DGKJP - Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie e.V. Geschäftsstelle • Reinhardtstraße 27 B • 10117 Berlin

Special Rapporteur on the right to health Mr. Dainius PURAS c/o
Office of the High Commissioner for Human Rights-Palais Wilson
United Nations Office at Geneva
CH 1211Genf 10
Schweiz

Berlin, 12.09.2017

Dear Mr. Püras.

the German Association for Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy had the pleasure to read your "Report of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".

Thank you so much for advocating children's rights also in the field of psychiatry.

Your report refers to important basic principles and objectives, concerning the psychiatric and psychotherapeutic care of children and adolescents. Nevertheless especially the more generalizing points of criticism are untenable for the German context. For this reason, we came up to point out some aspects of relevance concerning the CAP treatment of children and adolescents in Germany, maybe this may be helpful to you in order to demonstrate what can already be done, and is really effected in the world of child and adolescent psychiatry.

Thus, we are grateful if you read our statement and would be glad to hear from you soon.

With best regards

Prof. Michael Kölch und Prof. Renate Schepker

OHCHR REGISTRY

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Recipients: S.P.B.



Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie e.V.

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Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie e.V.

Statement of the German Association for Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy in response to the report from the UN-Special Rapporteur of the 28.3.2017 for the General Assembly (UN).

Michael Kölch, Mareike Alscher, Renate Schepker, Tobias Banaschewski, Hans-Henning Flechtner

Summary

The "Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" addresses the topic of mental health worldwide. The German Association for Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy (DGKJP) advocates deepening and widening debate about the general mental health of humanity, especially focusing on that of children and adolescents in all countries and societies. Children and adolescents must be able to grow up mentally healthy.

The Report refers to important basic principles and objectives, concerning the psychiatric and psychotherapeutic care of children and adolescents. It as well criticizes fiercely mental health care systems worldwide. From the perspective of the DGKJP especially the more generalizing points of criticism are untenable for the German context.

Central and in the report named objectives of an optimal psychiatric and psychotherapeutic care of children and adolescents, for which the DGKJP stands, are the abandonment of permanent institutionalization, as well as the orientation towards inclusion and improvement of care of children with mental disability and children of psychiatric ill parents. In the recent past, especially the latter named vulnerable group has obtained increased attention by the German Parliament. Overall, the German mental health care system distinguishes itself with a broad spectrum of treatment options for children and adolescents with mental health disorders. Up till now children and adolescents are still, with increasing demand, majorly treated by resident child and adolescent psychiatrists resident child well as and adolescent psychotherapists and by outpatient and ambulatory infrastructure.

Präsident

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Out of the perspective of the DGKJP the report comprises important statements and lack of clarity, which need to be revised for the German situation:

- The reference to the necessity for mental health services to be geographically and financially available everywhere is correct, however does not pay attention to structural requirements (lack of staff), which impede a regional widespread mental health care service immensely.
- The postulation to further mental health steadily and particularly under consideration of the UN Convention on the Rights of Persons with Disabilities (CRPD) is also an important concern, yet it ignores the current existing legal parameters in Germany. The SGB V calls for an indication based and economically justifiable service provision. Its cost-effectiveness principle is not compatible with the objectives of the CRPD.
- Critically viewed is a psychiatric and psychotherapeutic mental health care system, in which the involved actors cannot participate equally in its development. Child and adolescent psychiatry and psychotherapy (CAP) in Germany, represented amongst others by the DGKJP, the National Association of Clinical Directors in Child and Adolescent psychiatry, Psychosomatics and Psychotherapy (BAG KJPP) and the Specialist's association for child and adolescent psychiatry, psychosomatics and psychotherapy in Germany (BKJPP), commit themselves highly to the protection of children's rights and the improvement of participation of mentally ill children and adolescents and will continue to do so in the future. At the same time achievements could be recorded in the past, like an improvement in the protection of children from coercive measures (amendment of §1631b BGB) or establishing the possibility of home-treatment.
- The necessity to create inclusive living conditions for children and adolescents has been emphasized in the report, however due to the focus on selected disorders it has not been sufficiently elaborated, whereas for the DGKJP, an adequate participation of all children and adolescents with psychiatric disorders is important.
- The queried one-sided orientation to individual improvements of treatment does not suit the reality of the German child and adolescent psychiatry and psychotherapy. The report misrecognizes not only the politically visible efforts to improve prevention, but also the embodied realization, that it's only through cooperation of good structures in mental health care provision and improvement of access to individual therapy that the best quality of care can be ensured.

