Gutachten zur Wirkung der internationalen Konvention über die Rechte von Menschen mit Behinderung und ihres Fakultativprotokolls auf das deutsche Schulsystem. Dortmund, Berlin 2010.

<sup>218</sup> NAP, p. 45.

<sup>219</sup> Federal education report [*Bundesbildungsbericht*] “Bildung in Deutschland 2012”; authors’ group “Bildungsberichterstattung”, commissioned by KMK, p. 7.

<sup>220</sup> *Ibid.*, table D 2-7.

<sup>221</sup> Prof. em. Dr. Klaus Klemm, Universität Duisburg-Essen, Bildungsforschung und Bildungsplanung, input: “Eine Schule für alle: Bildungssystem und Inklusion”, Evangelische Akademie Tutzing, May 21, 2011.

<sup>222</sup> This means that these students did not even acquire a Hauptschulabschluss, a lower secondary education diploma. Source: Statistische Veröffentlichungen der Kultusministerkonferenz, Dokumentation Nr. 196 – Februar 2012 “Sonderpädagogische Förderung in Schulen” 2001 bis 2010; p. XVI.

<sup>223</sup> *Ibid.*, p. XI.

<sup>224</sup> Bildung in Deutschland 2010; p. 6.



Almost 50% of special needs school students receive special education specifically with regard to “learning” issues.<sup>225</sup> The German focus on learning issues is almost unique throughout the world. Expert assessments show that the percentage of children and adolescents from families who are exposed to socio-economic and educational disadvantages, as well as the percentage of children and adolescents from families with a migrant background or with communication impairments, is considerably higher than average in special needs schools. Also, the amount of boys in these schools is remarkably high.<sup>226</sup> The BRK-Allianz deplors the fact that it is primarily the responsibility of the parents to enforce the integration of their disabled children, and access “hard-won” resources. In this way, integration assistance benefits for adequate schooling<sup>227</sup> are often only granted alongside numerous restrictions to students with disabilities, and must thereby be fought for.<sup>228</sup> More deficiencies exist in the field of schooling assistance (integration peripatetics), including communication assistance and interpretation.<sup>229</sup>

### **Implementation deficiencies**

**Nonexistent comprehensive scheme:** There is no comprehensive, nationwide scheme for inclusive education in the school system. The Federal Government’s NAP for the implementation of the CRPD refuses to provide this scheme and restricts itself to a few individual measures. The Federal Government and the 16 Länder do not provide for a joint, coordinated and transparent overall procedure.

**Insufficient accessibility:** The accessibility situation at mainstream schools is entirely insufficient, and not only when it comes to their architectural layout and communication facilities. This is pointed out in a survey conducted by the education and science union [*Gewerkschaft Erziehung und Wissenschaft/GEW*].<sup>230</sup> Unfortunately, the Federal Government refuses to acknowledge these deficiencies: in 2009, a stimulus package that provided for 10 million EUR for school renovations did not include the condition that accessibility must also be created. As of now, the Federal Government has not planned any new programs.

**Nonexistent establishment of diversity pedagogics:** Diversity pedagogics that cater to heterogeneous groups of students with and without disabilities are still far from being sufficiently established in mainstream schools. Likewise, the diversity approach is not sufficiently mirrored in curriculum frameworks and schoolbooks. This is a hindrance to the inclusive development of schools and teaching schemes.

The high degree of expertise in special needs pedagogics and advancement measures must be systematically transferred on to mainstream schools. However, there is no clear scheme for this transition process.

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<sup>225</sup> Ibid, p. 71.

<sup>226</sup> Justin J.W. Powell, Lisa Pfahl, Wissenschaftszentrum Berlin: “Sonderschule behindert Chancengleichheit” 2008.

<sup>227</sup> According to § 54 SGB XII, 35 a SGB VIII.

<sup>228</sup> For example, one assistance person is deployed for several children with intense and specific needs at one time, each located in different classrooms, floors, and schools.

<sup>229</sup> We refer to both Sign Language and written language interpretation.

<sup>230</sup> Survey accessible at:

[http://www.gew.de/Binaries/Binary72997/PK\\_%20Umfrage%20Inklusion%20\\_Hamburg.pdf](http://www.gew.de/Binaries/Binary72997/PK_%20Umfrage%20Inklusion%20_Hamburg.pdf) (p. 8, question 19).

**Insufficient human, time and material resources:** Human resources are not provided to a sufficient extent in order to support on-site development of inclusive schooling. There is no nation-wide personnel scheme that defines the joint responsibilities of different professions with regard to inclusion, nor any measure that finally defines multi-professional teams as the standard within the school system. Special needs teachers and social education workers are by no means part of the staff at all mainstream schools. In some schools, human resources are even subjected to cutbacks. The situation regarding the employment of teachers with disabilities is entirely unsatisfactory in Germany.<sup>231</sup> Their specific skills remain unused. Likewise, many schools are not equipped with sufficient space and facilities, and teaching materials lack sophistication. Teaching personnel must be provided with conditions that ensure individual advancement schemes for each and every child. Currently, the teaching staff hardly has any time or resources in order to promote inclusion in schools and education. Neither the KMK nor the Federal Government and the Länder acknowledge the need for action in this regard.

The BRK-Allianz is concerned about the current attempts to implement the necessary changes for an inclusive education system in a cost-neutral or even cost-saving way. It is already obvious that the current integration standards have fallen short, and that in individual cases the successful integration of severely disabled students is reversed. Also, some “model integrative schools” are exposed to severe resource cutbacks. The BRK-Allianz points out that development towards inclusion must not be obstructed by the withdrawal of the necessary budgetary resources. The German constitution strictly prohibits the Federal Government and the Länder to cooperate with regard to educational policies; the Federal Government refers to this prohibition when it refuses to comply with obligations set by international law according to Art. 4, Para. 5 CRPD, and shifts responsibility onto the Länder. With regard to the necessary means for the implementation of the CRPD, the Federal Government stated: “The Federal Government was not presented with any statistical data. The Länder and municipalities are responsible for the CRPD implementation.”<sup>232</sup>

**Deficiencies in vocational training and further education:** None of the Länder provide consistent, mandatory further education programs for all teachers, pedagogues and social workers regarding inclusive schooling. Not one single Land has adopted any laws regarding vocational training for future teachers that include mandatory training elements for inclusive education.<sup>233</sup> There are few existing research centers that are dedicated to inclusive pedagogics. At the same time, university research that fosters special needs education expertise is in danger of facing cutbacks. Relevant projects must continue to be offered in universities all across the country, and study courses must include modules in inclusive pedagogics. The Federal Government and the Länder do not provide a structured overall scheme for this.

**Insufficient supervision of on-site transformations:** Mainstream schools must be prepared for the challenges that come along with inclusive education, and they must be provided with support during the transformation process. Differentiated learning must become mandatory; the schools must offer full-time classes and extracurricular activities for students; the links between school and life outside of school must be strengthened; the

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<sup>231</sup> In Schleswig-Holstein only 4.8% of education and cultural affairs employees were severely disabled in 2011. This percentage is considerably lower than in other fields, and even falls short of the mandatory legal employment quota of 5%.

<sup>232</sup> BT.Drs. 17/10376, p. 3.

<sup>233</sup> Some pioneering positive measures, for example at the Technische Universität Berlin, were even removed after a time.

transition processes from one schooling phase to the next must be improved; and vocational guidance as well as the preparation for vocational training in schools must be intensified. There is a lack of high quality and well-coordinated programs that systematically support all regular schools across the country during these comprehensive transitions.

**Insufficient participation of persons with disabilities and their associations:** The BRK-Allianz calls for the consistent involvement of persons with disabilities and their associations in the development of inclusive schooling structures, and for the corresponding necessary financial resources to make this possible. Up until now, participation in the Federation and the Länder did not occur on an eye-to-eye level with persons with disabilities and their associations.<sup>234</sup> Likewise, parents, teaching staff and notably the students must be consistently and proactively included in the democratic transition processes in education institutions. This is mirrored by the motto, “Nothing about us without us!” Considerable deficiencies also exist regarding peer support programs.

**Insufficient awareness-raising in society as a whole:** The BRK-Allianz deplores the fact that the responsible authorities failed to push a proactive and truly public debate that is in favor of inclusive education. Also, this debate should address all the responsibilities that come along with all school types and phases, with no exceptions. In too many cases, the debate on inclusion is limited to specific advancement schemes and school types. Up until this day, there has been no discussion about the question of whether a schooling system that is largely based on norms and grading schemes is really likely to achieve the goal of building an inclusive education system, especially since it is combined with the lack of, or insufficient, legal regulations for differentiated learning directed towards different schools qualification levels. The support that the responsible authorities have voiced regarding inclusion often appears to be just “lip service”.

### 3. Universities

8% of all students at German universities live with disabilities or chronic health conditions.<sup>235</sup> <sup>236</sup> The protection of their participation rights was improved in the context of the introduction of the BGG in the Federation and the Länder.<sup>237</sup> The laws pertaining to higher education [*Hochschulgesetze*] stipulate the obligation to ensure accessibility and compensation for disadvantages. The guidelines for the quality management of study courses consider the concerns of students with disabilities. The regulations pertaining to the funding of the students’ livelihood in the context of state funding and loans for students [*Bundesausbildungsförderungsgesetz/Bafög*] provide for the compensation of disadvantages, for example with regard to income deductions and the funding period. On the other hand, specific needs that result from a disability are not acknowledged. Funding for technical aids, personal assistance (such as Sign Language interpreters) and mobility aids that are necessary in individual cases and in the context of the person’s study courses, depends on the person’s own income and assets, and is often very restricted. The details are regulated in the stipulations on inclusion assistance for persons with disabilities (§ 54 SGB

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<sup>234</sup> Comparative statement of the German disability council (DBR) on the KMK recommendations 2011.

<sup>235</sup> In the following sections, we refer to them as “students with disabilities”.

<sup>236</sup> 18<sup>th</sup> social survey of the Deutsches Studentenwerk 2006.

<sup>237</sup> The higher education framework act [*Hochschulrahmengesetz/HRG*] puts universities under the obligation to make sure that “students with disabilities are not exposed to disadvantages in their studies, and that they can use the university’s resources and programs without assistance by third parties, wherever possible” (§2, Para. 4 HRG).

XII). There were only some individual cases where the stipulations in higher education law and in the social code were adjusted in view of the changed circumstances of the B.A. and M.A. university degree system.<sup>238</sup>

Everyday life in the German university system comes along with many difficulties for students with disabilities:

**A difficult education path:** The lack of regulations concerning the compensation of disadvantages in high schools, and insufficient vocational guidance programs make it more difficult for students with disabilities to access university studies. The stipulations on compensations for disadvantages were not adjusted to the extended preconditions for the applicant's admission to university with regard to undergraduate study courses. When it comes to the admission to Master study courses, regulations are nonexistent in most cases. In view of the increasing differentiation and specialization of study courses, the current hardship quota allocations are not sufficient anymore.

**Increased difficulties within the study courses:** Due to a stricter structure of many study courses, increased compulsory attendance and a higher volume of exams at the end of the study terms, the numbers of students who rely upon compensation for disadvantages in order to be able to adjust their studies to their needs resulting from their impairments are increasing. Due to the inflexible structures, these compensations are often insufficient and difficult to implement. Frequently, students encounter teaching staff and examiners who are not informed about their needs that result from their impairments or are unwilling to consider these needs.

This is especially true for students with invisible disabilities, such as chronic somatic conditions or mental impairments. The percentage of women is especially high in these cases. Another example is specific learning disabilities (SLD), such as dyslexia. This is the case with approximately 88% of all impaired students.<sup>239</sup>

**Insufficient accessibility in buildings, communication facilities and didactics:** Many educational buildings and administration facilities as well as counseling offices in universities and student unions are still not accessible. In many cases, there are communication barriers. The teaching staff lacks awareness and knowledge about diversity, and accessible university didactics (for example, the visualization of the study course content) are not provided. The same is true for further education programs. Also, there is a lack of specific services and support (for example, a service that converts teaching material into Braille, computer workplaces that are designed according to the needs of persons with disabilities and so on).

**Insecure funding for studies:** Many students are not provided with sufficient funding to cover higher expenses that result from their impairments. This includes accessible housing, hygiene products and medicine, as well as study-specific expenses for technical aids or personal assistance. This increases their difficulties in accessing university education or pursuing an academic career (for example, PhD studies). While the Federal Government points this out in their NAP<sup>240</sup>, they have not yet introduced any corrective measures. Mobility of students with disabilities outside Germany is often restricted because inclusion

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<sup>238</sup> The standing conference of the heads of universities [*Hochschulrektorenkonferenz*] also points this out in the recommendations ("Eine Hochschule für Alle") adopted during their general assembly on April 21, 2009.

<sup>239</sup> See the 2011 survey conducted by the Deutsches Studentenwerk on the situation of students with impairments and chronic health conditions 2011, "beeinträchtigt studieren".

<sup>240</sup> See NAP, p. 47.

assistance as well as health insurance and care insurance benefits are not at all or not sufficiently provided.

**Inadequate information and counseling:** Most universities provide counselors for the concerns of students with disabilities. However, most of them are not equipped with the necessary resources in order to meet the growing demand for counseling and to contribute to the necessary structural transformations within the universities. The student lobby groups have limited participation opportunities for students with disabilities. The general information and counseling services at universities often do not consider the concerns of students with disabilities.

**Limited career opportunities in academia:** Junior researchers with disabilities are underrepresented in universities and research institutions. The insufficient consideration of disadvantages caused by disabilities in the relevant legal regulations (for example, in the Länder laws with regard to funding for PhD students and the law on fixed term contracts in academia) puts them at a disadvantage.<sup>241</sup>

#### 4. Lifelong learning

Most Länder laws pertaining to adult education include the statement that these programs must be open to everyone. The obligation to ensure comprehensive accessibility is only regulated in isolated cases, or is deferred to some point in time after an undefined period.<sup>242</sup> With the exception of further education within a profession, lifelong learning for persons with disabilities is often not promoted. There are no clear regulations or assurances when it comes to the funding or the compensation of expenses. Moreover, these measures represent social welfare benefits that depend on a person's income and assets. For this reason, many gainfully employed persons with disabilities are excluded from such funding.

“Sheltered workshops” and residential facilities for persons with disabilities are prompted to offer personality-building programs. For this reason, education measures are usually conducted within the field of services for persons with disabilities, a field with predominantly segregated structures. People classified as having a fully reduced earning capacity<sup>243</sup> have very little opportunity to participate in further education programs outside institutions from the field of services for persons with disabilities, especially if they are reliant upon aids such as mobility or communication assistance. This is specifically true for all people working in “sheltered workshops”.

De jure, it is possible to make use of the Personal Budget (as contained in SGB IX) in order to receive funds for inclusion assistance. Personal Budgets for education measures are often only granted after tedious wrangling and must often be contended for in court. The special needs adult education schemes that were established in the segregated institutions within the field of services for persons with disabilities especially discriminate against persons who were already systematically excluded from inclusive education due to the special needs schooling system. This is true for people with learning difficulties and people with complex disabilities.

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<sup>241</sup> See Bundesbericht zur Förderung des Wissenschaftlichen Nachwuchses 2008 (BuWiN).

