

## **Submission of ISL e.V. to the Committee against Torture on Germany, 47<sup>th</sup> session (31 October – 25 November)**

This submission has been prepared by ISL e.V. (Interessenvertretung Selbstbestimmt Leben in Deutschland e.V.) and concentrates on the following issues relative to the CAT Committee's mandate: involuntary placement and involuntary treatment in psychiatric institutions, harmful therapies for persons with autism, conditions in nursing homes and forced sterilisation. Proposed recommendations for Concluding Observations can be found at the end of each topic of this submission.

### **About the organisation**

ISL e.V.: The "Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. - ISL" is the umbrella organization of the Centres of Independent Living of people with disabilities in Germany. ISL was founded in 1990 by disabled women and men. For us disability is a human rights issue and not a medical problem.

Our guiding ideas are „Independent Living – Self representation – Inclusion – Empowerment“! ISL e.V. is the German branch of the international organization of people with disabilities "Disabled Peoples' International - DPI".

Information has also been provided by the "Enthinderungsselbsthilfe- von Autisten für Autisten", and "Wir! Stiftung pflegender Angehöriger" (foundation for caregiving relatives).

### **1) Psychiatric institutions**

#### **1.1) Harmful therapies for persons with autism: Attachment therapy and ABA**

- **Attachment therapy** is the most commonly used term for a controversial category of alternative child mental health interventions intended to treat attachment disorders. It is found primarily but not exclusively in the United States and is also widely practiced in Germany.

Attachment therapy is a treatment used with autistic children who have behavioural difficulties, sometimes severe, but including disobedience and perceived lack of gratitude or affection for their caregivers. It is practiced in the way that a child is strongly held (or lain upon) by therapists or parents. Through this process of restraint and confrontation, therapists seek to produce a range of responses such as rage and despair in the child with the goal of achieving catharsis. In theory, when the child's resistance is overcome and rage is released, the child is reduced to an infantile state in which he or she can be "re-parented" by methods such as cradling, rocking, bottle feeding and enforced eye contact. By using this therapeutic method it is believed that emotional closeness which is allegedly lacking within an autistic child can be reached. Control over the children is usually considered essential. Partly it is even suggested to sit on the child, even if that confronting situation causes urination for the child, as it is practiced by some church carriers in Germany. These accompanying parenting techniques are based on the belief that a properly attached child should comply with parental demands and they are in fact based on false assumptions made by non-autists since they are usually not able to interpret the body language and expressions of autistic people in a proper manner.

This form of therapy, including diagnosis and accompanying parenting techniques, is scientifically invalidated and is not considered to be part of mainstream psychology. This method shows furthermore that people with a pervasive development disorder are being judged by assuming their disability must be eliminated as it is understood as a deficit.

- The second harmful therapeutic method **ABA** (Applied Behavioural Analysis)<sup>1</sup> is a modern form of behavioural learning therapy mostly used with autistic individuals. By functionally assessing the relationship between a targeted behaviour and the environment, the methods of ABA can be used to change that behaviour. Within this method parents are required to achieve total control over their child's surroundings. Therapists train the parents to judge situations very much different as they have done before, for example as they are forced within this therapy to ignore the crying, screaming and protesting of the child while being treated. Behavioural elements therapist and parents would claim to be unusual and bad will be "deleted" whereas desired behaviour and skills will be trained. Also, it is very common to make use of punishments as the suspected goal is to train the child according to the conceptions and ideas of parents and therapist. For the autistic child this behavioural training leads to inhuman and degrading pressure to adapt which is likely to cause traumas.

Both mentioned therapies are partly supported by public financing. This therapeutic method is contradictory to Articles 2 and 16 of the CAT and Articles 12,15,16 and 17 of the CRPD as it shows a disrespect of individual autonomy and denial of moral and physical integrity.<sup>2</sup>

#### Recommendation:

- Eliminate the use of harmful therapies on children and adults with autism and promote the establishment of peer support programmes and ongoing consultation with persons with autism and their representative organisations.

