



Enthinderung

**Alternative Report under the UN-CRPD  
for Germany  
of the Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) –  
ESH**

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Autism - without it the normality would be disordered

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*Abbreviations*

ABA	Applied Behavior Analysis / Verbal Behavior / Operant Conditioning (a kind of ill-treatment, actual the globally most used early intervention therapy for autistic children)
AGG	Allgemeines Gleichbehandlungsgesetz (The German General Act on equal treatment)
BGG	Behindertengleichstellungsgesetz (The German Disability Discrimination Act)
DBR	Deutscher Behindertenrat (The German Council for the Disabled)
ESH	Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (Autistic self-advocacy organization)
EU	Europäische Union (European Union)
GdB	Grad der Behinderung (Degree of Disability)
GdS	Grad der Schädigung (Degree of Damage)
IDA	Internationale Behindertenallianz (International Disability Alliance)
KBV	Kassenärztliche Bundesvereinigung (The National Association of Statutory Health Insurance Physicians)
PGD	Präimplantationsdiagnostik (Preimplantation Genetic Diagnosis)

## **Introduction**

1. The *Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige)* – ESH is pleased to present this alternative report<sup>1</sup> on the situation of autistics in Germany. As autistics are a particular section of the population, they frequently are not understood by non-autistic people. The result of which is that great injustice with dangerous consequences is done to autistics and often even not recognized as such. Most of the autism advocacy groups are led by parents and "experts" (i.e. scientists, therapists and other persons working with autistics in a therapeutic way). These groups are criticized strongly by autistics for their misunderstanding of autistic needs. Because of this they cannot fulfill the function of an autistic self advocacy movement, however, they are accepted as such by most government facilities. This leads to an explosive situation that is not compatible with the *Convention on the Rights of disabled Persons* (Convention) which has been ratified in the German speaking area by Germany and Austria.<sup>2</sup> In Switzerland the Convention is being discussed in parliament.<sup>3</sup> The Swiss authorities decided in 2013 to ratify the Convention.
2. The aim of this report is to provide a first insight into the factual dimension of the problems autistics are facing – as the whole extent of these problems is very complex and can only be understood on the basis of a profound understanding of autism which, however, cannot be assumed for most people.
3. As the ESH is excluded by most government facilities it was impossible for us to contribute to an official state report. It is for this reason that the ESH presents its own shadow report.

## **Preparation and structure of the report**

4. This report has been prepared in accordance with the IDA's *Guidance document on parallel reporting*.<sup>4</sup>

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<sup>1</sup> In revising this report for submission to the CRPD in 2014, the ESH was supported by Autistic Minority International. <<http://www.autisticminority.org/>>

<sup>2</sup> United Nations Treaty Collection. 15. *Convention on the Rights of Persons with Disabilities*. Web. 27 Feb. 2014. <[https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=iv-15&chapter=4&lang=en](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=iv-15&chapter=4&lang=en)>.

<sup>3</sup> "Abgeschlossene Vernehmlassungen." *Admin.ch - Startseite*. Web. 28 Apr. 2011. <<http://www.admin.ch/ch/d/gg/pc/ind2010.html>>.

<sup>4</sup> "Guidance Document on Parallel Reporting." *International Disability Alliance | Representing More than*

5. This supplementary report includes specific informations on the deplorable situation of autistics. As this report refers to Germany, it is impossible to cover all legal aspects of the country. Nevertheless, the situation of autistics is in both countries in its main aspects very similar because of which it is appropriate to cover these aspects in one report.
6. It has to be mentioned that Germany's state report<sup>5</sup> is from our point of view characterized by an excessively positive presentation of the situation of disabled persons in Germany. Furthermore, the report is marked by plattitudes which are, however, written down in official documents, but do often not correspond to the real situation of disabled people in Germany. It is not a question of monetary investments which are made by the German government but rather a question of a general lack of accessibility and the fact that accessibility can only be gained by a marathon of bureaucratic barriers which often are – at least for autistics – not accessible. It has to be pointed out that Germany is within the European Union – despite assertions of the contrary – holding back development and placing a lid on the whole of European disability policy.
7. As scientific research on autism is strongly biased there are little scientific studies on negative environmental conditions influencing autistic being. Therefore, it has not been possible to support all our positions with scientific proof. Most of our positions arose from our activities in lobbying and family support.

## Consultation with State and Territory Governments

8. It is a worldwide phenomenon that autistics and their pressure groups are excluded from most of the substantial decision-making processes. In Germany, the on a legal mandate acting *Deutscher Behindertenrat* (DBR) attracted the attention of the ESH as he refused any communication on – for autistics relevant – issues and did not come back to the ESH's writings concerning the deplorable situation of autistics in Germany.<sup>6</sup> The DBR informed

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650 Million People with Disabilities Worldwide. Web. 27 Feb 2014.

<<http://www.internationaldisabilityalliance.org/sites/disalliance.e-presentaciones.net/files/public/files/CRPD-reporting-guidance-document-English-FINAL-print%5B1%5D.pdf>>.

<sup>5</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

<sup>6</sup> "Aktive Ausgrenzung und Diskriminierung von Autisten durch Behindertenverbände am Beispiel

the ESH that the autistic's concerns are covered by the parent-based organization *Autismus Deutschland* within the DBR. As mentioned above, there is such a profound knowledge gap about the real interests and needs of autistics (and it is even questionable whether it is possible for non-autistic persons to understand the concerns of autistics in full depth) so that *Autismus Deutschland* cannot be regarded as an adequate representation of autistics.<sup>7</sup> In general, a collaboration with government facilities not specialized on issues concerning disability is easier for the ESH than a collaboration with disability facilities. Apparently, this is on the one hand because of prejudices against autistics in disability organizations and on the other hand because of a general lack of barrier-free written access by Fax, Email, etc. for autistics to the relevant committees.

### **Part A: Articles 1–4**

9. Autistics are not only misunderstood by their families, but also dehumanized by persons in the environment. Advices by "experts" which would rather be expected regarding animals are fairly usual<sup>8</sup>. Therefore, many types of "therapy" resemble more animal training.<sup>9</sup> These "therapies" are not only questionable from an ethical point of view but also potentially dangerous as autistics are trained to behaviors being definitively harmful for them and may lead to dissociation. An autistic person said about that: "During these settings my answers weren't my own, that was not me." Another autistic person states: "This adaptation costs me approximately 50 IQ points." This utterance is is not exaggerated; we think that many autistics being thought to be mentally retarded are only extremely wiped out because of extremely unsuitable circumstances they are living in. Already Bettelheim compared the consequences of these circumstances correctly with inmates of concentration camps,

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Deutscher Behindertenrat und VdK" *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/ausgrenzung\\_behindertenverbände\\_dbr\\_vdk](http://autisten.enthinderung.de/ausgrenzung_behindertenverbände_dbr_vdk)>.

<sup>7</sup> "Deutscher Behindertenrat: „Autismus Deutschland Vertritt Die Interessen Von Autistischen Menschen.“ *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/deutscher\\_behindertenrat\\_autismus\\_deutschland](http://autisten.enthinderung.de/deutscher_behindertenrat_autismus_deutschland)>.

<sup>8</sup> Temple, Grandin; Barron, Sean: *Unwritten Rules of Social Relationships; Decoding Social Mysteries Through the Unique Perspective of Autism*, ACT TWO, Page 92, Texas, 2005. Print.

<sup>9</sup> Dawson, Michelle. "The Misbehaviour of Behaviourists - Michelle Dawson." *Sentex Data Communications - Internet Service Provider*. Web. 28 Apr. 2011.

<[http://www.sentex.net/~nexus23/naa\\_aba.html](http://www.sentex.net/~nexus23/naa_aba.html)>; Schramm, Robert. "Die Sieben Schritte." Web. 28 Apr. 2011. <<http://knospe-aba.com/cms/de/infos-ueber-aba/artikel-ueber-aba/die-sieben-schritte.html>>.

however, he drew basically wrong conclusions.<sup>10</sup> Although obsession with own feces also has been noticed in inmates of Guantanamo, these reactions are often wrongly thought to be "autistic behaviors" which leads to the consequence that wrong conclusions about correct dealing with autistics are drawn: Among other things when defensive behaviors are thought to be usual autistic behavior nobody considers the possibility whether there exist for autistics hurtful things in their environment.

10. Some autistics are socially integrated, for instance, as qualified freelancers; in Germany, there are occasional psychotherapists, doctors, teachers and kindergarten teachers. Nevertheless, the social exclusion is immense – especially the continual institutionalization of autistic children which await a lifelong inhuman stay in facilities for disabled. Sometimes, families are even pressed to give their children in such facilities or the children are even taken away from their homes in order to get a „better“ treatment – as the *Jugendamt* sometimes suspects that autistic children are made by their parents „autistic“ (like Bettelheim considered it in the past (refrigerator mothers) what, however, turned out to be a very wrong conclusion). In Vienna, a family has lost their municipal apartment with the argument that their autistic son has been too noisy.<sup>11</sup> Such pressure exists in many variants in Germany, too. It is often in the style of an attrition policy put into the parent's minds that autistic lives are more comfortable in facilities for disabled which is, however, not even close correct. It is likely that before the spread of the diagnosis these autistic children would not have been put into these facilities. We know a lot of children's biographies and cannot recognize significant differences – except the contemporary diagnosis and considerable discriminations resulting from this diagnosis<sup>12</sup>. From our point of view this is very alarming and we see even a further development towards the negative side. The often propagated claim that early diagnoses are important has to be regarded with caution.

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<sup>10</sup> Bettelheim, Bruno. *The Empty Fortress; Infantile Autism and the Birth of the Self*. New York: Free, 1967. Print.

<sup>11</sup> "Delogierung Wegen Autistischen Buben - 22., Donaustadt - DerStandard.at › Panorama." *DerStandard.at*. Web. 28 Apr. 2011. <<http://derstandard.at/1288659500797/Delogierung-wegen-autistischen-Buben>>.

<sup>12</sup> Kanner, Leo: *Childhood Psychosis: Initial Studies and New Insights*, How Far Can Autistic Children Go in Matters of Social Adaptation?, Pages 189-214, Washington, D.C., 1973. Print.



## Numbers of autistics

11. Approximately more than 1% of the global population is autistic. There is no evidence for an international deviation regarding the autistic population.<sup>13</sup> The number of autistics increases because of the broader use of the – relatively new – diagnosis. From our point of view this is the reason for the international deviation of diagnoses. In Germany live approximately more than 1.000.000 autistics trying to blunder along themselves as unobtrusively as possible.

## Definition of Disability

12. There is a number of different definitions of disability in the German speaking area. In Germany, the SGB<sup>14</sup> or the BGG<sup>15</sup> are two of the most relevant judicial frameworks containing legal definitions of disability. The common feature of these legal definitions is that disability is defined broadly. However, in common use, still the outdated definition of the medical disability model or critical attempts to fix the old view like the ICF of the WHO, which includes various culturally biased contents, plays an important role. This leads to the situation that there is a tendency to pass the buck to the disabled persons – for instance when barrier-free access to public schools shall be provided.
13. The ESH demands that the term 'disability' should be detached from questions concerning human health because disability is primarily not a question of health issues but rather a question of structural and systematic discriminations.

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<sup>13</sup> "CDC Features - What We've Learned about Autism Spectrum Disorder." *Centers for Disease Control and Prevention*. Web. 28 Apr. 2011. <<http://www.cdc.gov/features/countingautism/>>.

<sup>14</sup> "§ 2 SGB IX - Sozialgesetzbuch Neuntes Buch - Rehabilitation Und Teilhabe Behinderter Menschen." *Sozialgesetzbuch.de*. Web. 28 Apr. 2011. <[http://www.sozialgesetzbuch.de/gesetze/09/index.php?norm\\_ID=0900200](http://www.sozialgesetzbuch.de/gesetze/09/index.php?norm_ID=0900200)>.

<sup>15</sup> "§ 3 BGG – Gesetz Zur Gleichstellung Behinderter Menschen." *Juris BMJ - Startseite*. Web. 28 Apr. 2011. <[http://www.gesetze-im-internet.de/bgg/\\_3.html](http://www.gesetze-im-internet.de/bgg/_3.html)>. §3. For further information on legislative measures see *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

## The Declaration of the Convention

14. The Convention has been translated by Germany, Liechtenstein, Austria and Switzerland into German. This translation has taken place mostly without involving disabled persons into the process of translation. All efforts of disabled persons to correct at least the worst mistakes have been blocked by the relevant governmental institutions. *Netzwerk Artikel 3 – Verein für Menschenrechte und Gleichstellung Behinderter e.V.* has elaborated in cooperation with other disability organizations a shadow translation which shows some of the most striking deficits of the original report.<sup>16</sup> Especially the fact that in the original report „assistance“ is translated by „Hilfe“ (help) and „inclusive education“ by „integrative Beschulung“ (integrative education) has to be criticised from our point of view.