<sup>242</sup> See § 8 Para. 5 Thuringen adult education act [*Thüringer Erwachsenenbildungsgesetz/ThürEBG*], November 18, 2010.

<sup>243</sup> In 2011, more than 1.5 million citizens between the ages of 18 and 65 were classified as fully incapacitated for work according to the definition of the German pension insurance agency (Source: Statistik der Rentenversicherung 2012, p. 19).

Adult education centers [*Volkshochschulen*] are in charge of organizing and providing general, political, professional and cultural further education programs reachable from one's home. However, not all of them are accessible. In recent years, they have been offering some isolated classes that were specifically targeted at persons with disabilities, for example, on advocacy and inclusion or computer classes for persons with learning difficulties. Accessible public readings and guided tours in museums and exhibitions are rarely offered. Political education providers will be obliged in the future to provide programs on the issue of inclusive political education.

Specific programs, such as teaching skills for managing the Personal Budget or other disability-related issues, are still rarely offered on a peer-to-peer basis. There is a great need for change in this regard. These resources must be set in place in general educational institutions in or close to residential areas. It is rare that people with learning difficulties are professionally trained to become quality advisors with regard to programs from the field of services for persons with disabilities. The same applies to their further professional training to become peer counselors; most of these programs are one-time showcase programs.

**With regard to kindergarten and preschool facilities the BRK-Allianz calls for the following actions:**

- **The number of inclusive child daycare facilities that are situated in close proximity to residential areas must be increased, and early intervention measures must be introduced in these facilities. Daycare facilities for children need to be provided with regular training and support in order to create inclusive institutions.**
- **The extension of day-care for children must include professional qualification measures for day-care personnel. Institutions for children with disabilities who are not yet required to attend school must be included in the child day-care system.**
- **There must be better support provided by interdisciplinary early intervention centers [*interdisziplinäre Frühförderstellen/IFF*]. The IFF must continuously expand their expertise and must therefore receive better funding.**

**With regard to school education the BRK-Allianz calls for the following actions:**

- **The human right to inclusive education for students with disabilities must urgently and unconditionally be acknowledged. Legal clauses in the schooling law that delimit this right must be abolished.**
- **The implementation of the right to inclusive education must be supported and ensured in practice. This requires the creation of the necessary materials, personnel and organizational resources.**
- **The right to reasonable accommodations in individual cases must be firmly established in the law. The proceedings for the application and allocation of services must be free of discrimination. Students with disabilities and their parents must be included in the compilation of the individual advancement plans.**
- **The funding of schooling assistance and communication assistance services must be regulated and established in school laws instead of in social welfare codes.**
- **It is necessary to address both general and social pedagogy skills during the vocational training of teachers and in schooling practice. Likewise, the perspective of inclusive**

pedagogics must be included in educational training. High quality standards must be ensured.

- It is urgently necessary to ensure a cooperative, coordinated and committed joint approach by the Federal Government and the Länder.

With regard to universities the BRK-Allianz calls for the following actions:

- Federal equal opportunities standards must be included in the admission procedures.
- It is necessary to ensure funding for studies that is non-discriminatory and based on student needs. This includes all additional necessary funds that fulfill the needs deriving from disabilities, and must be applicable in both Germany and abroad.
- Study and exam regulations must become more flexible. Compensation for disadvantages must be comprehensively established and implemented on a non-discriminatory basis.
- A legal norm must be introduced to ensure the right to counseling and support as well as the entitlement to individual advancement and assistance.
- Disability-specific aspects must be included in the structure of the study courses. There must be more quality online courses.
- Comprehensive architectural, communicative, visual and didactic accessibility must be ensured. This requires better awareness and better qualifications for teaching and other university staff as well as more support for university teachers with disabilities.
- The ombudsperson function for the concerns of students with disabilities must be strengthened. Their position must be firmly established in the law, and provided with the necessary resources and right to participate in all issues. The same applies to the participation rights of students with disabilities.
- Measures must be introduced in order to improve the participation opportunities of junior researchers with disabilities.

With regard to lifelong learning the BRK-Allianz calls for the following actions:

- In order for all individuals to be able to use lifelong learning opportunities on the basis of comprehensive participation, funding must be established by law and in compliance with the UN CRPD. Programs must be separated from the segregating structures of the field of welfare services for persons with disabilities. All lifelong learning resources must be accessible.
- Qualification measures and financing for persons with disabilities must be established by law, in order for those concerned to be able to contribute their skills to society through peer support and peer counseling.

## Article 25 – Health

The German parliament [*Bundestag*], the Federal and the Länder health ministries, as well as the social services agencies and providers have long been aware of the deficiencies of the health care system when it comes to persons with disabilities. A comprehensive documentation of the deficits can be found in the publication from the conference series, “Participation relies upon health”<sup>244</sup> [*Teilhabe braucht Gesundheit*], that was facilitated by

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<sup>244</sup> Gesundheit für Menschen mit Behinderung. Zwischen Ansprüchen der UN-Konvention, Kostendämpfung und Wirklichkeit. “Teilhabe braucht Gesundheit”. Series of meetings, 2010-2011, ed. by the Federal Commissioner for Matters relating to Disabled Persons, Berlin.

the federal commissioner for matters relating to disabled persons. The current problems are, however, frequently denied or trivialized, for example in responses to inquiries made to the Bundestag.<sup>245</sup> Self-help organizations for disabled and chronically ill persons, welfare associations, individuals and others have repeatedly presented sophisticated analyses as well as precise, informed proposals for solutions.<sup>246</sup>

SGB IX is an essential legal code when it comes to persons with disabilities and their needs. Unfortunately, it has insufficient impact due to insufficient stipulations, such as in SGB V, XI, and XII. These other codes take priority over SGB IX.

The decree on the participation of patients [*Patientenbeteiligungsverordnung*, December 19, 2003]<sup>247</sup> regulates the patient organizations' right to participate in relevant health decisions. SGB V, § 140f contains the details. However, the implementation of this decree is not satisfying in practice. It does not allow for true participation in decision-making, due to the fact that the patient representatives have no say. Moreover, the health care system does not include the indispensable tool of the associations' right to take legal action in the form of class actions [*Verbandsklagerecht*]. For example, this tool would allow for proceedings against the decision to not include a particular service in the benefits catalog of the public health insurance providers, and would thus serve the interests of persons with disabilities. Disabled persons' organizations are therefore incapable of using legal means in order to verify the validity of decisions taken by health care providers or authorities. Unfortunately these issues do not result in specific steps on the legislative level, such as the adoption of new laws. For example, some associations within the BRK-Allianz suggested the establishment of a legal basis for out-patient care centers that cater to adults with intellectual and multiple disabilities, and that are based on the model of social pediatrics centers. Likewise, it would be desirable to improve some laws, for example, regarding the inadequate regulations on interdisciplinary early intervention measures, sociotherapy for mentally ill patients and on-site health care through integration assistance facilities. Similarly, the stipulations on early intervention measures for disabled children or those at risk of developing a disability are not implemented; the same is true when it comes to sociotherapy for mentally ill persons and dementia patients.<sup>248</sup> Executive and legislative bodies deny that there is a need for action. From time to time, they issue non-committal declarations of intent that remain inconsequential.

The complex and complicated legal and sub-legal regulations in the health care system represent a particular problem, as they make it more difficult for the affected persons to understand their own rights and entitlements, and to enforce them by law when necessary. It is often tedious and costly to use legal means in order to clarify and enforce legal claims; however, those affected, their relatives or their legal representatives are frequently forced to take legal action. Benefits agencies will frequently rather risk objections and lawsuits than

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<sup>245</sup> See for example the input given by Thomas Ilka, secretary of state in the Federal Ministry of Health (BMG). In: *Gesundheit für Menschen mit Behinderung. Zwischen Ansprüchen der UN-Konvention, Kostendämpfung und Wirklichkeit. Dokumentation der Abschlussveranstaltung „Teilhabe braucht Gesundheit“*, September 21, 2011, ed. by the Federal Commissioner for Matters relating to Disabled Persons.

<sup>246</sup> See for example, "Problemaufriss zur gesundheitlichen Versorgung von Menschen mit Behinderungen" by BAGFW, Fachausschuss Behindertenpolitik, January 23, 2012.

<sup>247</sup> <http://www.gesetze-im-internet.de/patbeteiligungsv/BJNR275300003.html>.

<sup>248</sup> See the final report "Strukturelle und finanzielle Hindernisse bei der Umsetzung der interdisziplinären Frühförderung", March 2012, at: [http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/fb419-frueherkennung.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/fb419-frueherkennung.pdf?__blob=publicationFile).



try to avoid them. The individuals in question are often overwhelmed due to resignation and ignorance of the law, and therefore refrain from legal means.

**General accessibility barriers:** Persons with disabilities who need to access the health care system because of an acute condition, or because of a chronic condition resulting from a disability, frequently encounter numerous types of barriers with regard to curative, rehabilitative and preventive medicine and care services. These comprise architectural barriers (such as door sills, narrow doors, turning handles on doors, non-existent elevators or accessible toilets), insufficient spatial orientation aids for people with sensory and cognitive impairments (for example, small or low-contrast labels), and communication problems (such as a lack of Sign Language and written language interpreters, or reverberant consultancy and treatment rooms where hearing-impaired persons have a hard time understanding spoken language). Likewise, the rejection of disabled persons by others, and their focus on the “deficiencies” of severely disabled persons, represents a barrier.<sup>249</sup> This impedes the chances of persons with disabilities to realize their right to freely choose their medical practitioners, as stipulated in SGB V. It can also stop them from obtaining adequate health care entirely. The health care situation for persons with disabilities and a migration background is also characterized by considerable accessibility barriers, in particular, due to the lack of resources provided in their native language, and intercultural understanding.<sup>250</sup> In this way, all possible kinds of barriers considerably reduce their individual right to choose according to their wishes, as defined by law.

State initiatives and self-governing bodies within the health care system do not support the necessity of accessibility to a satisfying degree.<sup>251</sup> There are no nationwide accessibility criteria regarding health care institutions, and no financial incentives and motivations to remove existing barriers. Likewise, equipment standards, general guidelines and recommendations are virtually nonexistent, and accessibility is not a quality criterion when it comes to medical licenses or remuneration arrangements.

Remuneration arrangements for medical and therapeutic staff do not provide for extra compensation when the disability of a patient requires additional treatment time.

**Doctors' surgeries and clinics:** In their State report, the Federal Government declares that they aim at the creation of accessible medical offices and clinics in due consideration of the specific needs of women and men. However, they do not provide for gender-equitable treatment (or for the equitable treatment of transsexual and intersex persons). In particular, the insufficient number of accessible gynaecological medical surgeries and clinics represents a problem for women with disabilities. These should not only provide for barrier-free access, but also for a gynaecological examination chair with adjustable height mechanisms and a lifter.

The right to a free choice of medical practitioners (§ 76 SGB V) is considerably restricted for persons with disabilities. The Federal Government claims it intends to promote a greater

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<sup>249</sup> See “Modell-Curriculum zur Sensibilisierung für einen barrierefreien Praxisalltag”, ed. by Interessenvertretung Selbstbestimmt Leben in Deutschland (ISL) e.V., December 2010.

<sup>250</sup> See Stiftung LEBENSNERV: *Zugangswege in der Beratung chronisch kranker/behinderter Menschen mit Migrationshintergrund. Eine Feldstudie*, Berlin 2009.

<sup>251</sup> See the letter dated November 23, 2011, that the umbrella organization of the national association of statutory health insurance funds [*Gesetzliche Krankenversicherung/GKV*] addressed to disabled persons' organizations, with regard to their call to change the recommendations for doctors' licenses according to §124 Para. 4 SGB V.

number of accessible surgeries among the service providers. In view of the massive cutbacks in the health care sector over the past years, however, it is obvious that the Federal Government cannot ensure this simply through uttering encouraging words.<sup>252</sup>

**Informed decisions – communication barriers:** Persons with disabilities and, in particular, women with learning difficulties, are frequently not provided with (sufficient) information about medical procedures by medical staff. When it comes to actual decisions, they are not involved at all. However, this kind of information is mandatory even when they are legally represented by a guardian responsible for health care issues. For example, they are often given a three-months-injection for the purpose of contraception. Because of side-effects, this contraceptive is avoided whenever possible in the case of non-disabled women. Likewise, sterilization is more frequently chosen as a means of contraception for women with learning disabilities. Women with other types of disabilities are sometimes not able to make informed decisions because of communication barriers, for example, when they are deaf. As is the case for the majority of intersex persons, hormone-producing organs are removed without their informed consent, which results in irreversible sterility.

**Knowledge deficiencies:** Knowledge deficiencies with regard to possible treatments, as well as deficient treatments themselves, represent significant barriers for persons with disabilities. This particularly affects people with autism spectrum disorders, with visual impairments, dementia, intellectual disabilities or severe movement disorders. Since the issue of “disability” is not sufficiently addressed in vocational training and further education for health professionals, health experts lack awareness of human rights, dignity, autonomy and the specific needs of persons with disabilities.<sup>253</sup>

Not enough efforts are made in order to provide women with disabilities with essential knowledge about pregnancy and childbirth, interactions between contraceptives and other drugs, the menopausal effects on disabilities etc. There is not sufficient awareness of disabled women’s exposure to physical, psychological and sexualized violence or of the fact that these can be the cause of their mental problems. Psychotherapists refuse to provide treatment for women with learning difficulties who were exposed to violence, claiming that they do not have the necessary skills to work with these patients.

**Hospitals:** Hospitals reveal considerable deficiencies. Economic pressure results in an ongoing shortage of staff and in privatization measures. Hospitals are increasingly striving for economic returns, which is to the disadvantage of quality medical services and other “soft” factors. The returns system is based on lump sums for patient care, and in this way promotes the early release of patients, which often comes at a time when they are in need of complex treatment because of their disability, or when they are still in great need of further hospital care. In other cases, patients are transferred to care facilities even though there is still a great deal of rehabilitation potential. Out of all institutions, hospitals are particularly poorly prepared for the demographic changes in society, and for the corresponding increase of multi-morbidity and multiply disabled patients. This is true for both medical expertise as well as hospital equipment.

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<sup>252</sup> See the suggestions for a “Förderprogramm 100.000 barrierefreie Praxen!” In: alle inklusive! Die neue UN-Konvention und ihre Handlungsaufträge. Ergebnisse der Kampagne alle inklusive!, ed. Federal Commissioner for Matters relating to Disabled People, Berlin 2009, p. 27.

<sup>253</sup> For example, there are no training measures on alternative communication types such as German Sign Language, manually coded language and speech-supporting signing or key word signing [*lautsprachunterstützend*] as well as communication technologies in everyday care situations.