### **1.2) Involuntary placement**

- In Germany, involuntary placement, where an individual is deprived of his or her liberty is categorised into private law placements, public law placements, and forensic placement governed by federal criminal law (§ 64 StGB, sec.7 paragraph 1JGG) which serves averting danger to the general public posed by the individual who is convicted for having committed a crime.
  - Private law placement is governed by federal private law (§ 1906 BGB [Civil Code] in the case of a person of full age. The placement of person by a custodian or a person with

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<sup>1</sup> More information at: <http://autisten.enthinderung.de/aba>

<sup>2</sup> The Enthinderungsselbsthilfe – von Autisten für Autisten warns parents of an autistic child, that it is very essential to have a very close look at these methods of therapy. The ABA procedures for example are as intensive as 40 hours per week for a child, meaning a severe loss of freedom as well as free development for the child. Also, they criticise the lack of scientific evidence concerning these two methods. More information at: <http://auties.net/aba-krankenkasse> and in English at [http://www.sentex.net/~nexus23/naa\\_aba.html](http://www.sentex.net/~nexus23/naa_aba.html)

powers of attorney (§ 1906, para. 5 BGB) is only admissible as long as it is necessary for the well-being of the individual.<sup>3</sup>

- Public law placement on the other hand, refers to the placement of a person with the purpose of preventing danger from the individual or other persons and is governed by the different laws of the 16 states (Länder)<sup>4</sup>. The procedure concerning involuntary treatment of both types is governed by sec. 312 *et seqq* of the Law on Family Affairs (FamFG).

Both above mentioned types of involuntary treatment require a previously obtained approval by a judge which can be retroactively obtained without delay only in exceptional cases.<sup>5</sup> However, case law shows this requirement is often disobeyed, especially in cases of temporary placement over the weekend (or over public holidays) where the placement is terminated before the person can be heard or the approval of the judge can be obtained. Further, the differing laws of the Länder lead to an unclear situation which impedes the assessment of the constitutionality of the laws and the practice according to these laws with respect to the right to liberty. The same critique applies to the ordinance or approval of involuntary placement by the courts in the first place. Numbers show that approximately 90% of placement proceedings lead to an approval.<sup>6</sup> This shows the disproportionate application of the placement laws according to which involuntary placement is supposed to be the last resort. A further deficit of proportionality can be found in the vague wording of the laws, especially considering danger thresholds which are not clearly defined. Thus, there is no legal guarantee the threshold is interpreted in a way as to require a concrete and immediate danger rather than an abstract danger. Further, public law placement is not restricted to the purpose of protecting equally high ranking values as the liberty of the person concerned. Some Länder laws allow involuntary placement for the purpose of protecting public order or security<sup>7</sup> which can be interpreted very broadly.

It is furthermore criticised that in practice, experts asked to provide an assessment on the necessity of the placement often do not possess sufficient professional competence. In this respect, it must be noted that § 321, para. 1 sentence 3 FamFG stipulates that the expert merely *shall* be a psychiatrist, but must at least be a doctor with experience in psychiatry.

## 1.2) Involuntary treatment

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<sup>3</sup> The law accepts the necessity of the involuntary placement for the well-being of the individual only in two cases: 1) if there is danger the person will severely hurt or kill him- or herself due to a mental illness or an emotional or intellectual disability; 2) if a medical examination of the health of the individual or a medical treatment is necessary which cannot be carried out without a placement.

<sup>4</sup> Unterbringungsgesetz (UBG) Baden-Württemberg of 1992; Unterbringungsgesetz (UnterbrG) Bayern of 1991; PsychKG Berlin of 1985 amended in 1994; Brandenburgisches PsychKG of 1996 revised version in 2009; PsychKG Bremen of 2000 amended in 2005; Hamburgisches PsychKG of 1995; Hessisches Freiheitsentziehungsgesetz (FrhEtzG) of 1952; PsychKG Mecklenburg-Vorpommern of 2000; Niedersächsisches PsychKG of 1997; Nordrhein-Westfalen PsychKG of 1999 amended in 2005; PsychKG Rheinland-Pfalz of 1995; UBG Saarland of 1992 amended in 2007; Sächsisches PsychKG of 2007; PsychKG Sachsen-Anhalt of 1992; Schleswig-Holstein PsychKG of 2000; Thüringer PsychKG of 1994

<sup>5</sup> §1906, para. 2 sentence 2 BGB. The laws of the Länder contain equal provisions and some laws even specify a time limit in which the approval of a judge must be obtained. These time limits range from one to two days with the exception of Baden-Württemberg where an approval must be obtained only after three days (sec. 4BW UBG).

<sup>6</sup> See Marschner/Volckhart/Lesting (2010): *Freiheitsentziehung und Unterbringung*.