## Part B: Articles 5–30

### Equality and non-discrimination (article 5)

15. In Germany, there are different laws on protecting disabled persons, e.g. the BGG<sup>17</sup> or the AGG.<sup>18</sup> In general, the German polity is forced by the EU to implement better standards, however, there is little attempt for own initiatives. Whilst a broad consensus to "help" disabled persons exists (which actually is an euphemism, as it should be the aim to break down active and passive discriminations),<sup>19</sup> there is strong displeasure regarding serious consideration of the topic. In the German speaking area seems to be the tendency to think: "You get so much from us, don't bother us in turn". This attitude can also be found in the legal system which interprets the existing law against discrimination in a narrow sense.
16. A degree of disability (GdB) of at least 50 in the autism sector has been assumed for a long

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<sup>16</sup> NETZWERK ARTIKEL 3 E.V. "Schattenübersetzung Des NETZWERK ARTIKEL 3 E.V. Korrigierte Fassung Der Zwischen Deutschland, Liechtenstein, Österreich Und Der Schweiz Abgestimmten Übersetzung Übereinkommen Über Die Rechte Von Menschen Mit Behinderungen." Web. 27 Feb. 2014. <[http://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Pakte\\_Konventionen/CRPD\\_behindertenrechtskonvention/crpd\\_schattenubersetzung\\_de.rtf](http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/CRPD_behindertenrechtskonvention/crpd_schattenubersetzung_de.rtf)>

<sup>17</sup> Gesetz zur Gleichstellung Behinderter Menschen. Online: <<http://www.gesetze-im-internet.de/bgg/index.html> >

<sup>18</sup> "AGG - Nichtamtliches Inhaltsverzeichnis." *Juris BMJ - Startseite*. Web. 28 Apr. 2011. <<http://bundesrecht.juris.de/agg/index.html>>.

<sup>19</sup> "Ziele Von Autismus-Kultur." *Autismus & Asperger Syndrom | Autismus-Kultur*. Web. 28 Apr. 2011. <<http://autismus-kultur.de/ak/autismus-kultur/ziele-des-projekts-autismus-kultur.html>>.

time. This value is especially with regard to compensation for disadvantages (Nachteilsausgleich) very relevant. The situation changed and the Value of Damage (GdS) became more relevant in this area. This value can lie between 10 and 100 for autism. GdB 50 is a important state, because there begins the status „Schwerbehinderung“ with better rights. From our point of view this step is absolutely correct, however, it can bear apparently disadvantages for some autistics as it can be seen in practice that the boundary between autism and not-autism is blurred. However, it is very precarious that the legislator assumes that the GdS can be derived from the fact wheter an autistic asks for assistance or not. Assistances or other integration support are far from an optimal solution and there are several compelling reasons to renounce them. From our point of view it is absurd to measure social discrimination on the fact wheter someone uses such assistance or not. In 2014 we see, that there is no objective jurisdiction of this legal change, so this change has led to a bureaucratic situation in which people are harassed. Additionally to this it is very problematic that "experts" are often incompetent as it is also mentioned below (art. 12)

17. As disability is a question of discrimination it is correct to determine compensation of disadvantages on the question to what extend a social group – e.g. autistics – is actually discriminated. Thus, it should be the aim to reduce discriminations and not to provide inadequate help which bears several problematic aspects in itself and not to implement universal design.
18. As assistants instead of possible barrier-freeness often cause more problems than they solve it is from our point of view a violation of the convention to determine the amount compensation for discrimination only based on the fact whether someone uses such an outdated model of help. It is absolutely necessary that this criterion gives way to an individual expertise about the individual circumstances the autistic is living in and the discriminations the autistic is facing. Furthermore, such an expertise has to include the individual circumstances of living. There are many mature autistics laying their foundations for a bearable way of living and retreat from society in order not to break down. Even if overstress is avoided and the autistic is able to compensate particular burdening situations, access to society is limited because of a general lack of universal design (taking autistic needs into account). During such an expertise these factors should not be excluded because it is not tolerable when mature autistics are „declassified“ only because consultants and

judges have an eclatant lack of knowledge about autism and determine discrimination only based on excluding assistance.

19. The assumption that mature autistics mostly ask for assistance is absolutely unrealistic – even if autistics are discriminated in an above-average way. Assistants are mostly hired by a certain type of parents which often dump their children into facilities for disabled. Mature autistics mostly do not purpose a living in the same way as non-autistic do. Often, they do not hire assistants but try to gain accessibility – e.g. the possibility to communicate by writing. However, the fact that an autistic follows the adequate path in terms of autistic cultural concepts does not implicate that this autistic is discriminated less than an autistic using assistance.
20. 2009, in Germany, there have been spent over 44 billion € for care, rehabilitation and inclusion.<sup>20</sup> For certain groups of disabled people the situation has improved, however, for autistics it is still rather deplorable. In the autism sector seems to be a lot of actionism but most of the measures are ineffective or even counterproductive – e.g. therapies.
21. The ESH sees huge potential in universal design for breaking down barriers. As already the contact with national decision-making bodies is astonishingly hard and anything but accessible, there is still – in spite of knowledge about the deplorable situation of the autistic's environment – a striking deficit. Because of this, autistics have not achieved yet so much – even in fields in which other groups of disabled could make improvements – unless those improvements have been imposed by parent-based organizations. These achievements are commendable, albeit, there are because of the one-sided consultation of relatives without inclusion of autistics clearly undesirable developments, e.g. regarding the level of training and knowledge of personal used for instance in schools as assistants or as experts. As a consequence, bad mistakes are widely spread which are comfortable for parents – for instance when the parent's inappropriate behavior towards their autistic children is systematically ignored and even whole therapies are aimed at confirming parents in their opinions and behaviors.
22. An example of possible universal design would be a general obligation of departments, the

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<sup>20</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

health sector, and the corporate sector to allow communication in written form without stating reasons and to get answers promptly in order not to delay the communication and provoke further disadvantages in comparison with oral communication.<sup>21</sup> It is all the more absurd that there are several approaches to provision of accessible communication mentioned, but written communication is excluded from most presentations.<sup>22</sup> This would be a very important action for autistics (and other groups like deaf persons) as autistics are often excluded, unless they do not out themselves and become discriminated, for instance, when being treated like a school child and not getting answers (rejection of a business connection).

23. It is far from clear why several services from private enterprises are not able to settle easy questions by Fax, Email, etc. without problems. Obviously, there are when somebody resorts by Fax or Email to the company direct instructions to refer to pay hotlines – if ever there is a published Fax number. A further fear is that some officials in charge often provide – when communicating orally – inaccurate informations (mostly to the disadvantage of the questioner) which leads to reservations about getting contestable – when communicating in writing. In consequence, written communication often turns out to be sparsely. This can result from general overwork but also from instructions of superiors to advise incorrectly, so that the department has to pay out less. This basic problem dominates different sectors, even the health system in which the access for autistics is severely impeded because of structural discriminations – serious health problems and even deaths can happen as a consequence. It is not acceptable that, for instance, an autistic is not able because of barriers (order of acceptance only by phone, claiming that this is the only way to arrange the delivery date), to procure heating material for his own house so as not to be cold in winter.
24. Even if in rare cases written communication is possible, it is treated as subordinate. A clarification which would take by phone 5 minutes can take many weeks or even months when being clarified in written form. This is also a considerable discrimination: on the one

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<sup>21</sup> "Hürde Nr.1: Verweigerte Barrierefreie Kommunikation." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/verweigerte\\_barrierefreie\\_kommunikation](http://autisten.enthinderung.de/verweigerte_barrierefreie_kommunikation)>.

<sup>22</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

hand because of the affair's striking delay, on the other because of the tormenting multiple uncertainty (How does the answer turns out? When does it arrive?). In this context the role of confirmations of receipt is underestimated, especially in the course of a dragging affair.

25. "Assistants" are no alternative to universal design, as they cause several new problems, e.g. when an "assistant" interferes in factual questions and tries to impose his opinion on the autistic. It is even possible that assistants work against their clients which can lead to an explosive situation when reports written by these assistants get relevant – for instance when somebody tries to incapacitate the autistic legally.
26. In some cases autistics are forced to attend a judicial hearing for reasons like insinuated by the passage above. It seems to be that decision makers reject written communication with much effort just to state that the autistic who is not able to explain properly orally his or her thoughts or happenings that cause him or her plenty of stress or harm - what other persons could misinterpret as "severe autistic" and as a legitimacy to put in a psychiatric ward or in a group home with strong sedation medicine or fixations. (See to the back references to article 13)
27. Even if an autistic provides a medical certificate as proof for his inability to attend a judicial hearing, it is possible that the court does not take appropriate account for this. The autistic may be forced to attend the hearing. Otherwise, the sentence is passed in the absence of the autistic and a proper hearing is not ensured.

### **Disabled Women (article 6)**

28. There is even less profound knowledge about autistic women because of which it is likely that autistic women often get wrong diagnoses and are treated in an inappropriate way.<sup>23 24</sup>

### **Disabled Children (article 7)**

29. Usually, the will of autistic children is not respected when deciding which treatment is

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<sup>23</sup> Bosch, Karin Fran De. "Frauen Mit Einer Behinderung Aus Dem Autismusspektrum.". *Aspergia - Für Menschen Mit Asperger Syndrom*. Web. 27 Feb. 2014. <[http://www.aspergia.de/cms/download.php?cat=50\\_Downloads&file=bosch-frauen.PDF](http://www.aspergia.de/cms/download.php?cat=50_Downloads&file=bosch-frauen.PDF)>.

<sup>24</sup> Preissmann, Christine. Web 27.Feb. 2014 <<https://www.aktion-mensch.de/blog/eintrag.php?id=626>>

adequate – despite of contrary claims in the rights of disabled children.<sup>25</sup> This leads to the situation that autistic children are forced into needless mainstream behaviors which are – from an objective point of view – harmful for them and without any benefit for the child. Children's natural defense behaviors are systematically ignored and suppressed – as they are mostly regarded as dysfunctional autistic behaviors without any reason. E.g. autistic children are put into psychiatries when they get bullied at school, get no help from teachers, bystanders or parents – or when they are unchallenged in school, especially so at “special need schools”. If the autistic child utters that it wants to be at home or to end the stay at the psychiatry – they are ignored or tried to “support” with remarks as “just another week – you are a tough boy and your mother will be happy.” Back at school afterwards they are asked to leave school because the bullies cannot stand its coming back and bullying will start again against the autistic child.

30. In spite of official statements,<sup>26</sup> disabled children are often not provided with the most adequate education and preparation for life. In some cases, education is aimed at easy handling in facilities for disabled – even if such an institutionalization is in no way justifiable. On the one hand, this can be explained by the fact that therapists and doctors are interested in keeping their clientel. On the other, this is also because of the fact that not-autistic parents often are not willing to reflect their own misbehavior, because of which it is easier for them to pass the buck to their children. Often parents are even affirmed by therapists in their behavior.

### **Awareness-raising (article 8)**

31. "Awareness-raising" about autism today is mainly dominated by ideas of parent-based DROs.<sup>27</sup> As a result, further disinformation is likely to be harmful to autistics and their self-determined lives. On conferences of parent-based organizations utterances of autistics

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<sup>25</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

<sup>26</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

are often censored – when they are not to the liking of these organizations. Such conferences and this kind of "awareness-raising" are often even more or less directly funded by state subsidy (and be it through subsidies for those parent-based organizations, e.g. through public health insurance). It is also problematic that persons trying to raise awareness lack often understanding for autistics, from which result wrong depictions<sup>28</sup> because of misinterpretations. As a consequence a fatal self-affirmation-mechanism supported by "experts" arises – using their research on the basis of these wrong ideas and do not choose approaches from which autistics would benefit and which would provide sustainable solutions without trying to exterminate a whole population group. **Mind you, autistics are not a population group suffering by disposition but suffering because of changeable circumstances.** Research with the aim of exterminating autistics is supported by million-euro state subsidies. Research for universal design is, as far as we know, not promoted in any public way whatsoever.

32. People-first language is often used in Germany, like it is used in the CRPD itself. Many disabled people reject this language as discrimination which does not fit into the social model of disability<sup>29</sup> <sup>30</sup>. Because of this, we write of the CRPD as *Convention on the Rights of disabled Persons*. We also reject impairment as a not neutral word and as a new term for the expression of the tinkering of the medical model of disability. Let us imagine a world in which 99% of the people can breath under water. In this world, if it is excluding minoritys like ours the people that feel not impaired in our world would be labelled as „impaired“ in this fictional world. So we see that it is necessary to recognize that „impairment“ is a discriminating term especially for autistics because we are just different from the majority. In a world with 99% autistics people that are nowadays normal would have very similar

<sup>27</sup> „Distanzierung der Enthinderungsselbsthilfe von Autisten für Autisten (und Eltern) vom Bundesverband Autismus Deutschland e.V. und dessen Regionalverbänden.“ *Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige)*. Web. 28 Apr. 2011.

<[http://autisten.enthinderung.de/distanzierung\\_autismus\\_deutschland](http://autisten.enthinderung.de/distanzierung_autismus_deutschland)>.