Regarding persons with severe mental conditions, the quality of psychiatric treatment in hospitals has gradually changed for the worse in most regions. Disregarding the current psychiatric staff decree [*Psychiatrie-Personalverordnung*], there have nevertheless been personnel cutbacks.<sup>254</sup>

Moreover, assistance in medical rehabilitation facilities (admission of an accompanying assistance person, as well as the granting of the necessary aids without any interruption in time) is only legally regulated for those persons with disabilities who are themselves the regular employer of their assistance person. Clients of outpatient services as well as residents in inpatient facilities are not legally entitled to assistance in the hospital.<sup>255</sup>

**Health insurance:** The large majority of people living in Germany (approximately 85%) have public health insurance. In Germany, persons with disabilities are not excluded from public health insurance. The BRK-Allianz finds fault with the increasing privatization of public health insurance. Out-of-pocket payments, additional charges, deductibles and necessary services that are not covered by the insurance, as well as many other examples represent a particularly heavy burden for persons with disabilities.<sup>256</sup> In addition, health insurance agencies are now allowed to offer differential rates and additional coverage plans. This puts people with bigger health risks at a disadvantage. The growing competition between the health insurance providers increases the pressure placed on insured persons who suffer from health impairments, and the social and shared-risk-based health insurance system in Germany is increasingly becoming a subject of debate. Some regulations were created in order to compensate for particular hardships (such as the regulation for chronically ill persons [*Chronikerregelung*] in SGB V), but they are not sufficiently effective.<sup>257</sup>

Private health insurance providers require persons with disabilities to pay higher premiums or refuse them membership if it is obvious that their medical needs exceed the average.<sup>258</sup>

**Granting of benefits:** Service providers often question the quantity and quality of therapeutic or care benefits for persons with advanced dementia or acquired brain damage (for example, unresponsive wakefulness syndrome/UWS, vigilant coma, apallic syndrome). This strategy is aimed at saving costs, and leads to considerable service cutbacks.

Likewise, the assessment proceedings by the medical consultancy service for healthcare providers [*Medizinischer Dienst der Krankenkassen/MDK*] result in the withholding of services.<sup>259</sup> For example, the MDK recommended rehabilitation services in a mere 2% of all long-term care assessment procedures for persons with higher health care needs.<sup>260</sup> On the

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<sup>254</sup> For example, the decubitus risk is much higher than the average. See Nicola Nowak's decubitus survey in: "Die Schwester Der Pfleger" 2-2011, p. 124 et seq.

<sup>255</sup> See [http://www.forsea.de/projekte/Krankenhaus/2012\\_10\\_17\\_Stellungnahme\\_Ass\\_Kur.pdf](http://www.forsea.de/projekte/Krankenhaus/2012_10_17_Stellungnahme_Ass_Kur.pdf).

<sup>256</sup> For example, health care agencies are not placed under the obligation to compensate for the costs of aids needed in daily life.

<sup>257</sup> See the guidelines compiled by the Gemeinsamer Bundesausschuss regarding the implementation of the § 62 regulations concerning persons with severe chronic conditions [*Chroniker-Richtlinie*], from August 20, 2008.

<sup>258</sup> On the issue of elderly persons whose membership applications were declined: <http://www.test.de/Gesetzliche-Krankenversicherung-Sonderrecht-fuer-privat-Versicherte-1772028-1772029/>.

<sup>259</sup> Such as the restricted or insufficient granting of aids and medical products (wheelchairs that are individually adjusted for the user, hearing aids, cochlear implants, technical communication aids etc.).

<sup>260</sup> See [http://www.sovd.de/fileadmin/downloads/pdf/positionspapiere/2011-11-03\\_Weckruf\\_Soz\\_Info.pdf](http://www.sovd.de/fileadmin/downloads/pdf/positionspapiere/2011-11-03_Weckruf_Soz_Info.pdf).

one hand, they often pursue a cost-saving strategy, and on the other hand, many MDK employees do not have the proper expert qualifications necessary for adequately fulfilling their assessment responsibilities.

Some elements of care are alien to the health care system in that they are subject to economic competition (such as calls for bids regarding aids like wheelchairs and incontinency products). In these cases, the cost-saving factor is given more importance than aspects such as quality, safety, and participation. Clients of public healthcare companies are required to accept certain providers or suppliers for cost-saving reasons, even if they are frequently incompetent and located a great distance away from the clients' place of residence. This leads to considerable accessibility barriers. It is more and more frequent for patients to be forced to pay additional charges for aids, especially if the granted minimum or standard benefit, or the fixed amount that was defined, is not sufficient in order to ensure benefits that meet the care needs.<sup>261</sup>

If persons with disabilities receive integration assistance benefits as defined in § 53 SGB XII, they must contribute the majority of their income and assets. This results in a high poverty risk (see also the sections on Art. 19 and 28), and can also create a situation where patients are not equipped anymore with the financial means that they need for out-of-pocket payments required by health care providers. Some individuals and associations call for the creation of a conceptually consistent network of integration assistance services (for example, target-group specific, high-quality therapeutic options such as physical therapy, ergotherapy, logotherapy, psychotherapy and medical services as well as assisted communication that are provided in residential facilities and at the workplace). Those who oppose this suggestion point to the "subordinate" status of social welfare services, meaning that other agencies are seen to be responsible.

**Care structure:** § 2a SGB V and § 27 SGB V explicitly stipulate that the needs of persons with disabilities and psychological conditions must be acknowledged within the health care system. Nevertheless, persons with disabilities increasingly encounter significant problems when they attempt to obtain adequate and comprehensive health care services that meet their needs. Notably, people who live in rural areas are exposed to care deficiencies, long travel distances, and long periods of waiting for appointments. All this is the case, for example, when it comes to interdisciplinary early intervention facilities, social pediatric centers, counseling centers for assisted communication, regional care offices, and specific out-patient services for rheumatism or muscle disorder patients.

There is no sufficient nationwide network of psychiatric outpatient care facilities (such as out-patient psychiatric care or sociotherapy). In this way, for example patients with limited self-motivation, self-guidance skills, mobility and sense of orientation are exposed to more disadvantages than the average patient. The same is true for psychiatric crisis intervention and psychiatric home treatment that explicitly target all groups of persons with disabilities. Psychotherapeutic options for persons with disabilities and with severe psychological conditions are insufficient. In particular, there are not enough native speaker therapists for persons with disabilities and migrant backgrounds.<sup>262</sup>

Until the present day, the planned improvements of the medical aids guideline, and the most recent care structure act, were of no help for persons in constant need of medical aids

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<sup>261</sup> See Felix Welti: Hilfsmittel zum Behinderungsausgleich: Rechtlicher Rahmen und Reformbedarf!, In: Rehabilitation 2010; 49, p. 37-45.

<sup>262</sup> See Tagesspiegel from September 17, 2012: "Das Heimweh der Seele".

due to severe or progressive disabilities. In contrast to what the legislators intended, the granting of benefits has become subject to even stricter limitations.

**Dental care:** Good dental care for persons with disabilities often fails because of the barriers mentioned above (architectural or financial barriers as well as a lack of skills). Due to their impairments, it is often hard for senior citizens and adults with disabilities to maintain good dental hygiene on their own, and in this way, they have particular needs when it comes to dental care. Given the fact that their financial means are also often limited, it is particularly difficult for them to pay out of their own pocket for preventive dental care services, as the law requires. Likewise, their curative and prosthetic dental care is subject to severe deficiencies.<sup>263</sup>

**Care research:** Many problems that experts have been criticizing over the years and decades still persist. One significant cause of this is the virtual nonexistence of care research commissioned by the state. Such care research would need to consider the psychosocial aspect of disabilities, and provide comparisons between different international systems, as required by the ICF.

**With regard to laws and benefits laws the BRK-Allianz calls for the following actions:**

- Health care and social benefits legislation as well as the decision-making processes within the internal health care management bodies must be conducted in a way that considers disabilities, and must be based on the notion of “disability mainstreaming”.
- It is necessary to ensure that health care is provided in accordance with the principle of shared risk, and that it is aimed at meeting individual needs. Moreover, with regard to out-of-pocket and additional payments, it must be taken into account that many people have limited economic capacities.
- Legislators must introduce penalties against internal health care management bodies and service providers that delay fundamental decisions and benefits grants, or unjustly cut back on benefits.
- They must introduce a dense network of interdisciplinary early intervention measures across the country.
- Outpatient services for people with psychological conditions (such as outpatient domestic psychiatric care, sociotherapy, outpatient crisis intervention services/crisis hotlines, and integrated care) must be set in place all over the country and in accordance with the legal stipulations presented in SGB V. In this regard, it is essential to strengthen cooperation and networking between inpatient and supplementary care services [*komplementäre Pflege*]. (Outpatient services should be prioritized over inpatient services.)
- The additional time that is needed in medical procedures for persons with disabilities must be adequately compensated.
- The rights of patient representatives in the relevant healthcare committees must be considerably strengthened.
- It is necessary to legally establish the associations’ right to take legal action as class action within the health care system, or to strengthen it where necessary.

**With regard to the elimination of barriers the BRK-Allianz calls for the following actions:**

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<sup>263</sup> See Bundeszahnärztekammer (eds.): *Mundgesund trotz Handicap und hohem Alter*, 2010, and IDZ-Informationen 3/12: *Zur Mundgesundheit von Pflegebedürftigen und Menschen mit Behinderungen in Deutschland – eine systematische Übersicht (Review) auf Grundlage aktueller Einzelstudien (2000 – 2012)*.

- Accessibility barriers within the health care system (such as mindsets, lack of knowledge, wide-ranging agency competencies, communication and intercultural skills, the provision of services far from the beneficiaries' place of residence, architectural barriers, deficient patterns of communication, stigmatization etc.) must be systematically eliminated.
- The legislator must use the accessibility of doctors' clinics and offices as a criterion for the licensing of new offices and clinics and new incumbants.
- A closely woven, nationwide network of comprehensive and accessible outpatient medical services must be available. Women with disabilities must be provided with a sufficient number of accessible gynaecological surgeries.
- The utilization of alternative types of communication (German Sign Language, manually coded language [*lautsprachbegleitend*], and speech-supporting signing/key word signing [*lautsprachunterstützend*]) and of alternative communication techniques (augmentative and alternative communication) as well as support by means of written interpretation, audio induction loops, microports, etc. must be made possible.
- Accessible information on health care, including contraception, must be provided.
- The inclusion of necessary non-medical support persons (such as assistance givers who work for the clients of outpatient services, or residents of inpatient facilities) must be ensured in all areas of medical rehabilitation.

With regard to the elimination of knowledge deficiencies the BRK calls for the following actions:

- Healthcare professionals must be made aware of dignity and comprehensive rights for persons with disabilities of all kinds.
- The issues of disability and additional needs deriving from disabilities, and basic knowledge about communication skills that are necessary when communicating with disabled persons, must become standard elements of vocational training and further education for all healthcare professions. This could be made possible through measures such as a review of the regulations regarding doctors' licenses, or the curricula of the other medical professions. Intercultural, gender and disability aspects must be taken into account (so that, for example, medical staff will be able to recognize when disabled women have been exposed to violence, and how to take the relevant steps to counter this risk). Specific information on sexuality, pregnancy and birth in combination with a disability must become an element of gynaecological curricula.
- When gender-sensitive research about medical treatments and their effectiveness is conducted, it is necessary to consider and listen to persons with disabilities in this research.
- The ICF (International Classification of Functioning, Disability and Health) must be comprehensively considered both during medical studies, vocational training and further education, and in health care practice.
- Medical research and care research must take the concerns of persons with disabilities into account. Persons with disabilities must be involved in the design and analysis of the research projects.

## **Article 26 – Habilitation and rehabilitation**

With a comprehensive perspective, Art. 26 CRPD stipulates that habilitation and rehabilitation measures be provided in and across all related areas of health, employment, education and social services. In contrast to this, the field of rehabilitation is strongly

subdivided in Germany. In addition to medical and occupational rehabilitation, some social rehabilitation measures are provided, but the field itself remains undeveloped. The vast number of rehabilitation agencies and responsibilities result in a system that is obscure to those who need it, and that entails many problems with regard to clear distinctions and defining sectional responsibilities. Numerous regulations in SGB IX<sup>264</sup> were introduced in order to improve the situation, but up until today they have not been implemented to a satisfying degree. The German rehabilitation sector is still dominated by inpatient facilities. In contrast, there is a lack of outpatient and mobile rehabilitation services that approach patients and cater to them in their everyday environment.

**Counseling:** The subdivisions within the system make it complicated to access counseling services. Starting in 2001, the “joint service points” [*Gemeinsame Servicestellen*] that are affiliated with the rehabilitation agencies were supposed to help solve this problem and to provide cross-agency and independent counseling. However, the situation remains deficient. Many people are not informed about the counseling offices or cannot locate them; the offices are not sufficiently independent, agencies are not equipped with satisfying expertise, and they do not provide case management.<sup>265</sup> The initiative “Reha Futur”, funded by the Federal Government, identified these problems<sup>266</sup> but was not able to solve them.

**Access:** Due to new legal regulations (2008 health care reform, reviewed rehabilitation guidelines), accessing rehabilitation services has become much more complicated. Even though the demand for medical rehabilitation measures increased considerably, the amount of granted measures was exactly as high in 2010 as it was in 1995. The German statutory pension insurance scheme [*Deutsche Rentenversicherung*] admitted self-critically that this was the case even though a considerably higher number of applications were filed<sup>267</sup> (see Art. 27 on occupational rehabilitation). The individual right to choose is de facto restricted, for example, due to additional payments and the lack of comprehensive accessibility. In many cases, rehabilitation institutions are chosen on the basis of the financial situation of the financing agency concerned, and not on the basis of the individual’s needs.

Sometimes, hospitals impede a prompt transfer to early rehabilitation facilities. This is because they are primarily interested in exhausting the maximum period of hospitalization, since acute care in hospitals is rewarded on the basis of per-patient lump sums, and the hospitals prioritize this interest over what is really necessary in terms of care. The fact that hospitals receive their funding on the basis of this case-based lump sum system results in early discharges into rehabilitation institutions, even though the patient may still have a considerable need for hospital care. Also, when discharges lack adequate preparation, this often results in the patients' immediate transfer to a long-term care facility, because the potential to return to their prior, familiar living environment remains unexploited.

**Service provision:** The right to services that enable the best possible inclusion and participation is contradicted by the case-based lump sums in rehabilitation services, and by

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<sup>264</sup> For example, the obligation for coordinated service provision according to § 10 SGB IX, the combination of services according to § 11 SGB IX, the cooperation obligation between rehabilitation agencies according to § 12 SGB X, and the declaration of responsibility according to § 14 SGB IX.

<sup>265</sup> Bundesarbeitsgemeinschaft für Rehabilitation: 3. Bericht der Gemeinsamen Servicestellen nach § 24 Abs. 2 SGB IX, February 16, 2011.

<sup>266</sup> “Reha-Futur” project results accessible at:

[http://www.rehafutur.de/fileadmin/DOWNLOADS/Publikationen/RehaFutur\\_Entwicklungsprojekt\\_Kurzfassung\\_Ergebnisse\\_end3.pdf](http://www.rehafutur.de/fileadmin/DOWNLOADS/Publikationen/RehaFutur_Entwicklungsprojekt_Kurzfassung_Ergebnisse_end3.pdf).