- The interaction between neurobiological aspects and mental health disorders is clearly disregarded in the report. It also criticizes the expansion of diagnoses and their missing validity. In both dimensions, from the view of the DGKJP, the current status of research of the German CAP is not sufficiently recognized. The CAP in Germany and Europe has always stood out for its fusion of pedagogic, sociological as well as developmental-psychological aspects. The integration of neurobiological and sociological research is inevitable for further enrichments of knowledge about psychiatric disorders.
- Rather superficial is the proposition of an overvaluation of psychopharmacotherapy. In Germany only few children and adolescents are treated via psychopharmacotherapy; there are no indications which suggest overprovision of minors with psychotropic drugs moreover a solid cost-benefit analysis in this area belongs to the basic principles of the DGKJP.
- Another point of criticism in the report states a shortened concept of evidence in the field of psychiatric and psychotherapeutic care. The DGKJP rejects an one-sided interpretation of evidence reduced to only economic aspects and has already committed itself to a broader interpretation of the term in practical and scientific regard (for example rejection of the tarification system for psychiatric care; implementation of several therapy studies at university chairs of CAP). This commitment, however, is impeded by the inadequate state of art in research on mental health disorders of children and adolescents in Germany and worldwide. For this reason, further efforts in research and care are necessary as well as the establishment of child and adolescent psychiatry as a compulsory subject in the course of medical, psychological and pedagogic studies, which is one of the central objectives of the DGKJP.

Statement

The special rapporteuer of the UN published the "Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" on the 23 of March 2017. Unlike the heading might suggest, this report solely discusses mental health, underlining the intention to reach a worldwide equality of efforts in mental health and efforts in physical health. From the perspective of child and adolescent psychiatry and psychotherapy (CAP) the health objective "There is no health without mental health" is welcomed.

Within the field of efforts for mental health partly harsh criticism is addressed to the orientation of psychiatric care, which is still neglected and seems, in the majority of the countries, to be enacted

by marginalization and "locking away" rather than real treatment and inclusion. Consequently extensive prevention and treatment approaches are demanded, which do not promote discrimination and exclusion, and exclude coercion. Further criticism addresses the adherence of psychiatry to a neurobiological paradigm, which is thought to contribute to the exclusion of patients. A social and community orientated research and care is claimed, which should be compatible to the Convention on Human Rights and the CRPD.

By doing this, it always needs to be kept in mind (by means of abstraction) that the rapporteur-statement refers to all UN Nations, and that developed health systems, like the German one, per se take a special position, so that some points of criticism apply less or rather need to be understood differently.

Thus, the German Association for Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy (DGKJP), generally welcomes this report, with some indeed very pronounced statements as to the necessity of better conditions for psychiatric wellbeing worldwide. Mental health is a topic which science, medical care, but also the society in all fields (like school, work environment, politics, etc.) need to embrace, and that deserves the same attention like other areas of health. This is of heightened importance when looking at the developmental perspective: for children and adolescents, approaches that lead to growing up mentally healthy are particularly meaningful, as half of the psychiatric disorders of adulthood start in childhood. They already involve the danger of chronification, in fact often it means a lifelong restriction of participation. There are important developmental thresholds to be mastered in this age span, which can often be endangered for the child due to a mental condition or high pressure, possibly leading to long-term consequences in many areas of life (such as school, education, etc.).

Yet out of the perspective of the DGKJP a few points of the report need to be amended relating to the situation in Germany. As suchlike statements might also confuse parents, families and the public, we think it is important to strike the following:

- As the report regards the situation worldwide, it naturally must be vague and in parts blunt. A few points, which the report names generalized, therefore do not apply to the situation in Germany. Particularly in Germany, a paradigm shift occurred in favour of a community orientated treatment and away from institutionalised accommodation. In the last 20 years, the average length of hospitalization of children and adolescents in CAP units was reduced to about a fifth of the time. A renaissance of the large treatment facilities is not recognizable in the in-patient field of CAP.

In contrast: in the last decades a regionalization took place, especially in the field of CAP, with an increase of offers close to the patient's residence. Equally, treatment in total has largely moved to outpatient care. This occurred due to the introduction of a social psychiatry agreement for the specialists in private practice as well as their numerical increase, such that now there are more doctors working in their own practice than at hospitals; as well as due to a quick expansion of day hospital treatments. Also, the "law for the advancement of care and reimbursement for psychiatric and psychosomatic services" (PsychVVG) provides new opportunities for outreach treatment. However, it certainly needs to be awaited if this will come to reality, due to many reasons (like refinancing).

The German care system for children and adolescents with mental disorders is highly differentiated and stands out with a broad spectrum of offers, to begin with early developmental aids, reaching up to advisory offices and school psychological offers and up to outpatient, part-time inpatient and inpatient child and adolescent measures. Such a differentiated system, seen internationally, surely is not the norm.