<sup>28</sup> Example for wrong depictions: AOK, *Gute Informationen zur Gesundheit, Autistische Psychopathie Schizoide Störung des Kindesalters*, Web 27. Feb. 2014,

<<http://www.aok.de/bundesweit/gesundheit/61623.php?id=2780&region=11&gender=m>>

<sup>29</sup> „The autism rights movement also rejects person-first language, on the grounds that saying "person with autism" suggests that autism can be separated from the person. Advocates of the social model of disability also reject person first language, defining themselves as "disabled people" and "disability" as the discrimination they face as a result of their impairments.“ Web 24. Feb 2014

<[http://en.wikipedia.org/w/index.php?title=People-first\\_language&oldid=590991089#Criticism](http://en.wikipedia.org/w/index.php?title=People-first_language&oldid=590991089#Criticism)>

<sup>30</sup> ESH. „7 allgemeine Distanzierungen“ Web 26. Feb. 2014

<<http://autisten.enthinderung.de/distanzierungen>>



problems that autistics have in our real world. As we see, this language is against real awareness rising. Antidiscrimination policy cannot work without a language clearly matching with the social model of disability because it is a big difference if someone recognizes that disability is a kind of discrimination like racism because of exclusion from political power related decision making processes of a society and that disabled persons are not disabled as persons and that it is not the question of how much a generous society „helps“ disables people (because there would be no need for help without exclusion in a world of wide Universal Design as a design of a whole society).

### **Accessibility (article 9)**

33. As already mentioned, there are significant barriers for autistics which prevent them from living self-determined: on the one hand barriers regarding communication, on the other barriers resulting from a lack of consideration with regard to autistic's sensitive sensory perception – which is even within universal design approaches not taken into consideration. These barriers cause perceptions which can be equated with physical pain, however, autistic sensory perception is – provided an adequate environment – perceived as an indispensable power of establishing identity.<sup>31</sup> Overloads/Meltdowns because of this more sensitive sensory perception can affect areas which would not be taken into account by other groups of the population even if they take care; e.g. "knock out patterns" like stripes on escalator steps.<sup>32</sup> These patterns may vary on a personal basis, nevertheless, there are statistical tendencies. Further, autistics can often hear sounds which cannot be perceived by the most non-autistic persons because of the limited hearing spectrum of non-autistics. The stimulus saturation in our western world is, though, so immense that even non-autistics get lasting problems like high blood pressure, stress, and illnesses, which are caused by permanent noise, however, the autistic's problems are even to a greater extent incriminating. Such barriers do not occur in a natural environment; this is why it is primarily the problem of a cultivated landscape – designed by the majority – not being compatible with needs of

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<sup>31</sup> Müller, Colin. "Autismus: Wahrnehmung Und Wahrnehmungsverarbeitung." *Autismus & Asperger Syndrom | Autismus-Kultur*. Web. 28 Apr. 2011.

<<http://autismus-kultur.de/autismus/autipedia/wahrnehmung-autistischer-menschen.html>>.

<sup>32</sup> "Was Ist Ein Overload? Ist Das Psychisch Krank“. *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <<http://autisten.enthinderung.de/overload>>.

autistics. It is self-evident that autistics were ever since part of a functioning human society and seem to have fulfilled a few hundred years ago important social functions. It has only been for a short time that autistics are becoming increasingly systematically pathologized.

### *Access to Education*

34. The school system in Germany is highly exclusive.<sup>33</sup> An easily feasible accessible education via web could not been realized yet despite of the ESH's efforts (without any state funding or at least noticeable support!).<sup>34</sup> It is all the more absurd that it is allowed to the members of the band Tokio Hotel<sup>35</sup> to visit a web school but not to autistics which often are not able to follow tuition because of avoidable barriers. The environment in school classes can usually be very encumbering for autistics, also because of a mostly non-accessible social an physical environment and resulting chronic pressure which limits existing possibilities of compensation. According to the ESH, autistic pupils should be educated in mainstream classes but with the addition that they could participate from home (in an appropriate environment) through a swiveling webcam placed in the classroom. The feedback channel would be provided through chat. Adaptations, for instance for first class pupils, would result from practice. The most economical version of the equipment (without internet access in class and the student's PC) would cost about 250€ – which is little for a much better access to education. A better system is a school-robot. According to the ESH-model the pupil should decide for himself without pressure whether he would prefer to attend classes physically or via „school robot“ or the older webcam-model. Objections that autistics should be forced to interact under "normal" circumstances with people are from our point of view ill-considered. It is not acceptable that a population group is forced into situations which do harm to them and result in worse educational opportunities. When autistics live in an adequate environment they begin spontaneously approaching to persons

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<sup>33</sup> Sozialverbund Deutschland. *UN-Behindertenrechtskonvention Umsetzen - Inklusive Bildung Verwirklichen*. Rep. Mar. 2009. Web. 28 Apr. 2011. <[http://www.sovd.de/fileadmin/downloads/broschueren/pdf/un-behindertenrechtskonvention\\_umsetzen.pdf](http://www.sovd.de/fileadmin/downloads/broschueren/pdf/un-behindertenrechtskonvention_umsetzen.pdf)>.

<sup>34</sup> "Onlinebeschulung in Regelklassen." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <<http://autisten.enthinderung.de/schule>>.

<sup>35</sup> Web Individualschule - So berichtet die Presse über uns, "Bochumer "Web-Schule" hilft Problemschülern und Tokio Hotel", Quelle: WAZ Stand 11-09-2012 Web. 27 Feb. 2014. <[http://www.web-individualschule.de/files/Pressebericht\\_WAZ\\_2012-09-11.pdf](http://www.web-individualschule.de/files/Pressebericht_WAZ_2012-09-11.pdf)>.

– for instance, to appear voluntarily in class. Specialized online schools are suitable for approval, however, they are with regard to inclusion not to be regarded as the best solution. In Germany, it is ever since a problem that disabled persons are pushed out of society and hidden. When there is no contact between the average population and disabled, then there is little acceptance for the disabled's needs. In the figurative sense, there are because of this pupil exchanges between nations. The opposite is practiced with disabled in Germany up to now.<sup>36</sup>

35. The risk for getting bullied is for autistics highly increased. It often happens that an autistic child is – when any kind of trouble arises – excluded from regular school and forced to visit a special needs school. Because of this, parents often do not dare to fight effectively back and great injustice towards autistics is tolerated<sup>37</sup>.
36. There are several official recommendations<sup>38</sup> about the correct schooling of autistics. From our point of view, these recommendations are far from adequate because they ignore both, autistic being, as well as the convention.
37. The transportation system to excluding school facilities often is obligatory in Germany, but not accessible for autistics, so that they are punished there too, if they show their pain.

#### *Access to Premises*

38. Continued effort is required in order to include autistic's needs particularly in future housing projects. Although, there are different attempts to provide accessible housing to disabled people, these attempts mostly target physically disabled persons<sup>39</sup> and not autistics. Autistic needs pertain in particular sound insulation (especially in conurbations), protection

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<sup>36</sup> *Gutachten Zu Den Völkerrechtlichen Und Innerstaatlichen Verpflichtungen Aus Dem Recht Auf Bildung Nach Art. 24 Des UN-Abkommens Über Die Rechte Von Menschen Mit Behinderungen Und Zur Vereinbarkeit Des Deutschen Schulrechts Mit Den Vorgaben Des Übereinkommens*. Rep. Gewerkschaft Erziehung Und Wissenschaft. Web. 28 Apr. 2011.

<[http://www.gew.de/Binaries/Binary48790/080919\\_BRK\\_Gutachten\\_finalKorr.pdf](http://www.gew.de/Binaries/Binary48790/080919_BRK_Gutachten_finalKorr.pdf)>.

<sup>37</sup> Heinrichs, Rebekah: *Perfect Targets; Asperger Syndrome and Bullying: Practical Solutions for Surviving the Social World*, Shawnee Mission, Kansas, 2003. Print.

<sup>38</sup> Germany. Kultusminister-Konferenz. *Empfehlungen Zu Erziehung Und Unterricht Von Kindern Und Jugendlichen Mit Autistischem Verhalten*. 16 June 2000. Web. 4 July 2011.

<<http://www.kmk.org/fileadmin/pdf/PresseUndAktuelles/2000/autis.pdf>>.

<sup>39</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

from buzzing of electrical installations, as well as the creation of a share of social housing with a separate – for other tenants invisible – exterior door allowing autistics to enter their flats without having to pass the staircase.<sup>40</sup> These apartments could also be rented to average persons and should not be disadvantageous for them. Significant additional costs would arise mostly because of the better sound insulation which, however, can be combined with a correct implementation (!) of heat insulation. For autistics it is very important to have a protected retreat room.

### **Right to life (article 10)**

39. The publicly subsidized endeavors to enable the – already mentioned – eugenic efforts to eradicate autistics through targeted abortion have to be stopped immediately.<sup>41</sup> Funds should be used for useful research in favor of autistics. This kind of research still has great potential.
40. Recently, in Germany preimplantation genetic diagnosis (PGD) has been legalized.<sup>42</sup> Also eugenic blood testings were legalized. From our point of view, this is an affront to the human dignity and the rights of disabled people and in a blatant way opposed to the right to live. It causes us great concern that – when a genetic cause for autism is going to be found – autistics will be killed on a regular or unpunished basis in law. This opens the door for further encroachments upon the rights of disabled people as it is based on the medical model of disability and even strengthens this model. And what the long-term consequences of such a breeding of a putatively "superior" human race are going to be cannot be assessed.
41. In this point, we consider the situation in Germany as a running genocide and as a planning of a broader genocide in the future affecting more minorities.<sup>43</sup>

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<sup>40</sup> "Mehrkosten Für Barrierefreie Wohnung - SGB9 §55." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/sbg9\\_barrierefreie\\_wohnung\\_kosten](http://autisten.enthinderung.de/sbg9_barrierefreie_wohnung_kosten)>.

<sup>41</sup> "Comments at March 14, 2008 IACC Meeting." *The Autistic Self Advocacy Network (ASAN)*. Web. 27 Feb. 2014. <<http://autisticadvocacy.org/2008/03/comments-at-march-14-2008-iacc-meeting>>.

<sup>42</sup> "Entscheidung Im Bundestag Parlament Erlaubt Gentests an Embryonen." *Sueddeutsche.de*. 7 July 2011. Web. 18 July 2011. <<http://www.sueddeutsche.de/politik/entscheidung-im-bundestag-parlament-erlaubt-gentests-an-embryonen-1.1117300>>.

<sup>43</sup> ESH Erstattet Strafanzeige Gegen BRD Wegen Völkermord. Web 25. Feb. 2014

42. The main problem is that medicine is mostly as a whole seen as a science but in reality it is because of its thinking in its categories of 'healthy' and 'ill' a group which makes politico-cultural separations similar to the „racial studies“ in the last century that can not logically formed out of a objective definition of „illness“. The autistic minority in fact is a ethnic and linguistic minority, too. The logic of this genocide is to „prevent pain“ with the elimination of the discriminated persons, that often only suffers, because of their discrimination, which is ethical nothing other than kill a pupil, because this pupil is mobbed by other pupils.

43. Highlights of the german genocide laws:

- Abortions are legal, if the „pain of the mother“ because of the born child will be probably large enough to make her ill. „Regular“ abortions are not legal, however, without punishment regulated in StGB §§218ff. To testify this, the state authorized medical doctors to do so, which use a wrong model of the situations, so that disabled children are seen as risk for pain (not the discrimination against the disabled children which causes the most pain for other people too!), but e.g. not children with a rare skin colour, which are in part discriminated too in a similar kind. Because of this Germany kills the victims of discrimination, not the discriminations itself. So this law is used as a eugenic law, because of its nature as a forbidden indirect discrimination (the german legal term is „mittelbare Diskriminierung“).
- It is theoretically legal to indirect-eugenically-kill an autistic child shortly before its birth according to the law StGB §§218ff which collides with or experience that some autistics remember their early life very precisely and remember times of their lifes before their birth.
- Semen banks use to select male sperms for fertilisation using selective eugenic criterias<sup>44</sup>, which is not forbidden in Germany.
- According to the VStGB §6 „Anordnung von Maßnahmen zur Geburtenverhinderung“ (arrangements of measures for prevention of births) are a serious crime called genocide. According to StGB §138 it is also criminal not to inform the relevant people or the

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<[http://autisten.enthinderung.de/strafanzeige\\_bremen\\_genozid](http://autisten.enthinderung.de/strafanzeige_bremen_genozid)>

<sup>44</sup> Richtlinie Donogene Insemination. Web 1. Aug. 2012

<[http://www.donogene-insemination.de/downloads/Richtl\\_Druckfassung.pdf](http://www.donogene-insemination.de/downloads/Richtl_Druckfassung.pdf)>

police about plannings of a genocide.