<sup>267</sup> Deutsche Rentenversicherung Bund. Reha-Bericht 2012, p. 23 et seq.

the de facto predominance of inpatient rehabilitation measures. A mere 12% of all medical rehabilitation services were carried out as outpatient measures in 2010.<sup>268</sup>

Also, rehabilitation services and in particular, inpatient rehabilitation services, are not sufficiently based on the individual potential rehabilitation goals, but are rather offered on a very standardized basis. In particular, the lack of follow-up services (such as outpatient neuropsychological therapy and in-home rehabilitation) provided close to the patient's place of residence adds a considerable disadvantage.

Many rehabilitation measures are linked to explicit preconditions that exclude persons with certain disabilities or complex issues (for example, intellectual disabilities, autism, severe sensory, physical or mental disabilities) from their services. Unfortunately, alternative rehabilitation services for these excluded groups do not exist. There are no structures that allow for the involvement of experts who work in associations of persons with disabilities and chronic health conditions.

#### **The BRK-Allianz calls for the following actions:**

- **Medical, occupational and social rehabilitation must be interlinked in a more efficient way, and cross-agency counseling as well as a coordinated provision of services must be ensured.**
- **It is necessary to establish a cross-agency procedure for the determination of each patient's needs. This procedure must consider the International Classification of Functioning, Disability and Health (ICF).**
- **In order to avoid gaps in the care system and the interruption of rehabilitation programs, applications must be processed promptly.**
- **Any accessibility barriers that children, adolescents and adults with disabilities as well as disabled people with migrant backgrounds encounter must be eliminated. The best possible, prompt transition from acute care to immediate rehabilitation must be ensured.**
- **The individual person must be the main focus of rehabilitation measures. Also, those concerned must become more involved in the determination of the rehabilitation goals, and peer support must be ensured.**
- **It is necessary to establish a comprehensive care system in residential areas all across the country (mobile rehabilitation services etc.) as well as outpatient services for persons with severe mental impairments.**
- **Joint service points must be reviewed with regard to their structure in order to ensure comprehensive independent counseling, to allow for the coordination of all involved persons and institutions, and to accelerate the procedures.**

## **Article 27 – Work and employment**

### **1. Labor market**

In Germany, persons with disabilities are much more often affected by **unemployment** than other people. The unemployment rate for severely disabled people reached 14.8% in 2011, while the general unemployment rate was 7.9% (see chart 1). The high unemployment rate among severely disabled persons remains unmentioned in the NAP, even though it would be a good indicator for measuring how inclusive the labor market is. Likewise, no mention is

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<sup>268</sup> Deutsche Rentenversicherung Bund. Reha-Bericht 2012, p. 25.



made of the obvious regional differences. In comparison to West Germany, the unemployment rate for severely disabled persons in East Germany is particularly high, as is the general unemployment rate.

According to an OECD survey, when it comes to the unemployment rate of severely disabled people, Germany, Slovenia, Czech Republic and Belgium are found at the bottom of the list in comparison to other industrialized nations.<sup>269</sup> The labor force participation rate among severely disabled people between the ages of 15 and 65 amounted to 52% in 2009, and to 79% among non-disabled people.<sup>270</sup> When compared to both non-disabled women (72%) and disabled men (56%), women with disabilities represent the lowest employment rate, 47%. Women with disabilities and a migrant background have to contend with even lower employment opportunities on the labor market.<sup>271</sup>

**Chart 1: Yearly comparison of unemployment rates** (Source: Statistics compiled by the federal labor agency [*Bundesagentur für Arbeit*])

Unemployment rate	2005	2006	2007	2008	2009	2010	2011
Altogether <sup>272</sup>	13.0%	12.0%	10.1%	8.7%	9.1%	8.6%	7.9%
Severely disabled people <sup>273</sup>	17.8%	17.7%	15.8%	14.7%	14.6%	14.8%	14.8%
Men	18.3%	18.2%	16.1%	15.1%	15.3%	15.6%	
Women	17.1%	17.1%	15.4%	14.2%	13.7%	13.7%	
East Germany	26.2%	27.2%	25.5%	22.2%	21.4%	22.5%	
West Germany	16.1%	15.8%	13.6%	12.8%	12.9%	13.4%	

In Germany, companies with 20 or more employees are obliged to staff at least 5% of their job positions with severely disabled people. If they do not comply with this so-called **employment obligation** [*Beschäftigungspflicht*], they must pay staggered compensation levies (currently, a maximum of 290 EUR per month for each job position that was not given to an employee with a disability). Altogether, approximately 1 million persons with disabilities were working in the private sector and the public administration in 2010. Just as in previous years, the minimum employment quota of 4.5% was not met. Private employers reached an employment quota of only 4.0%, while employers from the public sector reached a percentage of 6.3%. In their State report, the Federal Government claims that there are several measures that have had a positive impact on reaching the employment quota for severely disabled people, and that this quota increased from 4.0% on 2003 to 4.5% in 2009. Unfortunately, this positive development is almost solely limited to employers in the public sector.

<sup>269</sup> OECD: *Sickness, Disability and Work*, 2010, p. 53.

<sup>270</sup> Pfaff, Heiko et al. (2012): *Lebenslagen der behinderten Menschen. Ergebnis des Mikrozensus 2009*, <https://www.destatis.de/DE/Publikationen/WirtschaftStatistik/Sozialleistungen/Lebenslagenbehindert032012.pdf>.

<sup>271</sup> BMFSFJ (ed.), Libuda-Köster, Sellach (2009): *Lebenslagen behinderter Frauen in Deutschland. Auswertung des Mikrozensus 2005. Short Version*, p. 21/22.

<sup>272</sup> Unemployment rate based on number of wage and salary earners.

<sup>273</sup> The unemployment rate from each year is based on the number of severely disabled wage and salary earners from the previous year.

Some facts indicate that the current terms and conditions of the employment obligation do not adequately ensure equal access to the labor market. For one, regarding almost one third (31%) of all German employers who are under this obligation, severely disabled persons actually make up zero or less than 1% of employed staff members. The majority of employers who do not employ any severely disabled persons belong to the private sector. Secondly, the employment obligation does not change the fact that the unemployment rate for severely disabled people is higher than the average (see chart 1).

In addition to obliging business companies to employ more severely disabled people, it is also necessary to introduce adequate **labor market policy measures** in order to promote the participation of persons with disabilities in working life. A wide range of programs exists in Germany in order to help redesign workplaces, provide qualification opportunities for persons with disabilities and grant subsidies to employers. However, professional further education and training programs or trained workplace assistants would be more adequate means for creating better opportunities for persons with disabilities on the labor market.

In 2010, the Federal Government adopted extensive austerity measures with regard to guidance and job placement for the unemployed. In the upcoming years, the means will be subjected to severe cutbacks; the Federal Government explains this decision by pointing out that the unemployment figures have decreased since the 2009/2010 financial and economic crisis. However, the cutbacks far exceed the decrease of the unemployment rates. For example, the number of unemployed persons decreased by 8% in 2011 as compared to the previous year. Nevertheless, the number of people who participated in labor market measures decreased by much more, namely by 21% (see chart 2). In contrast to the overall trend, the number of unemployed persons with severe disabilities even increased by 2.8% in 2011, and this development was not countered by specific measures to promote their employment. On the contrary: the number of severely disabled persons who participated in labor market measures decreased by 22% in comparison to the previous year. In this way, persons with severe disabilities are even more negatively impacted by the cutbacks made by the Federal Government.

**Chart 2: Development of figures for unemployed persons and participants in labor market (training) measures** (Source: Statistics compiled by the federal labor agency, calculations made by the German federation of trade unions (DGB))

	2010	2011	change in %
Total sum of unemployed persons	3,238,421	2,975,823	-8.1%
Total number of participants in training programs	1,553,449	1,227,110	-21.0%
Severely disabled unemployed persons	175,356	180,307	+2.8%
Total number of severely disabled participants in training	54,216	42,336	-22.0%

Another successful tool for persons with disabilities (and others) is the so-called employment subsidy [*Beschäftigungszuschuss*] as defined in § 16e SGB II. If employers hire people who have been unemployed for a long time, and who are considered to be especially difficult to place on the labor market, up to 75% of the salary will be subsidized by the government. Following the 2011 cutbacks, the number of participants in these measures decreased by 54%. Moreover in 2012, the possibility to receive this subsidy for an unlimited amount of time was cancelled, and tariff-based salary levels were lowered.

By cutting back on the guidance for unemployed people, the Federal Government drastically minimized their contributions and virtually eliminated successful measures. In view of the fact that severely disabled persons do not benefit from the labor market recovery as much as non-disabled people, and that their average unemployment periods are longer, their opportunities for adequate work and employment are continuing to deteriorate. The Federal Government labor market scheme, "Initiative Inklusion", is entirely insufficient. It is temporary, aimed at small changes (a mere 4,000 new jobs for older persons with severe disabilities) and exclusively funded with the means collected from compensation levies, which must anyway be spent for specific purposes serving persons with severe disabilities.

In "**sheltered workshops for persons with disabilities**" [*Werkstätten für behinderte Menschen/WfbM*], the number of persons with disabilities who are permanently employed increased from 211,246 in 2005 to 248,441 in 2010.<sup>274</sup> This partly results from the lack of job opportunities on the regular labor market.<sup>275</sup> Altogether, the average annual growth rate amounts to 3%. 0.16% of WfbM employees transition to the regular labor market.<sup>276</sup> Women remain in WfbM for longer periods of time as compared to men, and they are less likely to transition into the regular labor market.<sup>277</sup> In 2010, employees of the so-called regular work section [*Arbeitsbereich*] in a WfbM earned an average monthly salary of 180 EUR, or 2,160 EUR throughout the entire year.<sup>278</sup> The law stipulates that at least 70% of the income generated by a WfbM must be paid out in employee salaries. The pension funds contributions are not calculated on the basis of the de facto salaries, but on a figure that corresponds to 80% of the reference value in the social insurance. After an entitlement period of 20 years of work in a WfbM, the persons concerned obtain a pension that is subsidized by federal funds, based on their full incapacitation for work.<sup>279</sup>

Social insurance is tied to institutions, not to individuals. A transition to a different labor market measure often results in the deterioration of that individual's social insurance situation. For this reason, transitions between different measures are complicated, and frequently fail due to bureaucratic obstacles (for example, the transition from a WfbM to supported employment [*unterstützte Beschäftigung*]).

Moreover, considerable deficiencies exist in companies when it comes to protecting the health of their staff with the help of good working conditions, comprehensive protection programs, and **occupational health management**. Nevertheless, disabilities and chronic health conditions often result from work. This particularly applies to mental health. The number of people who had to withdraw from working life due to mental health conditions reached a new peak in 2011. Mental health disorders are currently the main reason for people having to accept pensions based on reduced earning capacity.<sup>280</sup> Unfortunately, companies do not sufficiently acknowledge the concerns of these persons, and of other

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<sup>274</sup> 2010 statistical comparison conducted by the BAGüS, p. 90. The numbers of WfbM employees in the admission and the vocational education sections are not included.

<sup>275</sup> According to a 2008 BMAS survey, the number of persons with mental disabilities who attend WfbMs has particularly increased. Altogether in 2011, according to BAG WfbM, more than 285,000 persons with disabilities were attending 2,500 WfbM.

<sup>276</sup> ISB-Bericht (2008): Entwicklung der Zugangszahlen, p. 111.

<sup>277</sup> Barbara Vieweg (2009): JobBudget. Frauen mit Behinderung und der Übergang aus der Werkstatt auf den Arbeitsmarkt in: WeiberZEIT No. 18, p. 6-7, December 2009.

<sup>278</sup> Quoted in: Bundesarbeitsgemeinschaft Werkstätten für behinderte Menschen e.V.: <http://www.bagwfbm.de/page/101>.

<sup>279</sup> According to § 43 Para. (6) SGB VI in combination with § 50 Para. 2.

<sup>280</sup> See Reha-Bericht der Deutschen Rentenversicherung 2012, p. 84 et seq.

persons with disabilities. Also, not enough low-threshold, easy-to-access support, counseling and placement services are provided for these groups.

Some legal regulations in the field of employment have discriminatory effects on persons with disabilities. According to the **workplaces decree** [*Arbeitsstättenverordnung*], enterprises are not obliged to provide accessible work places per se, but only in the case that they are already employing disabled staff members. Moreover, the integration offices [*Integrationsämter*] are not necessarily forced to cover all costs that accrue from (re)designing an accessible workplace (see § 27 SchwbAV). Disabled persons are not legally entitled to this service, since it is not defined as a “reasonable accommodation”. These regulations put persons with disabilities at a disadvantage when applying for jobs: as employers fear costs of redesigning accessible workspaces, they prefer to employ persons without disabilities.

In everyday life and in their working lives, persons with communication impairments (for example, blind and visually impaired persons) rely upon accessible IT facilities. Accordingly, technical specifications, such as the accessibility criteria defined in BITV2.0, must be included in the visual display units (VDU) decree [*Bildschirmarbeitsplatzverordnung*].

Regarding accessibility specifications for the public procurement of products and services in the field of information and communication technologies<sup>281</sup>, it is necessary that ergonomic and accessibility requirements are considered as a joint issue. Also, the regulations on public tenders must become legally binding for workplaces.

To this day, persons with disabilities are exposed to disproportionate disadvantages when it comes to **setting up businesses** and the path to self-employment. The relevant conventional counseling centers are largely uninformed about disability issues or specific funds. The procedures that must be undertaken in order to apply for funding or support at the employment agency, the integration offices or the former central welfare authority [*Hauptfürsorgestelle*], are not sufficiently comprehensible or accessible. Coaching services, an extended budget for workplace assistance and other tools are not available to persons with disabilities by default, or tailored to their needs. Adequate equipment is a precondition for successfully setting up a business (for example, computers with text-to-speech software for blind users, interpretation services that translate between hearing and deaf communication partners, and so on).<sup>282</sup>

## **2. Transition from schools to working life, vocational guidance, education and training**

It is nearly impossible for severely disabled students who are in need of special pedagogical advancement measures to transition from schools to the regular labor market. This is especially true if they need advancement measures with regard to physical and motor development. Unfortunately, there are no reliable data either on the Federal or the Länder level regarding the transition from special needs schools to working life, or to general **vocational training** [*Berufsvorbereitung*] **measures**. Young people with learning impairments often get caught at the so-called second threshold: while many of them successfully complete their vocational training in a facility instead of within a company, they do not manage to transition into a steady employment position within a business enterprise.

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<sup>281</sup> See EU mandate 376 II: <http://www.mandate376.eu/>.

<sup>282</sup> An archive for the documentation of discrimination experiences of deaf and hearing-impaired persons who set up businesses was established at the Deutscher Gehörlosen-Bund.

While a total sum of 1.5 million vocational training positions were available in 2010<sup>283</sup>, a mere 6,700 adolescents with severe disabilities were able to start their **regular vocational training** within the dual education system.<sup>284</sup> This mirrors the general situation for young persons with disabilities on the labor market as described above. In particular, young women with disabilities experience considerable restrictions when it comes to choosing a vocational training program. Moreover, the overall percentage of women with severe disabilities in vocational training is lower than in the male reference group.<sup>285</sup>

It is urgently necessary to offer vocational training within the dual education system to young people with disabilities, in order to comply with the framework regulations provided by the board of the Federal Institute for Vocational Education and Training [*Bundesinstitut für Berufsbildung*].<sup>286</sup> This is the only way to ensure professional training that is in line with existing recognized apprenticed professions, and that allows for the potential transition into a regular vocational training program. This would considerably increase their opportunities in the labor market.