- In Germany innovative care models are promoted, such as the "continuum of care" at school (https://innovationsfonds.g-ba.de/projekte/neue-versorgungsformen/ccschool-continuum-of-care-school-verbesserung-der-versorgungskontinuitaet-bei-kindern-und-jugendlichen-mit-drohender-seelischer-behinderung.117). Regional offers, which are often more expensive and complex than large central institutes, must also be refinanced and recognized as a social task. Therefore we appreciate that the report alludes to this, and focuses its attention on the problematics of diverging economic and ethic interests and furthermore stresses that constant institutionalizing (explicitly of patients with mental retardation) cannot be an acceptable solution seen for long-term.
- We are astonished and alarmed that the report neglects to describe which obstacles, out of demographic reasons, remain for a changeover in the care systems of industrial nations. These offer in general, compared to newly industrialised countries, and regardless of all points of criticism, the best psychiatric care. Thus the development in Germany (lack of staff) makes it rather unlikely that widespread care could easily be maintained in the future, and hence for example centralization out of need for qualified staff is depicted as a real danger for the regional care.
- The report refers to the CRPD and states that the aim is to reach the highest possible level of mental health for each individual. Here a fundamental problem needs to be pointed out. The SGB V provides far from the highest possible standard of care for the

community of the insured, but rather the necessary and economic standard; both the providers as well as the insured are obliged to obey this economic guideline. The national policy is based on the principle of solidarity by insurance and does not primarily draw money from the state, therefore it implicates an incompatibility with the goals of the CRPD in the field of health care for people with disabilities. At this point the legal dichotomy is to be pointed out at least, as often the necessity of the duration of the inpatient stay for psychiatric patients is doubted regarding the economic guideline, for example in the procedure of the Medical Service of the Health Insurance (MDK).

- When the report states a misbalance between patients, institutions and opinion leaders concerning the enforcement of parameters in health care, then it is important to stress that in the field of the CAP, especially DGKJP and BAG KJPP committed themselves for the improvement of the protection of children from coercive measures (amendment of the §1631b BGB). This amendment improved participation and public control of custody and coercive measures and was initiated by DGKJP and BAG. Both a nationwide monitoring of the number and duration of coercive measures of children and adolescents as well as nationwide visitation committees could contribute to the protection of children's rights. DGKJP and the BAG CAP support their implementation. The participation of minors and parents in individual treatment and in the design of mental health care was an important topic in the report of a project named "Inventory and needs assessment for the care of mentally disordered children and adolescents in Germany", funded by the German Ministry for Health and carried out by "Action for the disordered". (http://www.apk-ev.de/projekte/psychischkranke-kinder-und-jugendliche/ueber-kiju/). Thus, the preservation of children's rights and participation of mentally ill children and adolescents are essential targets of the expert associations, and the criticism of the report does not apply to the situation of CAP in Germany - even though it is true that the rights of minors in the patient's laws are not yet adequately formulated, despite changes made in the year of 2016.
- It needs to be positively emphasized that in Germany, with the new legislation on reimbursement of psychiatric hospitals (PsychVVG) we were able to establish the option of replacing inpatient treatment with care in the domestic surrounding (as intensive home-treatment with the inclusion of the families). In the field of inpatient treatment, many possibilities exist to admit parents as well. Younger children (under the age of five) usually are not admitted on their own, but rather treated in a complex setting, which is differentiated and focused on the parent-child interactions. In

Germany there are only few offers especially for toddlers, and the report might be misunderstood to be saying these offers should be reduced further. That would be fatal. In Germany, day-hospital and outpatient care is widely extended, such that the large majority of children and adolescents with mental disorders are treated by child adolescent psychiatrists child or and adolescent psychotherapists in private practice (yet paid by health insurance). The "social psychiatry agreement", allowing for psychosocial teams in private practice who work like a multiprofessional hospital team, has already marked an important political step to move away from the "medical primacy" coined as "biomedical approach" in the report. In social psychiatric teams, psychologists, pedagogues and special therapists team up with the doctors.

- DGKJP supports the initiation of inclusive setups in the everyday environment of children with and without disabilities. This affects all children with mental disorders or (impending) mental disability, which often manifests itself in the field of education. Therefore it is irritating that the report explicitly names autistic disorders, but leaves unnamed many more frequent disorders, such as ADHD or depression in child and adolescent age. DGKJP considers that adequate participation of all children and adolescents suffering from any mental disorder is important. All the more frequent disorders, with the exception of adjustment disorders, are able to produce lifelong effects on participation, similar to autism. The principles named in (62) must apply for all disorders!
- It is welcomed that there is a focus on the special needs of children with mental retardation, as they are an especially vulnerable group. On part of CAP, we have warned against unacceptable care practices in some areas. The amendment of §1631b BGB mentioned earlier explicitly concerns this group. In the debate, DGKJP vehemently committed themselves for obligatory court-appointed patient backers, for a critical assessment of any deprivation of freedom, and for a reduction in the length of possible placement decisions.