- The German state has the duty to protect disabled people because of the Grundgesetz Art 3 and human rights. It is the opposite of protection to make a law that makes disabled people or minorities as a whole rightless related with respect to the right of life.
  - The existing German GenDG uses similar discriminations like the abortion law. The German state has not made a law to protect disabled minorities with respect to the uncontrolled usage of genetic and other testings. Therefore we think that it is not longer tolerable to punish abortions in general because of the huge risk of upcoming culturally biased vandalism in the human genome. This vandalism is a great danger for the biodiversity of mankind, which is a basic criteria for biological stability and strength.
44. Internment in facilities for disabled is, from our point of view, also opposed to the right to life. As a pressure group, we demand access to all relevant facilities in order to contact the inmates and we demand rights to take these persons quickly out of this often unacceptable situations if they wish to leave those facilities. Further, we demand removal of the most significant barriers and heteronomy, the disposal of superfluous placement under legal guardians; we demand to inspect whether inmates are kept out of access to means of communication (as so often) and information. Further, we demand the careful preparation of as many autistic persons as possible towards a release – if necessary into – to be prepared – interim-facilities organized by (real) DPOs dominated by autistics in which autistics can recover from dreadful experiences often lasting for years. The ESH started the *Autistenauswilderungsprojekt*<sup>45</sup> for this reason, which is sabotaged by lack of state fundings (Leistungsvereinbarung).
45. Our view is, that the German statutory interpretation of the criminal act of deprivation of liberty and, derived from it, denial of assistance is mostly restricted to physical freedom of movement by courts, although, it does not result directly from law.<sup>46</sup> It is not taken into account that, for autistics, access to communication technologies such as internet (Email, Chat, Wikis) or Fax plays a similar role like physical freedom of movement for the average

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<sup>45</sup> Web 26. Feb. 2014 <<http://autistenauswilderung.unen.de/>>

<sup>46</sup> "Freiheitsberaubung Durch Psychopharmaka Oder Unterbringung." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/freiheitsberaubung\\_psychopharmaka\\_unterbringung](http://autisten.enthinderung.de/freiheitsberaubung_psychopharmaka_unterbringung)>.

population. As a consequence, help is provided to persons which are deprived from their physical freedom of movement but not to autistics whose possibilities to interact socially and live independently are factually nonexistent because of the omission of communication channels. A clarification by the legislator is needed.

## **Equal recognition before the law (article 12)**

46. There is danger that disabled persons are legally incapacitated because of the German double-justice-system in which a small crime can lead to a life long sentence in a special facility if some „experts“ feel this would be right because of the mental state of the person. In Germany these „experts“ do not need any qualifications<sup>47</sup> <sup>48</sup>, they are viewed as witnesses. Largely, it is not only for autistics a huge problem that "experts" often only possess terrifyingly low knowledge regardless of their formal qualification. In this system everyone its endangered to be treated as mentally ill like the german whistleblower Gustl Mollath who has been arrested for many years because of his correct whistleblowing<sup>49</sup>. The fact that „experts“ in cooperation with the justice trusts into the fact that, these experts can write a paper, so that a citizen will get the „benefit“ to beome rightless in part is not only a fact that leads especially to hard discriminations against disabled persons. It is a threat for democracy itself<sup>50</sup> <sup>51</sup>. The argument that not-disabled persons can also become legally incapacitated is from our point of view objectionable as (mentally) disabled persons are often considered incapable which leads more often to according legal consequences (see to the back reference to article 14, point 44)<sup>52</sup> The german system of shadow-justice includes

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<sup>47</sup> ARD. Panorama. Web 26. Feb. 2014

<[http://daserste.ndr.de/panorama/archiv/2013/gutachter103\\_page-1.html](http://daserste.ndr.de/panorama/archiv/2013/gutachter103_page-1.html)>

<sup>48</sup> „Diskriminierungsfreie Begutachtung“ Web 26. Feb. 2014

<[http://autisten.enthinderung.de/barrierefreie\\_begutachtung/](http://autisten.enthinderung.de/barrierefreie_begutachtung/)>

<sup>49</sup> The Guardian „German man locked up over HVB bank allegations may have been telling truth“ Web 26. Feb. 2014 <<http://www.theguardian.com/world/2012/nov/28/gustl-mollath-hsv-claims-fraud>>

<sup>50</sup> Der Freitag. „Ist der Rechtsstaat noch zu retten?“ Web 26. Feb. 2014

<<http://www.freitag.de/autoren/sarah-liebkind/ist-der-rechtsstaat-noch-zu-retten-2>>

<sup>51</sup> „Eine Reform ist überfällig“ Web 26. Feb 2014

<<http://www.zwangspanychiatrie.de/2014/02/eine-reform-ist-ueberfaellig/>>

<sup>52</sup> IAAPA. „Chronicle“ Web 26. Feb. 2014 <<http://www.iaapa.de/zwang4/chronicle.htm>>

torture and ill-treatment<sup>53 54 55</sup>.

47. We maybe have to recognize, that the „benefit“ of the category „Schuldunfähigkeit“ and „Deliktunfähigkeit“ (not able to be guilty) is only a phantom. So we maybe have to stop this historically grown legal discrimination as a whole. Statistics do not tell us „mad“ persons are a bigger danger for the society than other people<sup>56</sup>. A very failable system of „experts“ and double-standards in justice is likely worse, than a equal justice system.
48. The other side of this very insecure system of „expert“-inquisition is that this system also has been used to prove, that a disabled person that is disabled in a way that gives her the right of different benefits and a right for some barrier-free settings. Those benefits mostly are a small compensation of the still broadly running discrimination by society. This system is the reason many autistics and other disabled persons have to live a bad life or die like the young autistic women in the attached report. This system also binds accessibility to systematic insultings of autistics as „ill“, „disordered“, etc. which is the opposite of awareness rising following the objectively wrong medical model of disability which is something like a apartheid-thinking. In what way is the state able to check something that nobody can really prove in an objective way? The better solution would be Universal Design for all procedures of a society, so that everyone can take the accessibility he needs without the need to prove himself that there is a need in his single case. We have to start an open discussion in order to determine how we can realize this new model of accessibility globally.
49. In Germany the Facilitated Communication (FC) is recognized by law in the KHV §3,2,2,b)<sup>57</sup> as a communication method. However, its not usual in Germany to make a prove

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<sup>53</sup> „U.N. Rapporteur On Torture Calls For Ban On Forced Treatment“ Web 26. Feb. 2014  
<<http://www.madinamerica.com/2013/03/u-n-rapporteur-on-torture-calls-for-ban-on-forced-treatment>>

<sup>54</sup> ND „Weisse Götter Folterknechte“ Web 26. Feb. 2014  
<<http://www.neues-deutschland.de/artikel/915866.weisse-goetter-folterknechte.html>>

<sup>55</sup> Web 27. Feb. 2014  
<<http://www.zwangspanpsychiatrie.de/more-contradictory-news-from-germany-september-2013>>  
<<http://www.zwangspanpsychiatrie.de/good-and-bad-news-from-germany>>  
<<http://www.zwangspanpsychiatrie.de/alliance-against-torture-in-psychiatry>>  
<<http://www.zwangspanpsychiatrie.de/now-obvious-psychiatry-is-brute-force>>

<sup>56</sup> Tina Minkowitz „Psychiatric Profiling As Blood Libel“ Web 26. Feb. 2014  
<<http://www.madinamerica.com/2013/10/psychiatric-profiling-blood-libel>>

<sup>57</sup> *Verordnung zur Verwendung von Gebärdensprache und anderen Kommunikationshilfen im Verwaltungsverfahren nach dem Behindertengleichstellungsgesetz.* Web 26. Feb. 2014  
<[http://www.gesetze-im-internet.de/khv/\\_3.html](http://www.gesetze-im-internet.de/khv/_3.html)>



whether this very doubtful method really works in a certain case of a person. This can lead to a situation in which an assistance person takes the hand of an autistic and writes her own thoughts which are taken for words written by the autistic. We see in the actual German regulation a discrimination of autistics because there is no possible legal protection against such misuse<sup>58</sup>. There are simple testing methods like asking different questions through headphones. Studies show that in most cases (more than 80%!) not the autistic answers through this method, but the „assistance person“<sup>59</sup> that is mostly a parent. Imagine the horror your parents can legally put their words as yours.

### **Access to justice (article 13)**

50. The federal court Bundessozialgericht strengthened the right of accessible written communication in its decision from 14. Nov. 2013 Az. B9SB5/13B<sup>60</sup> fought out by our NGO. At this time we cannot know, how much impact this decision will make.
51. Although equality is granted by law, autistics are often discriminated in court to some extent because of their deviating body-language etc. Assessors often do not provide accessible assessments – with the consequence that autistics seem to be more incapable than they actually are. It is not acceptable for us that accessibility is no matter of course in such important situations (See to the back reference to article 5, point 19).
52. Access to legal counsel is much more difficult for autistics – as lawyers often do not respond to contact by writing. Even if contact is provided it is much more difficult to find out whether the lawyer is competent at the required field. Consultations in the office or by phone are usually much more efficient than the usage of, for autistics more accessible, written means of communications. When a lawyer accepts the representation his attitude can change after some initial solidarity in the course of time into annoyance and the lawyer can come to the conclusion that he has already done enough, knowing, how much impact this decision will make. This is particularly fatal when in an instance the assistance of a

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<sup>58</sup> *Gemeinsame Erklärung für ein Verbot schädlicher Autismustherapien und sonstiger Methoden*. Web 26. Feb. 2014 <[http://autisten.enthinderung.de/verbot\\_autismustherapie](http://autisten.enthinderung.de/verbot_autismustherapie)>

<sup>59</sup> Web 26. Feb. 2014 <<http://www.uni-koblenz.de/~proedler/fc.htm>>

<sup>60</sup> "BSG stärkt Anspruch von Autisten auf barrierefreie Kommunikation" *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 25 Feb. 2014. <[http://autisten.enthinderung.de/BSG\\_barrierefreie\\_kommunikation\\_2013](http://autisten.enthinderung.de/BSG_barrierefreie_kommunikation_2013)>

lawyer is prescribed by law.

53. The medical model of disability is among lawyers and judges still dominating which leads to further discrimination – e.g. when it is assumed that lack of accessibility is due to the autistic being and not associated with (structural) discrimination. Granting of compensation of disadvantages is still determined by the medical model of disability.
54. As lawyers usually are not autistic, they do not understand their autistic clients empathetically and misunderstandings are preprogrammed. This can be, depending on the case, additionally unfavorable. Judges also have the commonly assumed prejudices because of which an outing before court can entail further indirect and direct discrimination.
55. Court cases usually are not accessible to autistics which can have many consequences: from pain to unintentional "false testimonies" or false confessions for the purpose of ceasing the unbearable situation. Including many breaks is only relatively useful and can have even an escalating effect. Due to question of the ESH the possibility of a video conference into the courtroom has been suggested (hopefully without increasing the legal costs). It can be helpful to prevent problems, however, it is not comparable with the possibility of a barrier-free written form of expression. A risk of discrimination which is connected to the usage of accessible means of expression could only be minimized when this possibility could be used within the framework of universal design – without justification in the individual case.
56. There are legislative measures ensuring barrier-free access to court cases, however, these measures mostly aim at needs of hearing impaired or blind persons which cannot be transferred to the needs of autistics.<sup>61</sup> Even if written communication is accepted during lawsuit, autistics face further structural discrimination. When an autistic communicates only by writing everything he mentions is included into the court record. When a non-autistic communicates orally not everything is included. This leads to the situation that the non-autistic party gets much more information about the autistic than vice versa. Even exhibits are not always included into the court record when shown during hearing. In order to reduce this kind of discrimination, there should be either the obligation to include every

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<sup>61</sup> *Übereinkommen Der Vereinten Nationen Über Rechte Von Menschen Mit Behinderungen Erster Staatenbericht Der Bundesrepublik Deutschland*. Rep. Bundesministerium Für Arbeit Und Soziales, 3 Aug. 2011. Web. <[http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/staatenbericht-2011.pdf?__blob=publicationFile)>.

utterance and exhibit into the court record or an arrangement which enables persons communicating by writing not to include everything into the court records.

57. At least a few German courts regard a personal hearing as inevitable when a prohibition of contact in accordance with the protection act against violence is striven. Because of this lack of accessibility it is very hard for maltreated autistic partners to get a protecting prohibition of contact. Especially in such personal crisis situations it is far from clear why it has to be fought for accessibility – however, with an uncertain outcome in the personal case.
58. The protection act against violence is only insufficient with regard to the internet – meaning, that autistics that often use the internet especially intensively, can only get insufficient protection in the internet.
59. Especially problematic is the fact that agencies often reject mostly everything. When opposition is filed it often takes years until a final decision is taken. On the one hand this leads to the situation that agencies have to pay out less (as some services are not funded in retrospective), on the other hand it can cause massive discriminations when for instance a child is schooled into a special needs school and the final decision arrives after the completion of elementary school – after this period a schooling in a mainstream school is even harder.
60. As social courts are often acutely overburdened delays that can last for years are likely. When a case drags on for five years or more it is unacceptable – especially when parents try to school their child in a regular school and the sentence is passed not until the child has finished primary school – mostly in a special needs school.
61. Even if an autistic wins a court case it is not granted that he is able to assert his right. For instance, it is known to us, that an autistic won a court case against an enterprise. The enterprise had to pay him an amount out, however, the payment was not performed. The usual way would be to contact the judicial officer in charge. Unfortunately, there was neither an E-mail address nor a Fax number published. A non-autistic would contact the officer in charge by phone or visit him in his office. However, both possibilities were not accessible for this autistic. Because of this, the autistic is still waiting for his money, although, he even asked the court for help and wrote a letter to the officer in charge, which,

however, has not been answered yet. When something is unusual, there are often significant additional problems. The legislator would now expect that the autistic hires an assistant which is able to handle the autistic's problems. However, this is very rarely done by mature autistics because assistants bear further problems. In 2014 this case from 2011 version of this report is still not fully closed, the money has not been fully paid because 2013 only the local parliament was able to correct a „mistake“ by a local court (Thüringer Landtag Petitionsausschuß e-490/13 (210003)) and after this other „mistake“ happened which is unsolved to this day the autistic did not receive any answers for months.