In order to be able to offer more sophisticated dual vocational training programs, training supervisors and instructors have the opportunity to complete an additional course that allows them to provide adequate vocational training for young people with disabilities. The majority of adolescents with disabilities complete their vocational training outside regular enterprises, in special institutions. However, if these young people receive their vocational training in a segregated system, only some of them will find work in the regular labor market. This system especially puts adolescents who are classified as “incapacitated for the labor market” at a disadvantage.

### 3. Counseling, placement, guidance

Accessible counseling, placement and guidance, including assistance, are indispensable for persons with disabilities to obtain access to the regular labor market. Considerable deficiencies exist, and the situation has even changed for the worse in recent years. 60% of all unemployed persons with disabilities are managed by job centers [*Jobcenter*].<sup>287</sup> In contrast to the federal employment agencies [*Agentur für Arbeit*, see § 104 SGB IX)], job centers are not legally obliged to provide specific counseling and placement services for (severely) disabled persons. However, considering that many of these persons have been unemployed long-term and have complex support needs, these services would be essential in job centers.

The quality of counseling and guidance in the job centers is deficient. They do not focus on the tested and approved participation goals defined in the SGB IX (long-term, quality job positions), but instead, on the fast placement of clients into low skill level jobs. Many job center employees are not qualified enough to properly recognize their clients’ needs. This impedes access to rehabilitation and results in persons only obtaining basic benefits and no additional means necessary to meet their needs arising from their disability. Likewise,

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<sup>283</sup> Statistisches Bundesamt, 2010 figures.

<sup>284</sup> Bundesagentur für Arbeit: Beschäftigungsstatistik Schwerbehinderte Menschen in Beschäftigung, Berichtsjahr 2010, chart 6.

<sup>285</sup> Bundesagentur für Arbeit (BA): Arbeitsmarkt in Zahlen – Förderstatistik: Teilhabe behinderter Menschen am Arbeitsleben – Rehabilitanden. 2012.

<sup>286</sup> Framework guidelines for vocational training regulations according to § 66 BBiG and § 42 HwO for persons with disabilities, June 20, 2006.

<sup>287</sup> Bericht der Bundesagentur für Arbeit zur Arbeitsmarktsituation schwerbehinderter Menschen. 23. Sitzung des Beirats für die Teilhabe behinderter Menschen, November 23, 2011, p. 4.

general benefits for employment promotions are allocated to severely disabled people far less frequently when they fall under the responsibility of SGB II, instead of SGB III.<sup>288</sup> When looking at recent developments<sup>289</sup>, we are concerned that the number of severely disabled persons who are managed by job centers will continue to increase. This will further hinder them from accessing the regular labor market, and their right to participation will be fundamentally questioned.

In 2000, the **integration expert services** [*Integrationsfachdienste/IFD*] were established all across the country. Their mission consists in providing continuous and “one-stop” counseling, placement and guidance for specific groups of severely disabled people. However, these goals are increasingly subject to negotiation. Starting in 2004, the IFDs have received fewer and fewer assignments and less funding from agencies in charge of job placements.<sup>290</sup> Also, since 2010, the Federal Government requires the tendering of placement services. This contradicts the IFDs’ mission to offer one-stop placement and counseling services, and to provide reliable and continuous guidance to the clients. It encourages wage dumping, raises doubts about the expertise of the IFD staff and impedes a high-quality provision of services.

#### **4. Vocational education and participation in professional life for people with extensive support needs**

Among other things, the UN CRPD outlines the right to vocational education and training and participation in working life for all persons with disabilities. This right also applies to persons with extensive support needs or severe intellectual and/or multiple disabilities.<sup>291</sup> In Germany, however, this right is not reliably implemented. Currently, as a rule 15 out of the 16 Länder exclude this group of persons from the regular labor market as well as from participating in vocational education and working life, and even from the “sheltered workshops”. This clearly qualifies as discrimination.

This exclusion is based on the legal stipulations in § 136 SGB IX which states that access to the work section in the WfbM is subject to the condition that the person is able to achieve an (undefined) “minimum amount of economically productive work output”. While this capacity is supposedly assessed during the so-called “admission procedure” [*Eingangsverfahren*] and in the “vocational training section” of the WfbM, it is the expert committee<sup>292</sup> [*Fachausschuss*] that decides if the person with a disability will be classified as

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<sup>288</sup> In 2010, the expenses for general employment promotion services in the domain of SGB III amounted to 118 million EUR. In the domain of SGB II, they only amounted to 45 million EUR, even though the majority of severely disabled persons are supervised by job centers.

<sup>289</sup> Bericht der Bundesagentur für Arbeit zur Arbeitsmarktsituation schwerbehinderter Menschen zur 23. Sitzung des Beirats für die Teilhabe behinderter Menschen, November 23, 2011, p. 3: “ Starting in April 2011, the unemployment rate among severely disabled persons (in the SGB III domain, author’s note) decreased. In the legal domain of SGB II, the unemployment rate among severely disabled persons increased each month when compared to the previous month. When the figures were last compiled in October 2011, there was an increase of 6.7%.”

<sup>290</sup> Bundesarbeitsgemeinschaft für Integrationsämter und Hauptfürsorgestellen, Jahresbericht 2009/2010, p. 28.

<sup>291</sup> UN CRPD, preamble lit. j.

<sup>292</sup> See § 2 WfbM decree.

“capacitated for a WfbM” or “incapacitated for a WfbM”<sup>293</sup> after transferring from school. If a person with a disability is deemed “incapacitated for a WfbM”, s/he will be transferred into so-called “daytime activity centers” [*tagesstrukturierende Angebote*] as defined in § 53 et seq. SGB XII (advancement centers [*Förderstätten*] etc.).

However, most of these **daytime activity centers** do not focus on vocational education and work, but advancement measures targeted at individual skills. This results in a more precarious social security situation when compared to work in a WfbM. Moreover, people in daytime activity centers do not receive any salary. Daytime activity centers are not subjected to any binding general or nationwide requirements and quality standards. In addition to daytime activity centers that are independent on or affiliated with a WfbM<sup>294</sup>, some residential facilities are equipped with associated advancement groups [*Fördergruppe*] or internal advancement facilities [*Förderbereich*]. Several Länder do not allow people who live in a residential facility to attend an external advancement center at all; instead they are forced to use a cheaper internal daytime activity facility.<sup>295</sup> The resulting exclusion is in direct conflict with the UN CRPD goals.

Even though the Federal Government and the Länder agree that any kind of discrimination against persons with disabilities must be opposed and overcome<sup>296</sup>, up until this day, the Federal Government has not made any attempt to de facto enable persons with extensive support needs to access vocational education and training, and to participate in working life. This becomes obvious, for example, in the fact that the State report does not contain any statements about this group of persons.

## 5. Qualification and professional advancement

Opportunities for disabled persons to engage in **further education** and training are restricted by the regulations on integration assistance (SGB XII). In particular, vocational education is only funded up until a first work or professional qualification or diploma has been received. In recent years, some exceptions were made, but in view of the current scarce financial resources, the regulations have again become stricter. General further education and training measures do not always comply with accessibility requirements, both with regard to structural layout and to communication.<sup>297</sup> (For example, induction loops for hearing impaired persons and funding for Sign Language and written language interpreters are not provided.) In this way, persons with disabilities often cannot benefit from further education measures, even though SGB IX, II, III and VI stipulate that funding may be granted for such measures wherever the costs for the compensation of any disadvantages that result from a disability (aids, assistance etc.) cannot be covered by either the education agencies or as defined in SGB XII.

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<sup>293</sup> From an inclusive point of view, the conceptual pair “capacitated for WfbM” and “incapacitated for WfbM” excludes and discriminates. A person who is classified as “incapacitated for WfbM” will immediately be excluded. However, since these notions are still used in the agencies and their administrative processes, we utilize them in this report as quotes.

<sup>294</sup> Currently, approximately 23,000 persons are employed there (see the statistical comparison between the regional social welfare agencies, 2010, p. 93).

<sup>295</sup> There are no reliable data regarding the number of users of these institutions.

<sup>296</sup> First State report, p. 71.

<sup>297</sup> A project facilitated by the BMAS will conduct research on “impacts of legislation with regard to the vocational integration of persons who are hearing impaired, are deaf or have become deaf, with the help of communicative and organizational means”. Research lasted until late 2012, and the first results can be accessed at: <http://www.fst.uni-halle.de/projekte/ginko/>.

## 6. Vocational rehabilitation/reintegration

While a number of high quality vocational rehabilitation programs exist in Germany, they are not easy to access. The number of recognized vocational rehabilitants managed by the Federal Employment Agency has been in continuous decline over the past years. This results in part from SGB II, which was put in force in 2005. The reintegration figures decreased from 50,000 in 2002 to 22,000 in 2007, the rehabilitation figures with regard to young people sank from 57,000 (2002) to 46,000 (2007).<sup>298</sup> Ever since then, the numbers have remained static at this low level.<sup>299</sup> Likewise, it became more difficult to obtain rehabilitation services from the German statutory pension insurance scheme [*Deutsche Rentenversicherung*]. While the demand and the number of applications increased in 2010 (by 3.3% compared to the previous year), the number of approvals decreased by 2%.<sup>300</sup> The law also delimits access to rehabilitation. According to § 220 SGB VI, the rehabilitation budget of the *Rentenversicherung* is not based on demand, but on the development of wages. Since wages did not increase in recent years, the rehabilitation budget remained at the same level, in spite of the increased demand.

Access to rehabilitation measures is particularly difficult for people who are managed by the **job centers** (SGB II) and not by the employment agencies (SGB III). They are half as likely to be recognized as rehabilitants as compared to clients from employment agencies. Surveys find fault with the fact that the recognition procedure became more difficult for these people.<sup>301</sup> Instead of promoting further education and training and the placement into occupations that include social insurance, job centers rely on underpaid, short-term job opportunities (“1-Euro-jobs”) that do not provide any professional prospects or include quality guidance. In 2010, 33,800 severely disabled persons were assigned to these types of job measures; this corresponds to 43% of all measures that were initiated.<sup>302</sup> In contrast, the numbers of people provided with qualification measures in rehabilitation facilities by job centers that are managed by the municipality agencies have been below 1% for years.<sup>303</sup>

**Older persons as well as women with disabilities** encounter particularly severe difficulties when trying to access vocational rehabilitation programs. From the participant age of 50 on, the percentage of completed vocational training services that are provided by the *Rentenversicherung* declines dramatically.<sup>304</sup> Since it is less common that women fulfil the conditions required for accessing services for participating in working life, they only received 38% of the benefits that were allocated by the *Deutsche Rentenversicherung* in 2010.<sup>305</sup> In the vocational training centers for people with disabilities [*Berufsförderungswerke*], where

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<sup>298</sup> Kurzbericht 25/2008 des Instituts für Arbeitsmarkt und Berufsforschung “Berufliche Rehabilitation in Zeiten des SGB II”.

<sup>299</sup> Statistics of the Bundesagentur für Arbeit: admission, number of people (annual average) and departure of rehabilitants according to §19 SGB III, Nuremberg, September 2011. According to these figures, 21,900 reintegration cases were recognized and 45,000 rehabilitation cases were recognized.

<sup>300</sup> Reha-Bericht 2010 der Deutschen Rentenversicherung, p. 55.

<sup>301</sup> Kurzbericht, l.c., p. 2.

<sup>302</sup> Deutscher Gewerkschaftsbund, Arbeitsmarkt aktuell November 2011 “Besserung am Arbeitsmarkt geht an schwerbehinderten Menschen vorbei”, p. 9.

<sup>303</sup> Die Deutschen Berufsförderungswerke, Anmelde- und Belegungszahlen der Berufsförderungswerke, State: September 30, 2011.

<sup>304</sup> Reha-Bericht, l.c., p. 60: Utilization rate based on 10,000 insured individuals in the relevant age group.

<sup>305</sup> See Reha-Bericht, l.c.



people receive occupational retraining measures that are tailored to their disability, the percentage of women is as low as approximately 27%.<sup>306</sup>

Currently, rehabilitation agencies usually provide for vocational training, but not for **university studies** as a means of vocational rehabilitation. This puts persons with disabilities at a disadvantage, as it restricts them to vocational training options.

The **quality** of rehabilitation measures is increasingly fundamentally questioned. This results from the increasing number of tenders, because decisions about tenders are based on cost and not on quality. For this reason, innovative providers that also cater to the specific needs of particular groups of disabled people are increasingly side-lined. Vocational rehabilitation options must be supported and improved. They must become accessible in all aspects regarding specific types of disabilities, and they must be aligned with the individual needs and resources of those concerned. Also, these services must be offered in close vicinity to the place of residence of those concerned. Moreover, it is necessary to establish integrated participation planning schemes for beneficiaries.

## 7. Representation of interests

In the workplace, the elected **representatives of severely disabled persons** [*Schwerbehindertenvertretung/SBV*] work for the interests of persons with disabilities and persons who are at risk of developing a disability. As defined by law, their main responsibilities include the integration of persons with disabilities into working and professional life, their professional advancement and safeguarding their job position. In order to achieve these goals, effective participation and decision-making are essential. Deficiencies exist in this regard, both at the legal level and at the practical level.

Due to demographic developments and the changes in professional life (physical and mental stress is on a constant rise), the work of the SBV is becoming more and more demanding. Likewise, the introduction of occupational integration management [*betriebliches Eingliederungsmanagement/BEM*, see § 84 Para. 2 SGB IX], and the compilation and implementation of integration agreements (§ 83 SGB IX) intensified the responsibilities of the SBV. This means that the human resources of the SBV are no longer sufficient for meeting the growing demands.<sup>307</sup>

By law, the SBV must participate in all decisions that are a matter of concern for disabled employees and employees with a similar legal position in this regard. Unfortunately, the employers do not always comply with this obligation as laid down in § 95 Para. 2 SGB IX. Consequently, appropriate penalties must be introduced for these cases.

The **WfbM committees** [*Werkstatträte*] represent the interests of WfbM employees. These committees can only partly assume their responsibilities, since they do not have equal decision and participation rights as compared with other employee and staff councils.

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<sup>306</sup> Survey in vocational education and advancement institutions about the situation of women and girls with disabilities: Teilprojekt aus dem Projekt "Bundesorganisationsstelle behinderte Frauen", Hermes, Gisela; Deutschland / Bundesministerium für Familie, Senioren, Frauen und Jugend (ed.), Berlin, 2001.

<sup>307</sup> § 96 Para. 4 SGB IX stipulates that representatives are only released from their other duties if they work in a company that employs at least 200 severely disabled employees. The same applies to the deputy representative if at least 100 severely disabled persons are employed in the company.