<sup>7</sup> 1 UnterbrG BAY as opposed to §8, para. 1 PsychKG Berlin which requires a danger to “particularly valuable interests of others”

- In its ruling from April 15, 2011 ([2 BvR 882/09](#)) the federal constitutional court has affirmed the freedom from involuntary treatment and violence in psychiatric institutions:<sup>8</sup> A 59-year old man from Rhineland-Palatinate had filed a constitutional complaint concerning involuntary treatment in a psychiatric institution against his involuntary treatment he experienced in a psychiatric institution. The complainant neglected a treatment with neuroleptica in the hospital “Pfalzkrankenhaus Klingenstein”. Due to a criminal act committed under exemption from criminal responsibility (according to criminal code § 63 StGB), the man was hospitalised into the above forensic psychiatric hospital and now feared that the mentioned medication would cause severe side effects and lead to personality disorder. As a result, clinic management declared the man unable to reason and against his will announced administration of medication. Courts in Rhineland-Palatinate granted him justice and his constitutional complaint led to success. We support this decision which can be seen as a challenge to involuntary treatment.<sup>9</sup> However, there remain problems as the judgment by the constitutional court does not explicitly declare involuntary treatment as generally impermissible<sup>10</sup>. In accordance with the CRPD<sup>11</sup> (Art.12, 14, 15, 17) and the CAT( Art.1)<sup>12</sup>; we are calling for a general prohibition of involuntary treatment and hospitalization as a matter of constitutional right.

### Recommendation:

- Compulsory measures as that inscribed in §1906 of guardianship law (§1906 BGB) and the mental health law of the Länder are neither in conformity with constitutional rights, the CRPD nor the CAT. Germany’s states must revise the Länder laws (see footnote 3) about mental health, hospitalization act, and abolish §1906 of the guardianship law.

## **2.) Nursing homes**

### **2.1) Use of high risk medication**

People with dementia are in need of intensive care, especially if a person shows extreme behaviour. Due to a lack of personnel in nursing homes in Germany and insufficient training, heavy sedatives, such as neuroleptica, are frequently used in large quantities when treating dementia of older persons.<sup>13</sup> This medication leads to an increased mortality risk: this psychopharmaceutical medication can have a strong sedative effect on the patient. A current

<sup>8</sup> For the constitutional judgment on Baden Württemberg (2 BvR 633/11 - April 2011) which declared an interim injunction, see [http://www.bundesverfassungsgericht.de/entscheidungen/rk20110421\\_2bvr063311.html](http://www.bundesverfassungsgericht.de/entscheidungen/rk20110421_2bvr063311.html)  
Also the regional court of Celle, that in his decision of August 3, 2011 has declared a general prohibition of involuntary treatment <http://app.olg-niedersachsen.de/efundus/volltext.php4?id=5718>

<sup>9</sup> Lawyer and human rights specialist David Schneider-Addae-Mensah sees big chances for this decision having impact on the regulations of involuntary treatment within the 16 states. “Formally Mainz’s law has been objected, whereas rules are similar throughout the states and the requirements of the constitutional court are not met throughout the country.”

<sup>10</sup> An overall prohibition had been the actual goal of the complainant.

<sup>11</sup> The Convention on the Rights of Persons with Disabilities (CRPD) states clearly that deprivation of liberty based on the existence of a disability is contrary to international human rights law, is intrinsically discriminatory, and is therefore unlawful.

<sup>12</sup> [http://www.ohchr.org/EN/UDHR/Documents/60UDHR/detention\\_infonote\\_4.pdf](http://www.ohchr.org/EN/UDHR/Documents/60UDHR/detention_infonote_4.pdf)

evaluation of 46 nursing homes within the region Munich (Bavaria) shows, that 51% of the patients living in these homes are being treated with this medication. As neuroleptica is a medication used in cases of psychoses, schizophrenia and psychomotor excitation, the number of patients to which it is administered in nursing homes is disturbingly high. The administration of this medication to persons with dementia can cause severe risks: heart strokes, symptoms of Parkinson's disease, unsteady walk and the inability to swallow.<sup>14</sup> Neuroleptica can also cause early death.<sup>15</sup>

## 2.2) Personnel and quality of care: development

- Situation of relatives functioning as care givers:

Mental or physical strain on persons caring for relatives can cause several problems: hard work, becoming ill themselves, and the mental strain and pressure to manage two jobs at the same time are some of the challenges. In general, relatives suffer from financial pressure. As an older person moves into a nursing home, an average of more than 50 % of the monthly costs have to be paid by pensions, private savings or by the support of children of the person concerned. It is mostly a difficult process to receive relevant information on how to apply for financial support to guarantee adequate care. As the reach of influence is very little, relatives must obey the rules of a nursing home which leads to the fact that it becomes very difficult to complain about inadequate care. Family members fear legal consequences and a ban on entering the nursing home.