62. This summary explains that the judicial system in Germany does not provide a broad equal access for autistics. Thereby, for autistics access to justice is psychically very important in order to feel safe.
63. These problems are valid in analogy also for contact to the police or prosecution, whereby the police seems to have a particular aversion against written communication.
64. Access to the police via emergency Fax and SMS should be standardized within Europe and provided through an uniform Fax number. Official templates for emergency faxes should include not only deaf persons but also autistics. Schoolings for rescue services (e.g. police, emergency doctors, fire brigade) have to be provided in cooperation with organizations led by autistics and not parents.
65. In prisons should be no unacceptable circumstances for autistics because the autistic inmates are not able to evade them.

### **Liberty and Security of Person (article 14)**

66. Up to now, autistics are often legally incapacitated by their parents – and after the parent's decease by other persons – when reaching adulthood. Autistics often never get the opportunity to recover from adverse circumstances, go their own way and develop themselves according to their specific disposition. Usually, non-autistic persons do not understand which circumstances are essential for recovery. There is barely any scientific research about this point; not to mention research realized by autistics or at least research involving autistics at eye level (this is something non-autistic persons have problems with in general).

67. In facilities, autistics are often sedated excessively by psychotropic drugs.<sup>62</sup> This sedation can be explained for instance by shortage of staff and rather by lack of appreciation of autistics and insufficient knowledge about them. These sedations are intolerable as they only seem to be "necessary" because of the adverse conditions autistics are living in. It is intolerable to scotch healthy defense reactions of autistics without being able to discover the reasons and overview the complex coherences.

### **Freedom from exploitation, violence and abuse (article 16)**

68. In the past, dubious therapeutic methods have been used on autistics throughout the world. ABA<sup>63</sup> still is a form of abusing autistics, however, it has been – after harsh criticism – softened towards the outside. Today ABA, a kind of ill-treatment, is the globally most used early intervention therapy for autistic children. We often see the lie, that this early intervention therapies make inclusion become true, however inclusion does surely not mean to recect accessibility and to brainwash disabled people, so that they do not argue for their health and rights<sup>64</sup>. Therapists and schools of therapy still teach parents to abuse massively their autistic children. Parents shall keep the control about everything the child does or is interested in. Partly, the autistic child is only allowed to do things it likes when it performed the dressage it was asked to do.<sup>65</sup> Children defending themselves against the abuse against their nature are punished in a number of ways, e.g. by spraying citric acid into their face or by being referred into punishing situations. When children cry for hours it is explained to the parents that the crying is a necessary evil on the mend. Usually, these therapists absolutely fail to understand autistics and are even not able to recognize basic connections. Causes of problems are usually ignored and problems are put down to the children's otherness because of which destructive aspects of everyday life usually are not eliminated.

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<sup>62</sup> Finke, Karl, comp. *Veranstaltung: Wie Kann Der Anspruch Auf Teilhabe Auch Für Psychisch Behinderte Menschen Zur Realität Werden? Am 24.04.2002*. Rep. Behindertenbeauftragter Des Landes Niedersachsen. Web. 27 Feb. 2014.

<[http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren\\_bblni/pics/Broschuere-32.pdf](http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren_bblni/pics/Broschuere-32.pdf)>.

<sup>63</sup> Dawson, Michelle. "The Misbehaviour of Behaviourists - Michelle Dawson." *Sentex Data Communications - Internet Service Provider*. Web. 28 Apr. 2011.

<[http://www.sentex.net/~nexus23/naa\\_aba.html](http://www.sentex.net/~nexus23/naa_aba.html)>;

<sup>64</sup> ESH. „Was Inklusion ist und was nicht“ Web 27. Feb 2014.

<[http://autisten.enthinderung.de/was\\_ist\\_nicht\\_inklusion](http://autisten.enthinderung.de/was_ist_nicht_inklusion)>

<sup>65</sup> Schramm, Robert. "Die Sieben Schritte." Web. 28 Apr. 2011.

<<http://knospe-aba.com/cms/de/infos-ueber-aba/artikel-ueber-aba/die-sieben-schritte.html>>.

It can be compared to a situation when somebody has a splinter in his foot because of which he does not walk properly and is taught to walk properly without getting removed the splinter.<sup>66</sup> These therapies have not been elaborated with the cooperation of qualified autistics and can be compared to attachment therapies<sup>67</sup> or other therapeutic models being regarded as abusive nowadays. This kind of adaptation against autistic disposition often has severe psychological consequences for autistics. Regarding ABA it is especially objectionable that parents are instructed on drilling permanently their children which deprives the children of their childhood and takes them the important experience of parents being their emotional backing<sup>68 69 70</sup>. This traumatizes many autistic children in a heavy kind, so that its difficult to speak about their experiences freely<sup>71 72</sup>. These methods often are similar to the Judge-Rothenberg-Therapy, just instead of electric shocks other means of pain are used. For similar reasons, sign language was usually forbidden – on the grounds that it is contra-productive for their integration – to deaf persons. In the autism sector such a development up to an ethically acceptable human contact is still to come. ABA is advertised with strong marketing effort and uses many different brand names or no special name as early intervention therapy.

69. Because of the immense daily pressure lasting on autistics, resulting from their adverse living conditions, they often do not speak. As a consequence it is easy to depict them as stupid and incredible. Potential for sexual abuse of autistics is increased<sup>73</sup>. Numerous cases

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<sup>66</sup> *Warnung Vor Zeitgenössischen Therapiemodellen*. Rep. Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige). Web. 28 Apr. 2011.

<<http://dokumente.perfektibilistenorden.de/esh-flugi7m.pdf>>.

<sup>67</sup> Feuser, Georg. "Aspekte Einer Kritik Des Verfahrens Des "erzwungenen Haltens" (Festhaltetherapie) Bei Autistischen Und Anders Behinderten Kindern Und Jugendlichen." *Jb. F. Psychopath. U. Psychiatr* VII (1987): 73-134. Web. <<http://bidok.uibk.ac.at/library/feuser-festhalten.html>>.

<sup>68</sup> Schramm, Robert. "Die Sieben Schritte." Web. 28 Apr. 2011.

<<http://knospe-aba.com/cms/de/infos-ueber-aba/artikel-ueber-aba/die-sieben-schritte.html>>; Dawson, Michelle. "The Misbehaviour of Behaviourists - Michelle Dawson." *Sentex Data Communications - Internet Service Provider*. Web. 28 Apr. 2011. <[http://www.sentex.net/~nexus23/naa\\_aba.html](http://www.sentex.net/~nexus23/naa_aba.html)>.

<sup>69</sup> Baron-Cohen, Simon. *Radical Behaviorism*. Web 27. Feb. 2014

<<http://www.edge.org/response-detail/25473>>

<sup>70</sup> *Using Punishment In Behaviour Modification*. Web 27. Feb. 2014

<<http://suite101.com/article/using-punishment-in-behaviour-modification-a166857>>

<sup>71</sup> ESH. *Zehn Jahre danach – Erinnerungen eines ABA-Geschädigten*. Web 27. Feb. 2014.

<[http://autisten.enthinderung.de/aba\\_erinnerungen\\_1a](http://autisten.enthinderung.de/aba_erinnerungen_1a)>

<sup>72</sup> *Language of Therapy*. Web 27. Feb. 2014

<<http://journalofanautist.blogspot.de/2009/05/language-of-therapy.html>>

<sup>73</sup> Lugstein, Teresa. "Behinderung Und Sexueller Missbrauch - Abhängigkeit Wird Ausgenutzt." *Bizeps*. 30 Apr. 2008. Web. 28 Apr. 2011. <<http://www.bizeps.or.at/news.php?nr=8807>>.

of sexual abuse in facilities have been brought to light. It can be assumed that the number of unreported cases is much higher. In addition, descriptions of autistics often are not considered trustworthy or reduced to autistic "distortion of perception". On that score, many cases of sexual abuse are not investigated and autistics do not get necessary support.

70. As autistic body language is because of its otherness often not or wrongly understood, exclusion arises which can culminate into violence or abuse – both from private persons and office holders. It is comparable to misunderstandings between cat and dog and non-autistics usually are – in spite of theoretical knowledge – not able to reflect on the impact of supposed cues, not to mention when there is – as usual – not even general basic knowledge about autistic body language.
71. German courts reason in decrees over and over with medical documents about autistics involved or solely with the fact that someone is autistic – leading to the consequence that in sentences psychiatric diagnoses are weighted more strongly than the actual crime – e.g. when claiming that the autistic did not understand something properly.
72. Internment of autistics in facilities for disabled has also to be regarded as abuse, although, it is often the result of a lack of knowledge. It can sometimes also be explained from the dynamics of former exclusion together with pathologization within medical records. So far, the ESH has not been able to gain support or funds in order to contact autistics (mostly without their clear will) in such facilities and take them, if necessary, over to houses led by autistics with the aim to prepare them to a self-determined humane life.<sup>74</sup>
73. It is very disturbing that nowadays early diagnoses are forced,<sup>75</sup> albeit they often are the start signal for grueling discrimination. Autistics being diagnosed in adulthood are not less "ill", they often only escaped this discrimination resulting from an early diagnosis – which produces although its supposed mission to help only "human scrap".

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<sup>74</sup> Finke, Karl, comp. *Veranstaltung: Wie Kann Der Anspruch Auf Teilhabe Auch Für Psychisch Behinderte Menschen Zur Realität Werden? Am 24.04.2002*. Rep. Behindertenbeauftragter Des Landes Niedersachsen. Web. 27 Feb. 2014.

<[http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren\\_bblni/pics/Broschuere-32.pdf](http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren_bblni/pics/Broschuere-32.pdf)>.

<sup>75</sup> "Frühe Diagnose." *ABA/VB - Melody Learning Center*. Web. 28 Apr. 2011.

<<http://www.melodycenter.ch/german/links/abavb/studien/fruehediagnose/>>; "Chancen Und Risiken Einer Frühen Diagnostik." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011.

<[http://autisten.enthinderung.de/fr%C3%BChe\\_diagnose](http://autisten.enthinderung.de/fr%C3%BChe_diagnose)>.

## **Protecting the integrity of the person (article 17)**

### *Consent to medical treatment*

74. Unnecessary use of psychotropic drugs on autistics is, especially in facilities for disabled, widespread<sup>76</sup> and causes irreparable damage on healthy autistics. A reason is lack of understanding of autism and of problems arising from the inappropriate environment – even by "experts". The fact that psychotropic substances are used on children is alarming. We know that many problems (e.g. aggressions) only occur because of these substances and decrease when ostensible sedatives are slowly phased out.

## **Living independently and being included in the community (article 19)**

75. It can generally be said that the disintegration of autistics is strongly developing in Germany. Early diagnoses being promoted by politicians in the hope that they will result in improvements are mainly responsible for this development. However, a diagnosis is nowadays rather a starting point for a lifelong discrimination – because of different "help" systems preventing autistics even from education which has been formerly a socioeconomic niche for autistics.<sup>77</sup> When known, the diagnosis develops an independent existence, being traceable for consultants and other decision makers which usually have no knowledge about autism. In the public administration, data protection is usually informally ignored which has as consequence the causing of incomprehensible discriminations. A diagnosis gives reason for further exclusion through "special support" which makes quality education and important experiences in life (regarding the autistic person as well as average persons which have no opportunity to get in touch with autistics) impossible. We can expect that the increasing exclusion of autistics proceeds further on.

76. Ambulant Assistance organized by the german „wellfare organisations“ in its structure

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<sup>76</sup> Finke, Karl, comp. *Veranstaltung: Wie Kann Der Anspruch Auf Teilhabe Auch Für Psychisch Behinderte Menschen Zur Realität Werden? Am 24.04.2002*. Rep. Behindertenbeauftragter Des Landes Niedersachsen. Web. 27 Feb. 2014.

<[http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren\\_bblni/pics/Broschuere-32.pdf](http://archiv.behindertenbeauftragter-niedersachsen.de/broschueren_bblni/pics/Broschuere-32.pdf)>.