With regard to the labor market the BRK-Allianz calls for the following actions:

- Stronger incentives must be put in place so that companies will fulfil their legal employment obligations. This could, for example, be achieved through higher compensation levies.
- In order to help disabled persons who hardly stand a chance at finding regular employment, it is necessary to reintroduce a labor market policy tool that allows for the long-term promotion of state-funded, standard-wage jobs.
- Adequate measures should be introduced in order to improve the situation of disabled women with regard to gainful employment. For example, the share of disabled girls and young women in vocational training should be considerably increased.
- The right to freely choose between work in a WfbM and employment in a company (with the necessary support) must be legally established for persons with disabilities who cannot participate in the regular labor market. Moreover, individuals must have the right to return to a WfbM, without having to face bureaucratic challenges.
- Benefits that are currently provided in WfbM (according to § 39 SGB IX) must not depend on an individual's affiliation with a WfbM. They must also be allocated in the form of a Personal Budget outside of the WfbM if desired.
- The workplaces decree [*Arbeitsstättenverordnung*] must contain a binding stipulation requiring workplaces to be accessible, regardless of whether the company is already employing persons with disabilities. The same applies to internet, intranet and IT provisions for persons with sensory impairments. Persons with disabilities must have an entitlement, which can be legally enforced, to full cover of costs that accrue from the accessible design and equipment of a workplace.
- The visual display units decree must provide for a more comprehensive consideration of the ergonomic needs of persons with physical or sensory impairments.
- Counseling for setting up businesses must be accessible and competent with regard to the needs of persons with disabilities. Workplace equipment and facilities must be provided for disabled persons who set up a business.

With regard to the transition from school to professional life, vocational guidance, vocational education and vocational training the BRK-Allianz calls for the following actions:

- There must be a systematic and comprehensive compilation and analysis of data with regard to young persons in need of special pedagogical advancement measures, and in the process of transitioning from school or external vocational training to an occupation.
- With regard to the transition from school to working life, it is mandatory to clearly define and allocate responsibilities among the ministries (labor, social affairs, youth, school) and the governmental bodies (Federal Government, Länder and municipalities), and to ensure their cooperation.
- The different regional, and time-limited pilot projects aimed at supporting the transition from school to professional life must be combined to form a nationwide, high quality advancement system established by law.
- It is imperative to provide timely (starting with grade 7), full-scale, continuous and individual support and guidance for young people with disabilities, until their labor market participation is secure (vocational guidance process).
- The skills analyses, assessments and expert reports initiated by the various players and institutions in this field must be brought together and properly aggregated when it comes to planning an individual's future working life.

- The percentage of persons with disabilities who work in general vocational education and in vocational training must be increased. Employers must be put under the obligation to train a larger number of persons with disabilities.
- The range of potential occupations to choose from must be expanded, especially for young women with disabilities. Their potential choices must include a diversity of professions that are not based on gender stereotypes, and that offer a promising future.

With regard to counseling, placement and guidance the BRK-Allianz calls for the following actions:

- It must be ensured that employment agencies and job centers provide counseling, placement and guidance aimed at participation that is both timely and accessible. For this reason, job centers all across the country must establish, maintain and equip special contact points for severely disabled persons.
- Persons with disabilities must have the opportunity to test their load tolerance under variable conditions alongside their other activities.

With regard to vocational education and participation in professional life for persons with extensive support needs the BRK-Allianz calls for the following actions:

- It is essential to ensure the right to participation for all persons with disabilities, regardless of the type and severity of their disability. On this issue, the distinction between disabled persons as either “capacitated for a WfbM” or “incapacitated for a WfbM” (based on a “minimum amount of economically productive work output” according to § 136 SGB IX) must be abolished. In the opinion of the BRK-Allianz, according to § 27 CRPD, the right to participation in working life is indivisible, and therefore cannot be withheld from persons with severe disabilities. However, some associations within the BRK-Allianz hold the opinion that the granting of this right must not necessarily be tied to the institution of “WfbMs”.

With regard to further qualification and professional advancement the BRK-Allianz calls for the following actions:

- In addition to vocational training, the Federal Employment Agency and the other occupational rehabilitation agencies must also include university studies as a viable option for professional rehabilitation for persons with disabilities.
- Any additional costs that accrue during further qualification measures and that result from a disability must be taken into account, and the necessary specific support systems must be set in place.
- Further education measures must be accessible, and all target groups for qualification measures must be involved.

With regard to vocational rehabilitation/reintegration the BRK-Allianz calls for the following actions:

- Access to vocational rehabilitation measures must be facilitated, in particular for women, older persons and persons managed by the job centers (SGB II).
- A separate, needs-based financial budget for rehabilitation purposes must be established in the job centers.

- It must become imperative that the job centers prioritize the comprehensive assessment of the need for rehabilitation in order to avoid hasty references to simple, short-term job opportunities that offer few professional prospects or quality guidance.
- Expert knowledge on rehabilitation must be established in job centers and other institutions that are based on SGB II.
- Professional rehabilitation programs must be accessible, and they must cater to the specific needs of the different groups of persons with disabilities.
- Business companies must expand their internal integration measures in order to enable persons with disabilities to participate.

With regard to the representation of interests the BRK-Allianz calls for the following actions:

- The rights of the SBV and the WfbM committees must be expanded and strengthened. In order to achieve this, it is urgently necessary to review SGB IX and the corresponding decrees.

## Article 28 – Adequate standard of living and social protection

Just like in other countries, in Germany a disability often leads to poverty<sup>308</sup> and discrimination, and is aggravated by the limited opportunities to enjoy equal participation or to obtain an equitable education standard. Regarding the distribution of **net household incomes**, it is apparent that households with disabled persons are more likely to be found in low-income groups than households of non-disabled persons. For example, one third of all disabled persons between the ages of 25 and 45 who live alone have a net monthly household income below 700 EUR, while the percentage of these households among non-disabled persons amounts to only 19%.<sup>309</sup> In contrast to this, the average net monthly income was 2,706 EUR in 2009.<sup>310</sup> Women with disabilities are more frequently exposed to poverty than men with disabilities: according to the 2005 micro-census, 32.4% of all disabled women had a monthly net income below 700 EUR, while this was the case for only 12.8% of all disabled men.<sup>311</sup>

There are numerous reasons for the high **poverty rate** among persons with disabilities:

The education opportunities for persons with disabilities, and particularly the vocational qualifications that they acquire, are clearly substandard when compared with persons without a disability. Out of over 400,000 children with disabilities in special needs schools in Germany, more than 75% leave school without acquiring a recognized diploma, and a mere

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<sup>308</sup> According to the monetary (relative) notion of poverty that the EU member states agreed upon, and which represents the referential basis for the poverty and wealth reports by the Federal Government, a person is poor if s/he has less than 60% of the average net income of the population at their disposal.

<sup>309</sup> Lebenslagen in Deutschland – Dritter Armuts- und Reichtumsbericht der Bundesregierung. Chapter X.4., p. 162.

<sup>310</sup> [Rheinisch-Westfälisches Institut für Wirtschaftsforschung: Zur Einkommenssituation der privaten Haushalte in Deutschland.](#)

<sup>311</sup> See Statistisches Bundesamt, Wirtschaft und Statistik 2/2007, p. 199.

0.2% obtain the high school diploma [*Abitur*] that allows them to attend universities or universities of applied sciences<sup>312</sup> (see explications on Art. 24 CRPD).

Also, persons with disabilities participate much less in professional and working life than persons without disabilities, and they have lower incomes.<sup>313</sup> The employment rate among persons with disabilities is as low as 37%, which is far below the general employment rate of 76%. In addition to this, the unemployment rate among persons with disabilities is higher than the average (see explications on Art. 27 CRPD).

Moreover, persons with disabilities usually have higher living expenses that are, for example, caused by their need for a larger living space or additional payments for medication and aids. Accessible residential space is moreover rare in the municipalities, and rental costs are above average. While in the State report, the Federal Government points to possible subsidies for the construction of accessible housing, these subsidies only cover parts of the expenses, and are based on the assumption that those who make use of the subsidies can also provide their own capital. However, this is often not the case for persons with disabilities.

99.5% of all children under the age of 15 who are in need of care<sup>314</sup> are cared for at home, due to the lack of supervision, education, advancement, and care options. The child care network [*Kinderpflegenetzwerk*] found out that in 47% of the interviewed families one family member needed to entirely give up her/his gainful employment in order to care for the child, and 17% needed to decrease their weekly working hours by more than 50%.<sup>315</sup> As a result, childcare entails a poverty risk for entire families. The social and political assumption in Germany is that a child is a "family affair", regardless of whether s/he has a disability or not.

Also, **gainful employment** does not guarantee an adequate standard of living for persons with disabilities in Germany. This results from their low incomes, as well as from the fact that services provided for social participation, such as personal assistance, depend on a person's income and assets and are means-tested. Hence, any income and assets provided by persons with disabilities or their spouses or partners (or by their parents, if they are unmarried minors)<sup>316</sup> that exceed a certain limit defined by law, are counted against the social welfare payments, thus reducing the amount of such payments.

Non-existent or insufficient earned income, as well as participation services that are based on income and assets, also prevent equitable pension planning, and result in more **poverty among older persons with disabilities**, as most of them are only entitled to minimal benefits from the statutory pension insurance scheme. While private, state-subsidized pension plans are thought to enable individuals to augment their pension benefits, these are not an option for low-income earners, because these earners do not have the financial means to make use of this opportunity. Unfortunately, the Federal Government ignores this fact when they refer to this option in their State report rather abstractly. Moreover, both statutory and private

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<sup>312</sup> Nationaler Bildungsbericht "Bildung in Deutschland 2008" im Auftrag der Kultusministerkonferenz, Tab. D 7-5A.

<sup>313</sup> [Lebenslagen in Deutschland – Dritter Armuts- und Reichtumsbericht, Kapitel X.4.](#)

<sup>314</sup> Pflegestatistik Bund 2009; BKK Faktenspiegel 2010.

<sup>315</sup> Survey of the Kinderpflegenetzwerk 2011(<http://www.kinderpflegenetzwerk.de/umfrage-zu-vereinbarkeit-von-beruf-und-pflege-des-kindes/>).

<sup>316</sup> See § 19, Para. 3 SGB in combination with § 85, Para. 1 SGB XII (use of income); § 90, Para. 1 SGB XII (use of assets).

pensions can only be utilized once a person has reached the retirement age, which means that these pensions are useless for persons whose lifelong accrued working time is shorter than the average because of their disability.

Regarding pension schemes, the Federal Government emphasizes in the State report that disabled persons who are fully incapacitated for gainful employment may obtain a **reduced earning capacity pension** [*Erwerbsminderungsrente*] from the statutory pension insurance, regardless of their age. However, they do not mention the fact that the reduced earning capacity pensions offered between 2000 and 2009 decreased dramatically: for men, they sank from 817 EUR to 767 EUR, and for women, from 629 to 611 EUR.<sup>317</sup> This is partly caused by considerable deductions (up to 10.8%) to the disadvantage of those persons concerned who take their reduced earning capacity pension before they are 63 years old. Reduced earning capacity is increasingly putting persons at risk of poverty in Germany.

Persons with disabilities receiving **social welfare benefits as means of subsistence** face severe obstacles. Guidelines often restrict needed additional living space to an extra 10 sq.m. Regarding rent benefits, the level of “appropriate” rent (i.e., what the welfare agency is prepared to pay for) is often much too low. Persons with disabilities living in full in-patient residential facilities are allocated a monthly allowance as low as 103.14 EUR (as of January 1<sup>st</sup>, 2013). This is justified by the fact that subsistence is fully covered by the institution.<sup>318</sup> In 2010, persons with disabilities who worked in a WfbM only earned a very low average monthly income of 180 EUR<sup>319</sup>, and they were allowed to keep a mere 46.75 EUR for themselves, plus 25% of their WfbM earnings that exceed this average remuneration sum.<sup>320</sup>

If the income of persons with disabilities, and especially of those persons who work in a regular occupation, exceeds certain income limits<sup>321</sup>, it results in cutbacks for claims for participation services. Consequently, the persons concerned must contribute to the costs (via an **income deduction** [*Einkommensanrechnung*]). Hence, a person with a disability who is in need of intense care (care level [*Pflegestufe*] 3) must use 40% of her/his income that exceeds the official income level as a personal contribution for out-patient care costs.<sup>322</sup> If the person concerned is married or living in a civil partnership, the personal contribution is calculated on the basis of the dual income. In many cases, individuals on a lower care level must even use their entire income that falls above the defined income limit. De facto, this means that a person with a disability on care level 3 who earns an average net income<sup>323</sup>, must use 543 EUR per month to pay for care out of her/his own pocket (calculated on the basis of a total rent of EUR 600/month, not including expenses). As a result, s/he has 543 EUR less at her/his disposal per month than a non-disabled person.<sup>324</sup> In their State report,

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<sup>317</sup> Fünf-Punkte-Plan des SoVD zur Verbesserung des Erwerbsminderungsschutzes. Forderungen und Vorschläge des SoVD zur Verhinderung von Armut durch Erwerbsminderung, 2010.

<sup>318</sup> Necessary subsistence in institutions according to § 27b SGB XII.

<sup>319</sup> Source: <http://www.bagwfbm.de/page/101>.

<sup>320</sup> Income of WfbM employees according to § 82, Para. 3(2) SGB XII.

<sup>321</sup> This income limit corresponds to twice the standard subsistence level 1 [*Regelbedarfsstufe*], i.e. 374 EUR (in 2012), plus adequate housing costs. For spouses or partners as well as for other persons who are essentially dependent, an additional family allowance [*Familienzuschlag*] that corresponds to 70% of the standard subsistence level, i.e. 262 EUR, is taken into account. (§ 85 SGB XII).

<sup>322</sup> See § 87 SGB XII and the corresponding implementation provisions in the Länder.

<sup>323</sup> In 2009, the average monthly net income per household was EUR 2,706. Source: Rheinisch-Westfälisches Institut für Wirtschaftsforschung. Zur Einkommenssituation der privaten Haushalte in Deutschland. Endbericht April 2009.

<sup>324</sup> Calculation: According to § 85 SGB XII, the income limit is set at EUR 1,348 (i.e. twice the standard subsistence requirement level 1 of EUR 748, plus a total rent of EUR 600, not including expenses).

the Federal Government ignores this problem, and only briefly points to the fact that care and integration services depend on income and assets.

Not only are participation services for persons with disabilities **dependent upon assets**, but this regulation also permits persons with disabilities to own a mere 2,600 EUR in “assets”. Spouses or partners are entitled to an additional 614 EUR in assets. However, these assets can only be earned by a “reasonable income”, which is already diminished by personal contributions that must be paid. In these circumstances, it is impossible to save for a private pension fund.

In January 2011, the Government introduced the new “standard subsistence level 3” [*Regelbedarfsstufe 3*]. Persons older than 25 years old and incapacitated for work, and who live in a shared household with their parents, now receive a **basic benefit**<sup>325</sup> [*Grundsicherung*] that amounts to 75 EUR less than for individuals of the same age and in the same living situation but who are capacitated for work. This regulation comes at a disadvantage for persons with disabilities.

Due to these numerous disadvantages brought about by legal regulations, persons with disabilities are subjected to long-term limitations when it comes to their economic development opportunities, and they are virtually forced to remain on a low economic level. A proper and acceptable evaluation of a “reasonable standard of living”, and its contextualization in a person’s specific living situation (for example, regarding their vocational training and position on the labor market), does not take place. These limitations are in contradiction to Art. 28, Para. 1 UN CRPD, which places the States parties under the obligation to ensure a continuous improvement of the living situations of disabled persons. In addition, this represents a site of discrimination according to Art. 4, Para. 2 CRPD.