Therefore specialists claim a support for caring giving relatives:

- an offer of case management (which would guarantee family members to continue their regular job)
- medical and psychological care and support in order to maintain their own health
- public recognition and support for efforts concerning the care of older persons
- support of exchange of experiences and aid services on local and national level
- family members shall be included and incorporated into the nursing concept of a nursing home
- co-determination in boards of nursing homes
- recognition of the value of voluntary care

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<sup>13</sup> A Cross-Sectional Study in 18 Homes for the Elderly in Berlin was published in the end of 2010 and can be found in English language including tables and figures under: <http://www.aerzteblatt.de/int/article.asp?id=74882>; see also: <http://www.zeit.de/2009/07/N-Neuroleptika>

<sup>14</sup> Symptoms mentioned by Dr. med. Jörg Lohse; see <http://www.br-online.de/bayerisches-fernsehen/gesundheit/gesundheitsmedizin-demenz-psychopharmaka-ID1309771564545.xml>

<sup>15</sup> A recent study on inadequate medication of older persons was published by the research network PRISCUS together with the Federal Ministry of Education and Research [http://priscus.net/download/PRISCUS-Liste\\_PRISCUS-TP3\\_2011.pdf](http://priscus.net/download/PRISCUS-Liste_PRISCUS-TP3_2011.pdf)

- Development of nursing care<sup>16</sup>

At the end of 2007, Germany had 2.25 million people in need of nursing care, 11.029 nursing homes (state run, privately run and non-profit), and 11.529 organizations providing nursing care to patients living at home. Approximately 32 % (ca. 716.000 people) were living in nursing homes, 22 % were looked after by mobile nursing services at home. 46 % were living at home and received nursing care solely from relatives.<sup>17</sup>

According to "Care Konkret," dated 12 March 2010, and the Süddeutsche Zeitung (German daily newspaper), dated 23 October 2010, by 2030 there will be at least 2.95 million people in need of nursing care in Germany. Already now there is a striking shortage of nursing care personnel in Germany. In 2000, we still had 2,800 nursing care trainees, by 2006/2007, the number had dropped to 1,400 according to "Heime in Not".<sup>18</sup>

- The quality inspections carried out by the medical service of the central health insurance organizations (MDS) in 2004 and 2007 revealed that approximately 41 % of its residents (ca. 293,000) in nursing homes in the Federal Republic of Germany suffered from an inadequate supply of food and liquids.
- About 307,000 residents were found to receive insufficient care in the treatment of injuries.
- The medical service of the health insurance organizations of the state of Rheinland Pfalz (Rhineland-Palatinate) found that approximately 40 % of the residents being fed by means of a stomach tube received an insufficient amount of nourishment.
- In nursing homes in the state of Hessen, 26 % of the residents were underweight, and 70 % were not provided with enough calories in their diet.
- A **study** published in June 2006, entitled "**Social Human Rights of Older People in Nursing Care**",<sup>19</sup> confirms that:
  - 384,000 people requiring nursing care who are looked after in their own homes and/or nursing homes do not receive an adequate supply of food and liquids.
  - in the case of 440,000 people there are serious deficiencies regarding prophylactic and therapeutic measures to avoid or deal with pressure sores (decubitus).

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<sup>16</sup>The international study RN4Cast (Registered Nurse Forecasting) by research staff of Berlin University of Technology examined how rationing of care services in nursing homes effects the quality of the care. The first data for Germany on this topic will be presented on November 25, 2011. <http://www.springerfachmedien-medizin.de/hamburg-pflegekongress-2011/450000.html>

<sup>17</sup> See the Annual Abstract of Statistics for 2009 published by the Federal Office of Statistics.

<sup>18</sup> Homes in Distress, No. 81, dated April 2009

<sup>19</sup> By Dr. Valentin Aichele and Dr. Jakob Schneider, commissioned by the "Deutsches Institut für Menschenrechte", the National Human Rights Institution of Germany.

- for 212,500 people suffering from incontinence there is no adequate care provided.
- approximately 400,000 residents of nursing homes are subjected to measures restricting their freedom of movement (bed rails, restraining devices applied to hands and feet).<sup>20</sup>
- According to a **study** conducted in 2008 by the **German Nutrition Society** (Deutsche Gesellschaft für Ernährung (DEG):
  - nearly two thirds of nursing home residents suffer from health threatening malnutrition or are even in acute danger.