<sup>77</sup> "Chancen Und Risiken Einer Frühen Diagnostik." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/fr%C3%BChe\\_diagnose](http://autisten.enthinderung.de/fr%C3%BChe_diagnose)>.



seems to be used as control system against disabled people<sup>78</sup>. Independent solutions of DPOs have very big problems to achieve the same financial support from the state, because of their different human rights/disability studies/social model strategies. Also the ESH gets no financial support for the „Autistenauswilderungsprojekt“, in which we as autistics like to lead autistics to a self determined life. Nonautistic persons can not do this like we can, because of their lack of *autistic empathy* – the „professional“ staff mostly have no idea how autistics feel and think, so they are a barrier and a binding to „professionalism“ is a heavy kind of discrimination, because the „professional attitude“ means a discriminating apartheid-like racist view on our minority. In this setting very sensitive autistics going to be more and more disabled and desintegrated in their good and healthy natural identity.

77. A „Persönliches Budget“ (personal budget) has been implemented in order to provide disabled persons the opportunity to buy necessary services (such as assistance, care, home help etc.). However, there is on the one hand the problem that it is often insisted that these services have to be provided by „professionally qualified“ persons which often have prejudices and are not suitable for such services. It is far from clear why a person with a professional special needs background should be more capable to clean up an appartement than a person without such an education for instance. On the other hand, there is the problem that this personal budget is abused by parents for financing therapies and other not by the personal budget covered services.
78. Financing acceptable personal assistance outside of excluding and very problematic facilities is a very big problem in Germany. In a case we advocated a young autistic woman with a SLE-disease, this woman died after a long fight for sufficient self-organised assistance. The state offices were informed long before the death, that their uncooperative behaviour will lead to the death of the woman (for more information see Sozialgericht Dortmund Az. S41SO388/12ER). SLE rises its damage because of stress so a life full of barriers and harassment for an autistic person was a factor that led to this death. This massive harassment of the state authorities in Germany is a big pressure against disabled persons to live in excluding structures with reduced practical rights and freedoms. These facilities often are not barrier free for autistics and cause massive life long pain for the prisoners of this excluding violence. The ESH investend a large amount of money in order to

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<sup>78</sup> ESH. „Anmerkungen zur Umsetzung von Assistenz“ Web 26. Feb. 2014  
<<http://autisten.enthinderung.de/assistenz>>

help this women, however, the state rejected to pay this money back to us after her death. So it is a factual punishment of engaged DPOs that try to help people escaping the broad exclusion of disabled people by the German authorities. We see a system of formal rights that only can be reached through massive fights against „formalities“ and harassments by officials. The actual ECRI report sees big problems with awareness rising and antidiscrimination in the near sector of racistic discrimination and intolerance<sup>79</sup>. The problems to fight disability as a socially constructed kind of discrimination in Germany are similar. We remember this young autistic women in a attached special report named „Entzugskost“.

### **Freedom of expression and opinion, and access to information (article 21)**

79. Especially autistics living in facilities are often kept from informations they are interested in. It is often justified with the claim that obsession with interests (the term special-interest is used solely when speaking about autistic interests regarded being dysfunctional) leads to a reinforcement of autistic stereotypes which has – according to specialists – to be prevented.
80. Utterances made by autistics often are not thought to be worth considering – especially when autistics do not agree in opinion with non-autistics. As a consequence, autistics claiming that autism is nothing bad are underrepresented in the media based public and have no access to the relevant decision making processes. From this the impression can arise that even autistics support therapies against autism and lead to the conclusion that autistics not supporting therapies are a minority which has not to be taken seriously.

### **Respect for privacy (article 22)**

#### *Access to the Internet for autistics*

81. Autistics living in facilities for disabled usually have no access to the internet. In this area it is important to develop technical solutions which ensure internet access for facilities'

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<sup>79</sup> „Europarat wirft Deutschland Ignoranz von Rassismus vor“ Web 25. Feb. 2014  
<<http://www.spiegel.de/politik/deutschland/europarat-kritisiert-rassismus-und-intoleranz-in-deutschland-a-955415.html>>

inmates secluded from personnel. Often, the personal has no respect for the private sphere of inmates and manipulates the inmates in the personal's interests.

82. In general, there is frighteningly little knowledge about data protection – consequences like serious discriminations and immense losses for members of minority-groups are often not taken into account. The planned introduction of electronic health cards and the central electronic storage of data causes us great concern as there is enough bad experience with asseverations regarding the security of such systems (especially autistics know about this problem).
83. We see with deep concerns, that state offices are digitalising more and more processes. Extremely sensitive datas related to medical and intime data is converted in a unsecure way<sup>80</sup>, which means that unauthorized persons maybe can read this data or publish it publically. This is a hard problems especially for autistics, because we often know beavuse of our high intelligence very good how insecure this technic is. So a number of autistics is in a trouble between the use of the rights and not spread data in these insecure channels. We see this development as a kind of new „eat-or-die“-harassment to reduce costs. The new alternativeless german electronic health insurance card (eGK) which is developed with a partner of the NSA<sup>81</sup> is another critical top of the iceberg, which is able to destroy the trust in the medical system as a whole. Additional reports about criminal infiltration of state organs with rights to read the datas make the picture worse again<sup>82</sup>, so we see the need to clarify a right for disabled persons, that their private data will not be digitalized without their permission under hard legal punishments.

## **Respect for home and the family (article 23)**

### *Support for parents, families and carers of young persons with a disability*

84. Parents of autistic children are forced into early diagnoses with the claim that autistic

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<sup>80</sup> „Umfrage zum Stand der Einführung elektronischer Versorgungsakten“ Web 26. Feb. 2014  
<[http://autisten.enthinderung.de/elektronische\\_versorgungsamtsakten\\_umfrage](http://autisten.enthinderung.de/elektronische_versorgungsamtsakten_umfrage)>

<sup>81</sup> IKNews. „eGK und medizinische Daten: Freie Fahrt für die NSA und Bertelsmann?“ Web 26. Feb. 2014  
<<http://www.iknews.de/2013/12/19/egk-und-medizinische-daten-freie-fahrt-fuer-die-nsa-und-bertelsmann>>

<sup>82</sup> SPON „Britische Polizei von Kriminellen unterwandert“ Web 26. Feb. 2014  
<<http://www.spiegel.de/panorama/justiz/britische-polizei-von-kriminellen-unterwandert-a-942985.html>>

children will not develop properly without adequate support. Therapies are often explained to be the only way to prepare autistic children for a self-determined life. Alternatives are usually not alluded.<sup>83</sup>

85. Support organizations led by autistics are not recommended (usually even not mentioned) by experts and it is suggested to parents to join parent-based organizations in order to represent the rights of autistic persons. This leads to dangerous disinformation and autistic children are forced into behaviors which are not healthy for them.
86. As parents are uninformed about alternatives they have no possibility to decide which offerings are adequate to the autistic's needs. Therapies, schooling in special needs schools and later institutionalization are often thought to be the only way an autistic can spend his life.
87. As soon as a prenatal diagnosis will be developed, it can be assumed that counseling interviews will be biased and most women will opt for an abortion – as it is already with women aborting children with trisomy 21. From our point of view this development is very alarming.<sup>84</sup>

## **Education (article 24)**

88. As already mentioned above, the school system in Germany is highly exclusive. Although the ESH has elaborated a suitable cost-effective alternative, the pushing off into special needs schools proceeds further and is even portrayed as an inclusive school system by relevant institutions.
89. Because of his non-inclusive special needs school system Germany is often being criticized. Especially autistics are still pushed out of regular schools, albeit they indisputable have the intellectual abilities needed for regular graduation. Because of a lack of accessibility, unnecessary social conflicts arise which serve as justification for an exclusion from regular schools. On special needs schools a lifetime of exclusion is set.

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<sup>83</sup> "Chancen Und Risiken Einer Frühen Diagnostik." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/fr%C3%B4he\\_diagnose](http://autisten.enthinderung.de/fr%C3%B4he_diagnose)>.

<sup>84</sup> "Comments at March 14, 2008 IACC Meeting." *The Autistic Self Advocacy Network (ASAN)*. Web. 28 Apr. 2011. <<http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=25>>. Web. 27 Feb. 2014. <<http://autisticadvocacy.org/2008/03/comments-at-march-14-2008-iacc-meeting>>.

Abitur (A-level exam) is on special needs schools almost unthinkable, the more so, as on these schools is no barrier-free access granted as well.

90. Autistic pupils not being taught in special needs schools often are exposed to discriminations by teachers. Parents often do not dare to combat this discrimination effectively because they fear their autistic children being pushed out of school and forced into special needs schools. Such kind of discrimination is especially for autistics, because of their acute sense of fairness, unbearable. Contrary to popular opinion, autistics mostly recognize fully structural discrimination and mobbing as such and are even more shaken by the acceptance of these situation by reference persons.
91. Parents of autistic children are often encouraged to out their children in school – for instance during parent's evenings – with the claim that the outing will raise acceptance for the otherness of their children. However, this outing often turns out to be a starting point for further discrimination which would not have taken place, if the child has not been outed – even a permanent expulsion from school can be a consequence of such an outing.
92. The best practice solution for schooling of autistic children, the ESH-model of online-schooling in regular classes<sup>85</sup> is nearly ignored by officials. The broadly used system of „Schulbegleitung“ is inadequate, because it do not solve often heavy barrier-problems. Especially this „Schulbegleiter“ mostly is not a assistance for the child, this person regulary is more something like a guard of the school, a part of e excluding and discriminating control system, which have to protect the school from the autistic child. So really engaged Schulbegleiter get fired by the school or the school do not allow them to come in the school-building, because of their criticism and engagement for the real human rights interests of the autistic child<sup>86</sup>.

### *Apprenticeships*

93. For young adults with an autism diagnosis it is, because of discriminations resulting from this diagnosis especially hard to get an apprenticeship in the first labour market. Therefore, they are often shut off into vocational education centers specialized on young adults being because of their diagnoses or other factors not able to find a more appropriate

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<sup>85</sup> ESH. „Onlinebeschulung in Regelklassen“ Web 26. Feb. 2014 <<http://autisten.enthinderung.de/schule>>

<sup>86</sup> ESH. „Positionen der ESH zu Schulbegleitung“ Web 26. Feb. 2014 <<http://autisten.enthinderung.de/schulbegleitung>>

apprenticeship in the first labour market.<sup>87</sup> These centers have a strong pedagogical or even therapeutic alignment and autistics are patronized and forced into behaviors not being healthy for them. After the apprenticeship it is very hard to get an adequate job in the first labour market and it is likely that they will live on welfare after the education.

## Health (article 25)

94. In Germany it is not possible to communicate in written form with persons from the health sector. Written communication is for autistics of the utmost importance in order to get barrier free access to the health sector<sup>88</sup>. A estimated minimum of 100 autistics dies because of this barriers in Germany every year, probably wide more. In other countries, for instance in the UK written communication is, as far as we know, allowed in this sector.<sup>89</sup>
95. A recent study showed that general practitioners have stunningly little knowledge about autism and are not able to enlarge upon autistics. As a consequence autistics do not always get the medical treatment they need.<sup>90</sup>
96. Often, funds are not used the way as they should be. This leads to the situation that the care allowance (Pflegestufe) is used for behavior therapies, although, these therapies are not related to maintenace services. These therapies should be declared as remedies, however, they often are – quite rightly – not accepted as such by insurances. Therefore it is essential for insurances providing care allowances to control in which way funds are used.
97. It has to be added that the relevant institutions have knowledge about the problems autistics are facing in the health sector. However, the *Kassenärztliche Bundesvereinigung* (KBV) has neither taken action nor permitted a dialogue about this issue including autistics (actual still in 2014).

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<sup>87</sup> "Bundesarbeitsgemeinschaft Der Berufsbildungswerke - BAG BBW." *Die Berufsbildungswerke – Qualifiziert in Die Zukunft*. Web. 28 Apr. 2011. <<http://www.bagbbw.de/>>.

<sup>88</sup> „Mangelnde Barrierefreiheit im Gesundheitswesen“ Web 26. Feb. 2014 <[http://autisten.enthinderung.de/barrierefreiheit\\_gesundheitswesen](http://autisten.enthinderung.de/barrierefreiheit_gesundheitswesen)>

<sup>89</sup> "Stand, Möglichkeiten Und Grenzen Der Telemedizin in Deutschland." *Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz* 52.3 (2009): 263-69. Print.

<sup>90</sup> "Wissen Und Unwissen über Autismus Bei Deutschen Allgemeinmedizinern." *3. Wissenschaftliche Tagung Autismus-Spektrum, Tagungsband* (2010): 70. Print.

## **Work and employment (article 27)**

98. There are several companies specialized on autistic employees.<sup>91</sup> However, these companies cannot be regarded as sufficiently accessible. Although these companies claim that they are specialized on autistic needs they are not able to adapt on individual needs. When an autistic is not able to fulfill the companies' expectation regarding formal aspects it does not matter how good he can do his work – he does not get hired. This leads to the situation that on the one hand there are companies claiming that they are appropriate for autistics (because of which they often get state-subsidies) without fulfilling their own requirements and on the other there seems to be for other companies no need to implement barrier-free working places for autistics – they often do not even hire autistics at all when the diagnosis gets known.