#### **The BRK-Allianz calls for the following actions:**

- **In order to prevent poverty caused by disabilities, participation services for disabled persons must be granted by means of a separate social services law [*Leistungsgesetz*], detached from social welfare. Also, these services must be granted independently from income and assets.**
- **It is mandatory to define specific participation needs, and to recognize them in terms of social services laws. This concerns, for example, living space for assistants, same-sex care, and needs resulting from disabilities.**
- **Regarding basic benefits, the subsistence standards [*Regelsätze*] must be calculated in a way that they actually cover the socio-cultural minimum subsistence level. The level of the rent costs must be calculated so that those persons in need of additional living space due to their disability are also able to afford adequate, accessible housing.**
- **Regarding basic benefits, persons above the age of 25 who are fully incapacitated for work and who live with their parents must be treated as equal to persons who are capacitated for work.**
- **The statutory pension insurance scheme must be strengthened on behalf of persons with disabilities. In order to counteract poverty among elderly persons with disabilities, it is**

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When considering the net income of EUR 2,706, the surplus sum of 1,358 will be taken as the basis for the calculation of the personal contribution to be paid. 40% of this sum, i.e. EUR 543, must be paid as personal contribution.

<sup>325</sup> See annex of § 28 SGB XII.

necessary to annul personal contribution requirements with regard to pensions for those incapacitated for work, since they are incompatible with the system. In addition to this, the periods of state subsidy to pension contributions [*Zurechnungszeiten*] must be extended by at least 3 years, until the persons concerned turn 64.

## Article 29 – Participation in political and public life

Due to the existing barriers, persons with all kinds of impairments frequently cannot participate in political and public life when these impairments are not adequately compensated for. For example, persons with impairments often cannot participate in volunteer work, due to the costs that accrue for necessary technical or personal assistance needed because of their disability.

Not only is it difficult for persons with disabilities to take part in independent regional governing processes [*kommunale Selbstverwaltung*], but likewise, they face specific problems when it comes to their **exercising their active and passive electoral rights**. According to § 13, Para. 2 of the federal election law [*Bundeswahlgesetz/BWG*], in Germany persons are denied their active and passive electoral rights if a legal guardian was appointed to permanently take care of *all matters*. According to the second half-sentence of this law, this also applies when the guardian's field of responsibilities does not include the duties of monitoring postal and telephone communication (see § 1896 BGB) and sterilization (see § 1905 BGB), which require additional court ordinances within the context of the guardianship law. Because of identical provisions in the relevant laws, the exclusion from electoral rights also applies to European, Länder and regional elections.

This **general exclusion from electoral rights** is arbitrary, as there is no factual relation between the issuing of a legal guardianship ordinance and electoral rights. The legal guardianship issuing process does not include an assessment of the individual's capacity to participate in elections. Sometimes, courts issue ordinances for legal guardianship *regarding all matters*, in order to simplify the transfer of comprehensive legal care to the individual's relatives. However, it is at the very least doubtful whether "complete guardianship" [*Totalbetreuung*] is lawful at all. In many cases, the persons concerned are neither aware, nor do they agree with the fact that they will automatically be denied their electoral rights.

Moreover, sometimes individuals are wrongfully **removed from electoral registers** by the electoral offices in charge, because guardianship courts notify them about legal guardianships that are de facto limited to certain responsibilities, but nevertheless incorrectly described as "complete guardianship". German legal statistics do not include any information about the number of persons affected by the problem of presumed "complete guardianship" that results in them being denied their electoral rights.

The European Court of Human Rights (ECHR) handed down a ruling on May 20, 2010<sup>326</sup> to the effect that indiscriminately denying persons their electoral rights is a violation of Art. 3 of the first additional protocol to the European Human Rights Convention. In these cases, the withdrawal of electoral rights is solely based on a partial legal guardianship that is justified by an intellectual or mental disability, without a lawful and individual assessment of the person concerned.

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<sup>326</sup> Kiss./Ungarn, Application No. 38832/06.



In contrast to the opinion of the Federal Government (see Deutscher Bundestag, Plenarprotokoll, October 19, 2011, p. 15637), the defining feature of "complete guardianship" that serves to deny individuals their electoral rights is not adequate. In fact, it contradicts the principle of equal participation in political life, because all those persons in Germany who are not affected by "complete guardianship" will not be exposed to the withdrawal of their electoral rights. Likewise, persons who appoint a guardian by means of a preventive authorization [*Vorsorgevollmacht*], to represent them when they are in need of support at some moment in the future, will not be denied their electoral rights.

In addition to this, individuals who committed a crime while they were in a state of diminished responsibility, and who are institutionalized in a psychiatric hospital, are denied their electoral rights (§ 13, Para. 3 BWG). This general withdrawal of electoral rights from persons with mental disabilities is discriminatory, since non-disabled offenders usually retain their right to vote.

With the denial of electoral rights according to § 13 Para. 2 and 3 BWG, Germany violates current international law obligations. On March 20, 2012, the UN Human Rights Council published their resolution, "Rights of persons with disabilities: Participation in political and public life".<sup>327</sup> In this resolution, they substantiated the right to participate in political and public life that was established in Art. 21 of the Universal Declaration of Human Rights, in Art. 25 of the UN Civil Pact and in Art. 29 CRPD. The Council determined that the withdrawal or limitation of the political rights of persons with disabilities on the basis of their disability is an act of discrimination, and is in contradiction to the CRPD.<sup>328</sup> Germany expressed their explicit consent to this UN Human Rights Council resolution.

Likewise, regarding the **exercise of active electoral rights**, persons with disabilities encounter many kinds of barriers.<sup>329</sup> These include non-accessible election programs, non-accessible websites of political parties, non-existent written language and Sign Language interpretation at electoral debates and rallies, non-accessible TV election spots, non-accessible polling places, non-existent election templates, non-accessible ballots (font size, contrasts), unclear funding regulations with regard to necessary assistance services, and so on.

As stated in Art. 29b, the States parties placed themselves under the obligation to proactively promote the creation of circumstances that ensure the **political self-representation** of persons with disabilities. The European Council's recommendation from November 2011 regarding the participation of persons with disabilities in political and public life<sup>330</sup> is in accordance with this obligation. Likewise, in the survey compiled by the High

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<sup>327</sup> Human Rights Council, Resolution A/HRC/19/L9/Rev. 1, March 20, 2012: Rights of Persons with disabilities: Participation in political and public life; accessible online at [www.ohchr.org](http://www.ohchr.org).

<sup>328</sup> "(the) exclusion or restriction of political rights of persons with disabilities on the basis of disability constitutes discrimination contrary to the Convention on the Rights of Persons with Disabilities".

<sup>329</sup> Deutsches Institut für Menschenrechte, erstellt von Leander Palleit: Gleiches Wahlrecht für alle? Menschen mit Behinderungen und das Wahlrecht in Deutschland. Policy Paper Nr. 18, 2. Überarbeitete Auflage, 2011.

<sup>330</sup> Council of Europe: Recommendation CM/Rec(2011)14 of the Committee of Ministers to member states on the participation of persons with disabilities in political and public life, November 16, 2011. They state: "[The member states] should take appropriate capacity-building and financial measures with a view to making sure that organisations of persons with disabilities (DPOs) have the capacity to fully participate and contribute to the conduct of public affairs."

Commissioner for Human Rights<sup>331</sup> with regard to UN CRPD Art. 29 (December 2011), item 19 emphasizes the obligation of the States parties to promote the creation of self-representation organizations on the local, regional, national and international level.

Unfortunately, this is not happening in Germany. Self-representation organizations of persons with disabilities do not receive institutional support, but instead, they are allocated short-time project funds that usually serve other project purposes rather than political self-representation.

**The BRK-Allianz calls for the following actions:**

- **In order for persons with disabilities to be able to participate in political and public life, it is necessary to not only provide regulations on accessibility, but also on opportunities to claim assistance services and compensation for disadvantages.**
- **The general exclusion of persons with disabilities from their electoral rights according to § 13, Para. 2 and 3 BWG and the identical regulations in the laws pertaining to Länder and regional elections as well as to European elections must be deleted without substitution.**
- **The Federation and the Länder must take effective steps in order to enable persons with disabilities to exercise their electoral rights according to accessibility standards.**
- **In order to allow for persons with disabilities to exercise their participation rights as defined in the UN CRPD, their self-representation organizations must receive institutional support.**

## **Article 30 – Participation in cultural life, recreation, leisure and sport**

In culture, recreation, leisure and sport, insufficient accessibility is an essential cause for the limited participation of persons with disabilities (see our explications on Art. 21 regarding broadcast programs). Cultural events frequently take place in non-accessible spaces. In many cases, event organizers refer to safety reasons in order to justify the exclusion of persons with disabilities.

**Museums and exhibitions** are largely inaccessible to persons with disabilities, and especially to persons with sensory disabilities and learning difficulties. This is particularly true for the contents and topics of exhibitions, rather than the spatial layout.<sup>332</sup>

When going to a **movie theater**, guests with disabilities frequently encounter various barriers. Due to stairs or non-existent elevators, guests in wheelchairs cannot access the screening rooms. Hearing impaired visitors encounter a lack of subtitles and induction loops, and the same is true for audio-descriptions for blind or visually impaired guests.<sup>333</sup>

The Federal Republic of Germany participates in the preservation of **World Cultural Heritage sites**, but on-site information is frequently not accessible. Likewise, these places include architectural barriers such as non-existent banisters and markings on stair edges, and many more.

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<sup>331</sup> Thematic study by the Office of the United Nations High Commissioner for Human Rights on participation in political and public life by persons with disabilities (A/HRC/19/36).

<sup>332</sup> [http://www.barrierefreiheit.de/barrierefreie\\_museen.html](http://www.barrierefreiheit.de/barrierefreie_museen.html).

<sup>333</sup>

<http://www.islev.de/attachments/article/680/Dossier%20Handlungsfelder%20barrierefreier%20Kino%20gestaltung.pdf>.

Only a small percentage of all **books** are published in a format that is accessible to blind persons. The situation is aggravated by the fact that copyright problems make it impossible for people to exchange accessible books across borders. This problem was named the "book famine". Up until this day, the Federal Government refuses to sign the WIPO Treaty for Improved Access to published works for Blind, Visually Impaired and other Reading Disabled Persons.<sup>334</sup>

In **sport** as well, inclusive options are very rare. In addition to this, the participants of the Paralympic games find fault with the fact that they receive considerably less prize money than the non-disabled Olympic athletes. The federal antidiscrimination office also finds this unequal treatment alarming.<sup>335</sup>

Adequate promotion and strengthening measures for Plain Language, German Sign Language, and the linguistic and cultural identity of the persons concerned are virtually non-existent.

#### **The BRK-Allianz calls for the following actions:**

- **Private legal entities that provide cultural events and programs or recreational and leisure facilities for the general public must be placed under the legal obligation to ensure accessibility.**
- **Safety regulations must be modified so that they do not result in the exclusion of persons with disabilities.**
- **Treaties regarding the preservation of the World Cultural Heritage should include stipulations on the accessible design of the visitor sites.**
- **The Federal Government must sign the so-called World Blind Treaty in order to eliminate the "book famine". For the same reason, school and other education materials must not be approved for use in education facilities unless they are adapted to fulfil accessibility requirements. .**
- **Inclusive sport programs must be promoted. The achievements of athletes with disabilities must be given the same recognition as the achievements of their non-disabled colleagues.**
- **The linguistic and cultural identity of persons with disabilities must be promoted.**

### **Article 31 – Statistics and data collection**

The statistical methods that are currently used in Germany are inadequate for "formulating and implementing policies to give effect to this Convention" (Art. 31 CRPD) to a satisfactory degree. On this basis, it is hardly possible to make any statements with regard to planning for better participation and inclusive social spaces. Moreover, the accessibility that Art. 31 requires regarding the access to information is incomplete in different ways. Not one single state or private institution has the relevant statistical information available. It remains entirely uncertain when such key data will be collected in a systematic way.

In Germany, § 131 of the social code IX (SGB IX) regarding statistics, and the 2005 micro-census law<sup>336</sup> provide the basis for any statistical research on persons with disabilities.

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<sup>334</sup> [www.buechernot.dbsv.org](http://www.buechernot.dbsv.org).

<sup>335</sup> [http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30123/ticket,g\\_a\\_s\\_t](http://www.kobinet-nachrichten.org/cipp/kobinet/custom/pub/content,lang,1/oid,30123/ticket,g_a_s_t).

<sup>336</sup> Gesetz zur Durchführung einer Repräsentativstatistik über die Bevölkerung und den Arbeitsmarkt sowie die Wohnsituation der Haushalte – MZG 2005.

According to the **provisions on statistics** in § 131 SGB IX, data on "the number of severely disabled persons with a valid disability ID" is collected in combination with other individual characteristics such as "age, gender, citizenship and place of residence" as well as the "type, cause and degree of the disability". This is based on the medical notion of disability as is used in SGB IX with its 55 sub-categories, some of which are discriminatory, such as category 32 that lists "disfiguration, and irritating or repulsive secretions or smell". The responsible authorities collect these statistical data once every two years, but only on the basis of applications filed by persons with disabilities, for instance with service providers and other agencies. Data on multiple disabilities are not collected, and one can assume that the estimated number of undetected cases is high.

Starting in 2005, the **micro-census law** [*Mikrozensusgesetz*] has been regulating an annual representative survey conducted on the basis of a 1% sample out of all German households. Unfortunately, this disregards the approximately 172,000 individuals who live in in-patient facilities.<sup>337</sup> Once every four years, the micro-census survey includes two sets of questions pertaining to the degree of the disability, in the section "Health questions". Answering these questions is optional. Also, these questions are based on the medical notion of disability used in SGB IX.

For these reasons, it is necessary to conduct a fundamental review of the official statistics. Instead of being based on "deficits", they should be based on the notion of **participation**. In their State report, the Federal Government explained that they are planning to reconceptualize their disability report in an indicator-based form. However, at time of writing the present parallel report, no such newly conceptualized disability report had been published.<sup>338</sup> The BRK-Allianz appreciates that the report plans to use these indicators; however, the indicators must also be based on human rights.<sup>339</sup>

All federal statistics in Germany refer only to men and women. This excludes **intersex persons** and renders them "invisible". Hence, no reliable statistical data on intersex persons are available. Without regard to their genetic, chromosomal and hormonal condition, without their informed consent, and without basing decisions on medical evidence, many intersex people become severely disabled women due to mutilating operations. The associations of the individuals concerned estimate that this group consists of 80,000-120,000 persons in Germany. 85% of all intersex persons<sup>340</sup> become "females" after the gender "reassignment" procedure. They are entirely excluded from any expert medical treatment. Other UN commissions have already observed and criticized this problem.<sup>341</sup>

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<sup>337</sup> See Seifert, Monika: Behinderte Menschen mit komplexem Unterstützungsbedarf. Statement before the BMAS board from May 23, 2012: According to numbers from December 31, 2012, 171,970 persons live in full in-patient residential facilities.