Malnutrition leads to exhaustion, lethargy and apathy, loss of muscle strength, which increases the risk of falls and pressure sores, loss of personal autonomy, mental confusion, increased morbidity (e.g. impaired wound healing processes), and an increased risk of mortality<sup>21</sup>

#### Recommendations:

- Adopt measures to ensure that all health care and services, including therapies, provided to persons with disabilities, including all mental health care and services and therapies for persons with autism, is based on the free and informed consent of the person concerned, and that involuntary treatment is not permitted by law in accordance with the CRPD (Articles 14, 17)
- Ensure sufficient training and skills development of personnel of nursing homes, including human rights training.
- Eliminate the use of restraint and the forced administration of treatments such as neuroleptic drugs.
- Ensure that the Federal Agency for the Prevention of Torture and the Joint Commission of the States, as independent inspectorate bodies, also visit places of detention of persons with disabilities and older persons, including psychiatric institutions and nursing homes.

### **3.) Forced Sterilisation**

- According to German law, sterilisation is generally prohibited up to the age of 18 years (§ 1631c Bürgerliches Gesetzbuch - BGB). After that time, persons are free to decide for themselves.

However, § 1905 BGB describes under which conditions sterilisation of persons who are

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<sup>20</sup> See the above-mentioned study entitled “Social Human Rights of Older People in Nursing Care,” pages 38, 39 providing further evidence of human rights violations; numerous human rights violations are also mentioned in “Pflege in Deutschland” (nursing care in Germany), Journalmed., dated 14 June 2006

<sup>21</sup> See MDS, final report 2003, Nourishment and Liquid Supply of older People, pages 41, 42); see also university study of 2009, ZDF-Mediathek (Second TV Channel Media Library), 11 Sep 2009, Malnutrition in Nursing Homes.

unable to consent is permitted by law. In this case, operations have to be approved by the guardianship court.<sup>22</sup>

Between 2002 and 2010 an average of 100 cases per year of sterilisation of individuals whose legal capacity has been restricted were approved, whereas an average of 23 cases were denied.

The UN Committee on the Rights of Persons with Disabilities specifically recommended “to abolish the administration of medical treatment without the full and informed consent of the patient, in particular sterilization; and ensure that national law especially respect women’s rights under articles 23 and 25 of the Convention.”<sup>23</sup>

The European Group of National Human Rights Institutions recently intervened in proceedings before the European Court of Human Rights in a case against France concerning the forced sterilisation of women with disabilities in France,<sup>24</sup> as has a group of NGOs.<sup>25</sup>

### Recommendation:

- Repeal § 1905 BGB as forced sterilisation as it is in violation of the CAT and falls within the definition of torture because forced sterilisation is conducted on the basis of disability discrimination. It also violates Article 12 of the CRPD concerning the right to exercise legal capacity of individuals with disabilities, and Articles 16 and 17 of CRPD on freedom from exploitation, violence and abuse, and the right to protection of integrity of the person

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<sup>22</sup> Data about approved and denied cases are accessible through the website of the German Ministry of Justice [http://www.bmj.de/SharedDocs/Downloads/DE/pdfs/Betreuungsverfahren\\_1992\\_2010.pdf?\\_\\_blob=publicationFile](http://www.bmj.de/SharedDocs/Downloads/DE/pdfs/Betreuungsverfahren_1992_2010.pdf?__blob=publicationFile)

<sup>23</sup> CRPD Committee, Concluding Observations on Spain, CRPD/C/ESP/CO/1, September 2011, para 38.

<sup>24</sup> More info at: [http://www.institut-fuer-menschenrechte.de/uploads/tx\\_commerce/stellungnahme\\_gauer\\_u\\_andere\\_2011.pdf](http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/stellungnahme_gauer_u_andere_2011.pdf)

According to this paper sterilisation by whatever process without free and informed consent is never permissible and will constitute a breach of the right to be free from torture. Authors are referring to Art 12 CRPD, indicating that German law violates governing law.

<sup>25</sup> See third party intervention submitted jointly by the International Disability Alliance, European Disability Forum, Interights, Mental Disability Advocacy Centre and the Centre for Reproductive Rights; <http://www.internationaldisabilityalliance.org/ida-edf-and-three-other-international-human-rights-ngos-submit-written-comments-to-the-european-court-of-human-rights-in-the-case-of-gauer-and-others-v-france/>