### *Reasonable accommodation in the workplace*

99. Companies tend to see the attempt to understand autistics as a nuisance. Open-plan offices and similar working environments are very inappropriate for autistics, however, companies do not tend to offer alternatives. The blame for otherness and difficulties in understanding resulting from it is usually put only on autistics because autistics are still pathologized due to cultural chauvinism without sustainable scientific explanation for the alleged reduced productivity of autistics. Homosexuals and left-handers faced a similar state of things a few years ago. This requires long-term educational work aiming at the development of consciousness about the value of otherness. Such educational work is only possible when involving organizations led by autistics. Companies like Specialisterne have weak parts in their compliance<sup>92</sup>.

## **Adequate standard of living and social protection (article 28)**

100. Particularly in areas with high rents it is difficult for autistics to find barrier-free apartments (i.e. flats having no special health risks or hindrances regarding participation).<sup>93</sup> Such

<sup>91</sup> "Angebote Für Menschen Mit Autistischen Erkrankungen." *SALO PARTNER - Dienstleistungen in Ganz Deutschland*. Web. 28 Apr. 2011. <[http://www.salo-ag.de/Website/reha/reha\\_autismus.php?>](http://www.salo-ag.de/Website/reha/reha_autismus.php?>).

<sup>92</sup> ESH. „Einige kritische Anmerkungen zu Specialisterne, Auticon & Co“ Web 26. Feb. 2014 <[http://autisten.enthinderung.de/specialisterne\\_auticon\\_SAP](http://autisten.enthinderung.de/specialisterne_auticon_SAP)>

<sup>93</sup> "Mehrkosten Für Barrierefreie Wohnung - SGB9 §55." *Enthinderungsselbsthilfe Von Autisten Für*

apartments often are considerably more expensive or rarely exist. Autistics living on state transfer payments often are illegally denied to take over such an appropriate apartment because of which autistics often are stucked in apartments in which they suffer psychologically and tolerate less additional strain – as a consequence they have less energy to win for themselves an appropriate housing. Many rental agreements fail because of slow examination by administrative bodies and the fact that many apartments are already rented before the administrative bodies came to a decision. Even after the take-over of the appropriate apartment problems with funding arise as appropriate apartments have to be rented immediately, however, the legal flat notice period amounts three months – meaning that it has to be paid rents for two apartments for three months. In this way, autistics are discriminated as they can only move house with greater difficulties than the average population. When disabled persons – being socially discriminated – are not able to cover their living they are kept in poverty and have no possibility to build up reserves or have even – when losing their income – to use up their fortune. Persons having a narrow fortune, however, are especially in regions with high rents hardly capable to pay rents for two apartments for three months even and especially if the house moving has to be paid – as usual – by the autistic. It should also be noted that it is more important for autistics than for average persons to have an environment to which they are habituated for years.

### **Participation in political and public life (article 29)**

101. Organizations led by autistics are systematically excluded from relevant committees, such as the DBR – however these committees often have a public contract according to which they are obligated to cooperate with organizations led by disabled persons.<sup>94</sup>
102. Usually, autistics are during conferences underrepresented and their opinions are not considered seriously. Barrier free access to such events is also highly unlikely.
103. The ESH also is a member of the BRK-Allianz, a project organized by *Netzwerk Artikel 3* –

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*Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört.* Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/sbg9\\_barrierefreie\\_wohnung\\_kosten](http://autisten.enthinderung.de/sbg9_barrierefreie_wohnung_kosten)>.

<sup>94</sup> "Deutscher Behindertenrat: Autismus Deutschland Vertritt Die Interessen Von Autistischen Menschen." *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört.* Web. 28 Apr. 2011. <[http://autisten.enthinderung.de/deutscher\\_behindertenrat\\_autismus\\_deutschland](http://autisten.enthinderung.de/deutscher_behindertenrat_autismus_deutschland)>.



*Verein für Menschenrechte und Gleichstellung Behinderter e.V.* to write a own parallel report related to the CRPD. Because of hard problems with communication barriers for the delegates of the ESH and from our point of view not sufficient motivation to create a accessible participation and very disturbing scenes like a well known harassment case from Florida<sup>95</sup> the ESH settled a lawsuit against the BRK-Allianz because of this discrimination which seems to us against regular german law. Also it was rejected to make a reference in the planned report that autistics could not participate adequately because of barriers. The *Amtsgericht Berlin-Wedding* decided in the following in its decision Az. 4C1004/12 from 17. Juli 2012 that the election of the members of the leading organ of the BRK-Allianz was not valid because of formal reasons (p. 2 last words) and that the question of dicrimination only would be relevant, if there would be a formally correct setting which could make real decisions. Other contens of this decision have need to seen critically because often german regional courts tend to reject discrimination suits like in the actual case decision Bundessozialgericht from 14. Nov. 2013 Az. B9SB5/13B related to the right of accessible communication of autistics<sup>96</sup>. The ESH warned all member organisations repeatedly that the report is going to be invalid but communication was mostly rejected. So the report submitted in the name of the BRK-Allianz to the CRPD-comittee is not a valid report because only the leading organ could make this report. In fact there never was a formally correct election of the members of this organ.

104. Because of this story its also very interesting, that *Netzwerk Artikel 3 – Verein für Menschenrechte und Gleichstellung Behinderter e.V.* had made a setting of the BRK-Allianz in which non disabled persons have the majority of votes and a formally responsible person of this organisation was a member of a local gouvernment at the relevant time<sup>97 98</sup>. So there could be asked, if this project for a „NGO parallel report“ was really free of gouvernment agenda. In 2014, after nearly two years of not responding the

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<sup>95</sup> THE ROOT „Autistic Boy Voted Out of Class Receives \$350,000 Settlement“ Web 26. Feb. 2014 <[http://www.theroot.com/articles/culture/2010/12/autistic\\_boy\\_voted\\_out\\_of\\_class\\_receives\\_350000\\_settlement.html](http://www.theroot.com/articles/culture/2010/12/autistic_boy_voted_out_of_class_receives_350000_settlement.html)>

<sup>96</sup> "BSG stärkt Anspruch von Autisten auf barrierefreie Kommunikation" *Enthinderungsselbsthilfe Von Autisten Für Autisten (und Angehörige) & Auties E.V. | Autismus - Ohne Wäre Die Normalität Gestört*. Web. 25 Feb. 2014. <[http://autisten.enthinderung.de/BSG\\_barrierefreie\\_kommunikation\\_2013](http://autisten.enthinderung.de/BSG_barrierefreie_kommunikation_2013)>

<sup>97</sup> „Vorstand Vertretungsberechtigt sind **Dr. Sigrid Arnade, Prof. Dr. Gisela Hermes, Ottmar Miles-Paul**“ Web 25. Feb. 2014 „Impressum“ <<http://nw3.de/index.php/impressum>>

<sup>98</sup> Ottmar Miles-Paul Geht, Matthias Rösch Rollt An. Web 25. Feb. 2014 <<http://rollingplanet.net/2012/09/21/ottmar-miles-paul-geht-matthias-roesch-rollt-an/>>

accessibility questions<sup>99</sup> related to the autistic delegates of the ESH we asked all other members of the BRK-Allianz with own Websites, if they support the full implementation of the CRPD. This was written in the Statut of the BRK-Allianz as criteria for participation of the BRK-Allianz<sup>100</sup>. Not one single other member of the BRK-Allianz answered us a „yes“ to this point. As we know in fact no member of the BRK-Allianz tried to fight for the reasonable accomodation of our delegates and the meaning of CRPD Art. 29 i) in this case in the worst times.

### *Support for disability organisations*

105. The ESH and its partners do not get any public funds whereas biased scientific research is funded with millions of Euro. It is to be expected that this pathologizing research is going to be worthless in a few years unless attempts started to eradicate autism with prenatal genetic test or other methods.

## **Part C: Article 32**

### **International cooperation (article 32)**

#### *Participation of disabled persons*

106. As the EU mostly cooperates with parent-based organizations it is for autistics astonishingly hard to get included into important international decision-making processes. As a consequence, the ESH and other organizations led by autistics have not been able to implement noteworthy changes. Thus, on the international level a similar situation like within the German speaking area is to be expected.

## **Part D: Conclusion and Recommendations**

107. It has been shown that the implementation of the Conventions shows striking deficits regarding the autistic's situation. Severe discrimination can be found in mostly all aspects covered by the Convention.

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<sup>99</sup> Barrieren Für Autisten Bei Gremienarbeit. Web 25. Feb. 2014  
<[http://autisten.enthinderung.de/barrieren\\_gremienarbeit](http://autisten.enthinderung.de/barrieren_gremienarbeit)>

<sup>100</sup> Abenteuer BRK-Allianz - Wehe Dem, Der Das Statut Ernstnimmt Web 25. Feb. 2014  
<[http://autisten.enthinderung.de/diskriminierung\\_brk-allianz](http://autisten.enthinderung.de/diskriminierung_brk-allianz)>

108. Especially, the proceeding pressure lasting on parents to diagnose their autistic children as early as possible causes us great concern. Often, this early diagnosis is the starting point for further lifelong discrimination. Autistic children are forced into therapies – without any scientific evidence – which are definitively harmful for them. Especially ABA is marketed with great financial expense, whereas very little is done in order to allow autistics to live a self-determined life without any easily avoidable structural barriers.
109. Often, autistic children are not allowed to visit public schools and they are pushed off into special needs schools in which they mostly get neither necessary adjustments allowing them to learn without any avoidable barriers nor an education according to their intelligence. Education has formerly been an socioeconomic niche for autistics. Being deprived of education, autistics often have no possibility to become a fully integrated part of society. Thus, they nowadays often live in poverty and try to blunder themselves along as inobtrusively as possible.
110. In the course of lifelong discrimination autistic children are often legally incapacitated when reaching adulthood. Custodians mostly have stunningly little knowledge about autism and often try to enforce their will on autistics. This leads to the situation that autistics are often determined by persons without any autistic empathy (which is only possible among similar persons) and do not get the possibility to live self-determined.
111. Internment in facilities for disabled is – even without any objective reason – also widespread. There are no real efforts to resolve such facilities and to release autistics into a self-determined life – or when appropriate into facilities led by autistics which would prepare them for a self-determined life and help them to come to terms with grueling experiences during their internment.
112. There are little attempts to enable autistics to find a job in the first labour market. Possibilities like teleworking are provided sparsely and alternatives to open-plan offices are usually not offered. When the diagnosis gets known autistics are often not hired.
113. Many autistics live in poverty and have big difficulties to find suitable accommodations. Structural factors in the welfare sector impede this further.
114. Although, autistics have an acute sense of fairness access to justice is aggravated because of barriers. Often sentences are passed under the influence of prejudices.

115. Risk of sexual abuse is increased and it is likely that autistics do not get the help they deserve because of their deviating body language which makes non-autistics often think that autistic utterances are not credible.

## **Recommendations**

116. We see great potential in universal design, however, there are hardly any efforts to promote these approaches. We demand the implementation of universal design (which takes into account autistic needs) in all relevant public areas in order to enable autistics to participate equally. Especially the possibility to communicate by writing is essentially important for autistics.

117. Autistic pupils have to be schooled in mainstream classes, however, a barrier-free access has to be provided in order to allow an adequate education. The ESH's proposal to school autistics via web in mainstream classes would ensure such an accessible education. Despite its cost-effectiveness this project does not get any public or financial support, yet. Without appropriate education autistics have no possibility to become an equal part of population which is able to afford its own living.

118. In order to prevent misuse of care allowances it is essential that insurances providing such allowances control in which way the money is used. Misuse of such funds causes unnecessary expenses and even irreversible damage on autistic children – for instance when harmful therapies are used on children.

## **Attachment „Entzugskost“**

*It is the aim of this case study to illustrate the scope of discrimination that autistics are exposed to. The title word „Entzugskost“<sup>101</sup> was used by the dead autistic women „P.“ itself to describe her impression of her own situation. This is a widely anonymised report, for more information see the legal case Sozialgericht Dortmund Az. S41SO388/12ER*

In the first quarter of 2011 the ESH has been contacted by the autistic P. P was living in a desolate situation. She was living in her parent's house and received weekly support by an employee of the facility EE. It was the aim of this support to enable P to live independently in an own apartment.

With the help of her assistant P applies for an appropriate recognition of her disability (SBA) and the disability marks (Merkzeichen). For months there is no activity.

After a long time of suffering under alternative medical treatment (which has been initiated by her parents), P visits on the initiative and with support of the ATZ AA a rheumatologist in AA. Systemic Lupus Erythematosus (SLE) is being diagnosed. P's health improves rapidly after the treatment.

It is the will of P to live independently as an autistic person. Her parents try to force her into non-autistic behavior what she refuses. The ATZ AA talks to her parents and describes them as resistant against advice.