<sup>338</sup> Status as of December 31, 2012. The disability report was announced for February 2013.

<sup>339</sup> See Hirschberg, Marianne: Menschenrechtsbasierte Datenerhebung – Schlüssel für eine gute Behindertenpolitik. Anforderungen aus Artikel 31 der UN-Behindertenrechtskonvention. Policy Paper der Monitoringstelle, Berlin, November 2012.

<sup>340</sup> Studie zu Lebenslagen intersexueller Menschen des Instituts für Sexualeforschung Hamburg (2008).

<sup>341</sup> CEDAW 2008, UN-Sozialpakt 2010, CAT 2011.

The BRK-Allianz calls for the following actions:

- The current statistical system must be reviewed and oriented around participation, so that it can allow for the development of measures for inclusive living on all levels of society.<sup>342</sup> Also, statistics must consider multiple disabilities.
- Human rights based indicators must be compiled in order to collect data on the living situations of persons with disabilities.
- It is necessary to conduct representative surveys about the living situations of persons with disabilities, following the example of the British Life Opportunities Survey (LOS).<sup>343</sup> Starting with the research design phase, these surveys must be guided by the professional skills of disabled experts, according to the principle of "participatory research".<sup>344</sup>
- Statistical systems must be changed in a way that enables intersex persons to become "visible", including those individuals who were made disabled through genital mutilation.

## Article 32 – International cooperation

When Germany ratified the UN CRPD, it placed itself under the obligation to include persons with disabilities in development programs, that is, to ensure inclusive development co-operation. This could be an opportunity for Germany to make an important contribution to poverty reduction and to the full and effective participation of all persons in development programs.

While some efforts were made in order to implement Art. 32 CRPD, Germany is a long way from a consistent and systematic **development policy**. Instead of understanding disabilities as a cross-cutting issue, such as the CRPD stipulates<sup>345</sup>, up until this day only isolated individual specific or inclusive programs and projects exist. An estimated 0.3% of all development measures are inclusive.<sup>346</sup> The model projects that are referred to in the State report are not representative examples of a systematic establishment of an inclusive development policy.<sup>347</sup>

The BRK-Allianz approves of the fact that persons with disabilities were included as a target group in some expert concepts and strategies compiled by the Federal Ministry for Economic Cooperation and Development [*Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung/BMZ*].<sup>348</sup> Unfortunately, up until this day the BMZ has failed to implement

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<sup>342</sup> See the demands of the German disability council [*Deutscher Behindertenrat/DBR*]: <http://www.deutscher-behindertenrat.de/mime/00064322D1302028715.pdf>.

<sup>343</sup> According to the suggestion of the national monitoring office [*Nationale Monitoringstelle*] dated March 16, 2012, see <http://www.esds.ac.uk/government/los/>.

<sup>344</sup> See [http://psych.wisc.edu/lang/pdf/Gernsbacher\\_ResearchParticipation.pdf](http://psych.wisc.edu/lang/pdf/Gernsbacher_ResearchParticipation.pdf) or <http://www.autismus-forschungs-kooperation.de/ueber-uns>.

<sup>345</sup> See CRPD guidelines (CRPD/C/2/3 E.§32.4).

<sup>346</sup> According to the 2012 progress report of the GIZ sector initiative "Persons with Disabilities", the BMZ conducted ten inclusive development projects over the course of the last 3 years, while the overall number of BMZ projects amounted to 3,000 in the same time period.

<sup>347</sup> In fact, these are just a few measures, some of which had a test-trial status, or were already completed and not continued. Binding regulations or guidelines for a consistent establishment of inclusion remain non-existent.

<sup>348</sup> Inclusion of persons with disabilities in strategy papers, such as the program "Human Rights in German Development Policy", the Sector Strategy on Social Protection), the Sector Strategy: German Development Policy in the Health Sector), the policy statement "Disability and Development, and the 2008-2010 Human Rights in German Development Policy.

keywords such as "inclusion", "empowerment" or "accessibility" that they use in these papers.

One of the reasons for the slow implementation of this inclusive **development co-operation** that the Government says they are intending are the insufficient financial and human resources provided by the BMZ for this issue.<sup>349</sup> In addition to this, the majority of BMZ directorates and implementing organizations do not (yet) consider themselves responsible for the cross-cutting issue of "disability". The responsibility must be distributed across all of the directorates. Another problem is the lack of expertise regarding the question of how the concerns of persons with disabilities can be considered in practical implementation. Many employees of the BMZ and its implementing organizations also do not know that Germany committed itself to inclusive development co-operation when it signed the CRPD.<sup>350</sup>

Even though **accessibility** is a fundamental principle of the UN Convention, up until this day there are no mechanisms to ensure that apart from a few exceptions the development measures conducted with German funds are accessible. A consistent implementation of the principle of accessible design with regards to the spatial, communication and information infrastructure remains non-existent today.<sup>351</sup>

In order to allow for the consistent inclusion of persons with disabilities, measures and programs would have to be systematically researched, monitored and evaluated.<sup>352</sup> However, up until today German development policy does not include any systematic **data** collection regarding the number and range of projects and programs that are inclusive towards persons with disabilities. There is some information regarding planned projects that are exclusively targeting persons with disabilities, but even these do not include a consistent collection of data sets. Hence, it is impossible to monitor and evaluate the degree to which German development policy is inclusive.

In 2013, the BMZ will compile its own Action Plan regarding implementation of the CRPD. This will be an important step towards an inclusive development policy. The BRK-Allianz acclaims that this plan is likely to include some very concrete measures, and to involve different directorates and Länder desks. Moreover, these bodies followed the civil society's suggestion to include a section about the monitoring of the Action Plan. However, just like the Action Plan compiled by the Federal Ministry of Labour and Social Affairs [*Bundesministerium für Arbeit und Soziales/BMAS*], and in contradiction to the recommendations issued by the UN High Commissioner for Human Rights<sup>353</sup>, the BMZ Action Plan will most likely not provide for true liability and verifiability. An analysis of the current

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<sup>349</sup> The GIZ Sector Strategy, "Persons with Disabilities", is a lead example of the CRPD implementation within the German development policy. With only 3.5 employee positions and a budget of 1.5 million EUR for the period of 2010-2012, its complex task consists of undertaking an inclusive design of German development co-operation. The BMZ includes one single half-time position that is in charge of all questions regarding disabilities.

<sup>350</sup> This is also a result from non-existing binding provisions that would provide for a systematic establishment of inclusion.

<sup>351</sup> This applies to all types of German development co-operation: bilateral and multilateral co-operation as well as co-funding of development projects by NGOs and church-based relief organizations.

<sup>352</sup> See CRPD guidelines (CRPD/C/2/3 E. §32.2, §32.3, §32.6, §32.9). An effective monitoring mechanism should be mandatory for programs by the BMZ and its implementing organizations; as well as for co-funded projects by private donors.

<sup>353</sup> Office of the UN High Commissioner for Human Rights, Handbook on National Human Rights Plans of Action, UN New York and Geneva, 2002, p. 72 et seq.

situation, transparency with regard to responsibilities, information regarding the budget, as well as clear criteria for monitoring quality and results and stipulations about the further development of this plan will most likely remain absent. In view of these deficiencies, it remains yet to be seen if the Action Plan will be made a necessary priority, and if the entire Ministry will proactively be involved in its plan implementation.

On the international level, the **Millennium Development Goals (MDGs)** are part of a global development agenda and a key tool in the fight against poverty. Persons with disabilities represent a disproportionately large share of the poor population, and cannot be ignored when it comes to poverty reduction measures.<sup>354,355</sup> Regardless, until this day the German development policy has failed to include persons with disabilities in their policies and programs in the context of the MDGs.<sup>356</sup>

**The BRK-Allianz calls for the following actions:**

- **The new BMZ Action Plan for the implementation of the UN CPRD must be legally binding, realistic, and monitorable. This requires the introduction of a "trademark" for inclusive projects, in order to be able to assess their share in the overall budget.**
- **A sufficient and dense network of financial and human resources must be provided so that inclusive development can be firmly, sustainably and consistently established and implemented in German development co-operation.**
- **The database for inclusive development must be expanded, and indicators and criteria for inclusive programs and projects must be compiled.**
- **Inclusion as an integral element of international development strategies, such as the MDGs and the post-2015 agenda, must be promoted.**
- **International activities of ministries must be coordinated across directorates, and designed in an inclusive way.**
- **A better participation of persons with disabilities in the design, development, and evaluation of programs and projects must be ensured.**<sup>357</sup>

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<sup>354</sup> Likewise, the CRPD guidelines and the UN General Assembly emphasize this (see CRPD/C/2/3 E. §32.2; UNGA A/RES/65/186). For more information on inclusive MDGs, see [http://www.cbm.de/static/medien/CBM\\_Positionspapier\\_post-2015.pdf](http://www.cbm.de/static/medien/CBM_Positionspapier_post-2015.pdf).

<sup>355</sup> Even the former World Bank president, James Wolfensohn, stated that it will be impossible to cut poverty in half by 2015 if persons with disabilities are not considered.

<sup>356</sup> In contradiction to the CRPD guidelines, the German State report on the implementation of the CRPD disregards the issue of MDGs. Neither any programs for the MDG implementations nor any debates about a 2015 follow-up strategy to the MDG include any up-to-date German strategies aimed at the inclusion of persons with disabilities.

<sup>357</sup> This applies both to self-representation organizations in developing countries and to self-representation associations and NGOs in Germany.

## **Annex: List of organizations that participate in the BRK-Allianz**

### **A**

AKTION PSYCHISCH KRANKE e. V.  
Allgemeiner Behindertenverband in Deutschland e. V. – ABiD  
ALzheimer ETHik e. V. – ALZETH  
Arbeiterwohlfahrt e. V. – AWO  
Aspies e. V.  
autismus Deutschland e. V.

### **B**

Bundesarbeitsgemeinschaft Behinderung und Studium e. V.  
Behinderung und Entwicklungszusammenarbeit e. V. – bezev  
Bundesarbeitsgemeinschaft der Berufsbildungswerke – BAG BBW e. V.  
Bundesarbeitsgemeinschaft der Taubblinden – BAT e. V.  
Bundesarbeitsgemeinschaft für Unterstützte Beschäftigung – BAG UB e. V.  
Bundesarbeitsgemeinschaft Gemeindepsychiatrischer Verbände – BAG GPV e. V.  
Bundesarbeitsgemeinschaft Gemeinsam leben – Gemeinsam lernen e. V.  
Bundesarbeitsgemeinschaft Selbsthilfe – BAG SELBSTHILFE e. V.  
BundesElternRat (BER)  
BundesElternVereinigung für anthroposophische Heilpädagogik und Sozialtherapie e. V.  
Bundesverband behinderter und chronisch kranker Eltern – bbe e. V.  
BUNDESVERBAND DER BERUFSBETREUER/INNEN – BdB e. V.  
Bundesverband evangelische Behindertenhilfe – BeB e. V.  
Bundesverband Frauenberatungsstellen und Frauennotrufe – bff e. V.  
Bundesverband für Ergotherapeuten in Deutschland – BED e. V.  
Bundesverband für körper- und mehrfachbehinderte Menschen – bvkm e. V.  
Bundesverband Psychiatrie-Erfahrener – BPE e. V.  
Bundesverband Selbsthilfe Körperbehinderter – BSK e. V.  
Bundesvereinigung Lebenshilfe e. V. Bundesvereinigung der Landesarbeitsgemeinschaften der Werkstattträger – BVWR e. V.  
Büro zur Umsetzung von Gleichbehandlung – BUG e. V.

### **C**

Caritas Behindertenhilfe und Psychiatrie – CBP e. V.  
Christoffel-Blindenmission Deutschland – cbm e. V.

### **D**

Dachverband Gemeindepsychiatrie e. V.  
Der Paritätische – Gesamtverband e. V. – DPW  
Deutsche Alzheimer Gesellschaft e. V.  
Deutsche Gesellschaft der Hörgeschädigten – Selbsthilfe und Fachverbände e.V.  
Deutsche Gesellschaft für Soziale Psychiatrie e. V. -DGSP c/o Unionhilfswerk Regionalleitung  
Deutsche Rheuma-Liga Bundesverband e. V.  
Deutscher Blinden- und Sehbehindertenverband – DBSV e. V.  
Deutscher Gehörlosen-Bund e. V.  
Deutscher Gewerkschaftsbund – DGB  
Deutscher Schwerhörigenbund – DSB e. V.  
Deutscher Verein der Blinden und Sehbehinderten in Studium und Beruf – DVBS e. V.  
Deutsches Rotes Kreuz – DRK e. V.  
Deutsches Studentenwerk – DSW e. V.



Diakonie Deutschland – EWDE

## **E**

Eltern für Integration e. V.

Elternzentrum Berlin e. V.

Enthinderungsselbsthilfe von Autisten für Autisten – ESH

Bundesverband Forum selbstbestimmter Assistenz behinderter Menschen e. V. – ForseA

## **F**

Forum-Pflege-aktuell

## **G**

Gewerkschaft Erziehung und Wissenschaft (GEW) – Hauptvorstand

Grundschulverband e. V.

## **H**

Handicap Netzwerk – Freundeskreis Menschen mit Handicap e. V.

## **I**

Interessengemeinschaft Gehörloser jüdischer Abstammung in Deutschland – IGJAD e. V.

Interessenvertretung Selbstbestimmt Leben in Deutschland – ISL e. V.

Intersexuelle Menschen e. V. – Bundesverband

## **K**

Kreisverband der Gehörlosen Potsdam und Umgebung e. V.

Freie Kunst Akademie U7 gUG

## **L**

LAG GEMEINSAM LEBEN – GEMEINSAM LERNEN Niedersachsen e. V.

LAG Inklusion in Sachsen – LAGIS e. V.

Leben mit Usher-Syndrom e. V.

Lebensinsel e. V.

## **M**

Menschzuerst – Netzwerk People First Deutschland e. V.

mittendrin e. V.

MOBILE – Selbstbestimmtes Leben Behinderter e. V.

## **N**

NETZWERK ARTIKEL 3 – Verein für Menschenrechte und Gleichstellung Behinderter e. V.

Netzwerk behinderter Frauen Berlin e. V.

Netzwerk gegen Selektion durch Pränataldiagnostik

## **P**

PRO RETINA Deutschland e. V.

## **S**

Sozialverband Deutschland – SOVD e. V.

Sozialverband VdK Deutschland e. V.

Stiftung taubblind leben

**U**

unerhört e. V.

**V**

Verband Entwicklungspolitik Deutscher Nichtregierungsorganisationen – VENRO e. V.

Verbund behinderter ArbeitgeberInnen – VbA – Selbstbestimmt Leben e. V.

ver.di – Vereinte Dienstleistungsgewerkschaft

Verband für anthroposophische Heilpädagogik, Sozialtherapie und soziale Arbeit e. V.

**W**

Weibernetz e. V., Bundesnetzwerk von FrauenLesben und Mädchen mit  
Beeinträchtigung

**Z**

Zentrum für Flüchtlingshilfen und Migrationsdienste (zfm) unter der Trägerschaft des  
Behandlungszentrums für Folteropfer e. V. (bzfo)