Because of the SLE P loses weight. Her assistant does not feel able to foresee the consequences on P's health. It is therefore that the assistant allies herself with the family doctor and the parents. They make an application at the Amtsgericht to withdraw P the right to move freely, to choose her place of residence and to implement a legal guardian in the area of health-related-issues. A social

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<sup>101</sup> „Once there, most of them were given soporifics and/or treated by means of so-called *Entzugskost* or *E-Kost* (a starvation diet). This 'therapy' weakened the children to the point that they fell prey to infectious diseases that kill them within days.“ Eduard Seidler. *Jewish Pediatricians: Victims Of Persecution 1933-1945*. p. 99. Web 27. Feb. 2014 <<http://books.google.com/books?isbn=3805582846>>

worker which has been appointed by the court, expresses the opinion that P is not able to live self-determined and independent. The expert which has been appointed by the court as well holds the opinion that P is perfectly able to live in her own apartment self-determined. The court decides in favor of P.

The application for the SBA has still not been processed. P is sent to an external expert in order to determine the degree of disability (GDB). P is not allowed to read the report without supervision of a medical person. According to the expert autistics are not allowed to read their own reports because of their personal identity disorder. The report of the expert is edited and shortened by a caseworker. P appeals against this practice. P's objection is not taken into consideration, it is being ignored.

The circumstances in the parent's house become more and more unbearable for P, especially because of the connection with the parental health insurance. P decides to move her place of residence. The ATZ refuses to help P and underlines its neutrality. P terminates her agreement with the ATZ and the Landschaftsverband related to the FF-Kreis. Alternative support opportunities are not presented to P. P also terminates the assistance plan because of breach of contact. She asks for access to her case-files and does not get any answer.

P applies on 1 March 2011 for a basic income support payment (Grundsicherung) and on 15 March 2011 for a personal budget (PB). In the context of the application for basic support payment an assessment by the public health officer (Amtsarzt) is being ordered. Contrary to the agreement the public health officer becomes in a medical way offensive. P presses charges against the public health officer, however, he does not remember the incident and the Public Prosecutor holds the opinion that there is no public interest in pursuing the matter.

The social office is not able to organize an apartment for an autistic. According to the social office it will take at least an year until an apartment will be found on the free market. Other help or advising is not being provided.

As P does not get any informations on her application for Personal Budget, the ESH conducts investigations. The ESH is told that probably the application for Personal Budget has been

forgotten by the authorities. The ESH is told by the regional authority (Überörtlicher Träger) that the granting of the Personal budget is possible without problems. After this utterance there is any activity on this matter. Upon the urging of P a medical assessment is organized by the FF-Kreis. P is being verbally attacked by the appraiser which leads to an outbreak of the SLE. An appropriate personal budget is refused to P until the day of her death.

Further help cannot be expected by the local authorities.

As P's living situation worsens more and more, a flat is being rented by the ESH. Informations by the local authorities about reimbursement of the rent within the basic income support payment (Grundsicherung) are not provided. The basic income support payments in connection with services of the ARGE are granted only delayed. P is being told that a processing time of 6 months is allowed.

P is without financial means. The local authorities refuse the payment of 100 EURO for food, because she has nothing left to eat for reasons of poverty because P does not have a daily statement of her bank account. An ESH's employee gets under her personal liability from the headquarter of the Sparkasse in X 100 EURO.

Neither the application for appropriate recognition of P's disability nor the application for personal budget (and in connection the examination whether there are other service providers responsible) are being processed. P lodges complaints (Dienstaufsichtsbeschwerde). She receives a letter in which the district administrator states that no mistakes were made by the employees of the relevant offices.

Because P is autistic she is not able to use public transport. The ESH rents an apartment near P's working place in Y. P asks the authorities to redirect her applications. The authorities take this move to Y as a reason to discontinue in paying the basic income support (Grundsicherung). They held the opinion that another service provider is responsible for the payments.

1 September 2011 P applies for basic income support payments in Y which are being granted. For the first time it is investigated whether P would be entitled with a pension. Because of the

medical diagnoses the pension insurance renounces to an assessment, however, it writes that P has no right for a pension.

Child allowances are counted as income, because of which P applies for a diversion of the child allowances to Y what is granted. P's parents are stalking her, therefore the public order office (Ordnungsamt) is willing to keep her address in secret.

P visits for another time the rheumatologist she visited already with support of the ATZ. An employee of the ATZ is also present and expresses her astonishment about P's surprisingly good condition and self-confidence. P asks the rheumatologist to avoid any disclosure of informations to third parties and as a consequence of this he refuses any further treatment as he is not able to follow this request.

P's medical care is being charged via her mother's private health insurance. The private health insurance enables P to attend longer meeting and treatment time which is more accurate to her autism. However, as the connections with her parent's health insurance are problematic and P is not able to pay her own private health insurance, P decides to get a public health insurance via her employer.

After P's movement to Y P finds a new empathetic family doctor that asks P to stay in specialized medical treatment because of her SLE. P contacts the Lupus-ambulance at the University BB. The SLE is for another time diagnosed in its seriousness. As an autistic, P is not able to bear an in-patient treatment. The in-patient treatment would cause a lot of stress on P which would activate the SLE. An out-patient treatment is targeted. As P is not able to use public transport means and the health-insurance refuses to pay taxi fares to BB P is being treated by the C-Hospital in Y. The C-Hospital works in strong connection with the Lupus-ambulance in BB. An out-patient chemotherapy is being conducted, as the therapy does not work, P is declared as incurable.

It is not possible for P to find a rheumatologist that possesses knowledge of SLE as costs of taxis are not paid by P's health insurance. As the Personal Budget has still not been allowed an assistant that would be able to accompany P does not exist.



The need of another assessment in order to investigate the necessity of special nutrition (which is necessary due to increased activity of the SLE) is being expressed.

The administrative district Z offers at the end of the year 2011 a personal budget of 300,00 Euro and asks for P's written acknowledgement which she refuses because the salaries on the market for assistance are way higher than the offered personal budget. P claims complaint against this decision regarding her personal budget. This complaint is regarded as a motion for help for reintegration (Eingliederungshilfe). P contradicts this in written form.

For medical reasons it is necessary for P to move into a two-room apartment. The ESH organizes an appropriate apartment.

As there has still been no decision on an appropriate degree of disability (Grad der Behinderung) and all the time limits have been exceeded by the authorities in Z, P becomes a Member of the VdK and sues the authorities in Z (Unterlassungsklage). As a consequence another appraisal by an expert is being conducted at the CC-hospital. P gets 90 degree disability (90 Grad Behinderung), however, she does not become any disability marks (Merkzeichen). As this is not correct, P lodges a complaint. This case has not been decided until the day of her death.

In August 2012 the ESH declares that it is not able to accompany P to a sufficient extent due to P's expanding needs because of the activity of the SLE. P's family doctor does not feel competent enough to treat P in an adequate way. A request for home care is being rejected by the health insurance because there is no legislative framework for such a case. A hardship ruling is not possible.

P finds a domestic help that is able to wait for her money until P gets the personal budget. Because of P's physical weakening she has already a need of assistance for 3 hours per day. The social court is irritated about this fact, although, the administrative district Z and the court have been informed that the stress causes an activation and expansion of the SLE. Still, P is not able to pay her domestic help and there is still no decision about P's personal budget. She repeatedly writes to the administrative district Z and to the court that the stress, which is caused by the slow

procedures, can cause her death.

P applies at the social court for interim measure. She is not able to attend the trial and the judge decides without communicating with P. The decision contains the utterance that it is not necessary to expect that a domestic help needs a salary. P does not accept the denying of urgency. The case is handed to the Landessozialgericht. There is still no decision in the main court proceedings.

P's domestic help withdraws from the contract. P stays for one month without help. She asks the ESH if help can be provided. The ESH helps P in making an application for acceptance of a care level (Pflegestufe).

The nursing service (Pflegedienst) offers a date for a domestic appraisal. Because of P's autism her home is absolutely private and visitors are not allowed. P asks for an appraisal at a neutral place, e.g. a conference room at the town hall or a coffee for disabled persons that meets her need to keep in motion. The medical service (Medizinischer Dienst) refuses the appraisal under such circumstances because it were necessary to conduct the appraisal in the domestic environment. However, the medical service is not willing to make this utterance in written form.

At P's request, the ESH contacts the Medical Review Service of the National Associations (Spitzenverband der Medizinischen Dienste). It is agreed that the appraisal can be conducted in the facilities of the Medical Service (Medizinischer Dienst).

P finds a praxis for palliative care, however, she terminates the contact with her new family doctor as the boss of her family doctor does not believe in P's SLE. He informs the C-hospital that P acquired a wrong diagnosis. The hospital terminates the medical treatment.

A new doctor is found that is able to assess the situation. P talks about the physical pain that is caused by food intake. P also talks about the bodily harm that is caused by injection into her arm. P's body is very sensitive. P holds the opinion that the insertion of a port would be a solution of her nutritional problems.

The C-hospital refuses the insertion of the port because the risk of infection is considered too high. The C-hospital does not have made a lot of experiences with ports.

P, ca. 173 cm high, weights 32 kilos. She is driven into the F-hospital in E and receives a Port. The medical services (Medizinischer Dienst) refuses a care level (Pflegestufe).

The social services of the hospital, the ESH and D-Pharma organize an out-patient port supply at P's home. The hospital system is too stressful (changing employees, another rhythm of organization, ignoring of her Patient Decree). She releases herself on own risk.

The family doctor and the ESH organize medical care at P's home (oxygen at the bed, wearable oxygen, a patient bed, a raised toilet seat, a wheelchair, a rollator...). The out-patient care fails as the care service is not able to adjust to P's needs in terms of organization of time. P's rhythm as an autistic is being ignored. They are not able to take care of her on demand.

P is able to deliver herself nutrition via the port. The services of D-Pharma are surprisingly good and personal. An employee of D-Pharma detects a closure of the port. As the glucose values are alarmingly low, P is being delivered into the C-hospital where she is fed conventionally. The port is not being opened. P takes a taxi to the hospital in E where the port is being opened and P released home.

P informs the ESH that she has had a breakdown and has been delivered via the C-hospital into the psychiatric hospital A. On the same time a judicial proceeding on disqualification of P's decision-making ability is begun. The psychiatric hospital holds the opinion that the psychologizing of P is inadequate. P is being delivered into the B-hospital in A.

The B-hospital is irritated on the fact whether P holds legal capacity. The ESH informs the hospital that P is a freely-living autistic person with SLE. P has no court-appointed carer and she knows perfectly what she wants.

The senior hospital physician does not accept P's Patient Decree (Patientenverfügung) and asks for a notarial certification of P's legal capacity. P tells that she has an appointment for recognition

of a care level (Pfleigestufe). She learns that her mother has cancelled the appointment without P's knowledge. Repeatedly the mother acted without legal permission into the private life of P. Very much involved persons accepted this illegal actions and gave private informations to the mother.

The ESH orders a notary to P's bed. The other day he calls the ESH and tells that P is not legally capable. He did not speak with P, he just asked a senior hospital physician and believed his utterance. He asks for P's address for the billing.

A judicial decision is taken according to which P is legally capable.

At the hospital the social services ask P if she would like to move into a facility for autistic people which is conducted by the Landschaftsverband. She rejects this offer because she fears that she will not be able to leave the facility.

Another appointment for recognition of a care level (Pfleigestufe) is offered, however the Landschaftsverband Westfalen Lippe conducts these appointments only in a nursing facility. A friend of P calls all the nursing facility in question, however, they either have a high level of capacity utilization or are not competent enough for an autistic person with SLE. P's friend initiates a call for help in the internet and finds a nursing facility in DD. P has to cope with a 5-hours long taxi drive as the driver takes a wrong turn and does not have a navigation system. He insults P because she causes him problems.

P enters into the nursing facility and friends of her explain autism and SLE to the employees. It is P's wish to have as many personal items as possible in her room because they will help her to calm down. She dies at the nursing facility accompanied by two employees that cooked with her at night after the end of service. She falls asleep and as they look after her she has died.

An employee of the ESH gets early on the morning of the 12 Mai 2013 a phone call at 3:30 o'clock. She is told that they do not find an identity card and as the emergency doctor is coming they need it immediately. Short time after this first call an emergency doctor calls and tells that she has a corpse and no identity card. The employee asks for a plan B and explains that P has only been for a short time in the nursing facility. The emergency doctor stays offensive. The ESH

declares that the identity card will be handed in later as soon as it will be found. After an hour the emergency doctor apologizes for her misbehavior.

P has ever since pointed out that her health condition depends on the stress level. She has also repeatedly pointed out that stress can cause her death if it is not taken account for her needs. It is to be expected that P's death has been knowingly taken into account.

It was very important for P as a disabled person to live independently and to have a personal budget with that she would be able to buy necessary services for participation and reduction of discrimination. She was strongly ashamed that she needed the services of the ESH for such a long time as her applications at the relevant state bodies have been ignored and she did not get any further help.

The ESH invoiced the authorities with approximately 1/5 of its services. Services that have not been conducted within the borders of a ordered support are hardly ever paid. The authorities in Z refused to pay the amount.

Two judges decided that P is legally capable and able to live independently. It is in clear contradiction with these decision when necessary services are not being provided and support is only paid when it is conducted by courtly appointed caretakers. It is essential for disabled people do decide who is about to help in which extend. This is the only way to get necessary and adequate support.