In the context of the inclusion debate for schools, DGKJP and BAG KJPP opposed inadequate cuts in specific offers compromising the special needs of this group, after some federal states hastily tried to implement premature changes.

- We hold that the criticism in the report concerning our thriving for improvement of individual-based treatment is unnecessary, as well as unsettling from the viewpoint of our patients. Individual improvements are not to be minimized, even though health politics needs a broad approach also including prevention and changes in the parameters of care. We were able to demonstrate – taking the example of child abuse, neglect and sexual abuse - the importance

of both for improved care: prevention and parameters as well as individual improvement of the access to therapy at the same time. DGKJP believes that a diminishment of the efforts to reach an improved individual based treatment (on the psychiatric. psychotherapeutic and psychopharmacological level) unreasonable, especially when taking into account the individual suffering caused by mental disorders. This however is to be seen in the light of Germany making many efforts to improve prevention lately (nonviolent schools, hotlines, child psychiatric sponsorships in preschool through our foundation "Achtung! Kinderseele!" (www.achtung-kinderseele.org) psychiatric consultation in schools, indicated prevention groups programs after alcohol intoxication). Nevertheless, nationwide prevention has not been reached yet and the prevalence figures of mental disorders have by no means decreased in the population of minors.

- DGKJP fails to understand the openly phrased denial of neurobiological aspects in the origin and the upkeep of mental disorders in the report. This also applies to the criticism of the expansion of diagnoses and the assumption of their missing validity. Many studies could prove the stability of the phenomena, especially over the lifespan. Even if singular diagnostic criteria shift and change, there is an astonishing stability in the key features and symptoms, so that diagnoses are at least comparable to other medical disciplines in terms of the prognostic stability. A purely neurobiological orientation in psychiatry would surely be devastating, however this criticism is going too far. For sure, it is not justified to neglect social psychiatric research and research programs ought to induce a paradigm change towards a greater inclusion of social psychiatric questionings. But this is not helpful or useful in the sense of "either-or". On the contrary, all is about the integration of neurobiological research and social psychiatric research: the research into causes and consequences of trauma or resilience was able to exemplify the meaning of both factors, neurobiological as well as social, in the development of mental illnesses. Therefore, DGKJP feels that the criticism in this area is a little outdated and too generalized. The report does not mention where they obtained the evidence for the statement that the "field of mental health is over-medicalized" (19). A re-affiliation of child and adolescent psychiatry and psychotherapy into social pedagogics, which could be derived from the report and which under the keyword of de-medicalization was already broadly effected in the Netherlands, must be rejected due to various good reasons.
- We feel irritated by the uncritical and seemingly little reflected account in the area of psychopharmacotherapy. On behalf of CAP research groups in Germany, we very critically appraised the value

of antidepressants as to their benefits and side effects. A general "condemnation" however, as the report portrays, is not scientifically sound. Even the less can this hold for the antipsychotics. Here the report is missing differentiation and with this, it unfortunately loses in value. DGKJP has always stated that it is dangerous to overestimate the efficacy of pharmacotherapy and that a solid cost-benefit analysis needs to be done. We have criticized any excessive marketing for pharmaceuticals all the way.

Here it has to be known that psychopharmacotherapy is only prescribed to a minority of child and adolescent patients, the main treatment in all sectors of care being psychotherapy. However, therapy by psychotropic medication is also indicated to improve participation, because it may lead to a more rapid improvement of psychosocial functions.

- Regarding the pharmacotherapeutic development, there was hope in CAP to obtain a better scientific basis for benefits and risks due to the EU regulation on medicinal products for paediatric use (https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-1/reg_2006_1901/reg_2006_1901_en.pdf). It's aim was now also to examine substances already available on the market as well as new ones for children. This hope was not fulfilled in the area of psychotherapeutic drugs. Therefore, the term "over-medicalization" is all the more confusing. On the contrary we see a problem in the neglect of pharmacotherapeutic research in the field of the CAP at present. For now, no innovations with higher effects or fewer side effects are foreseeable, and drug safety data are generated inadequately. A German network for Therapeutic Drug Monitoring (TDM), scientist-based without commercial interests, exists for CAP to increase the safety of psychotherapeutic drugs (www.tdm-kjp.de). In Germany, it is not adequate to talk of an alliance with the pharmaceutical industry in the field of the CAP. In the contrary, mentally affected children and adolescents are still "therapeutic orphans". Suggestions for ethically balanced research are published , but far from being realized¹. A pharmaco- epidemiological

¹ Glennon J, Purper-Ouakil D, Bakker M, Zuddas A, Hoekstra P, Schulze U, Castro-Fornieles J, Santosh PJ, Arango C, Kölch M, Coghill D, Flamarique I, Penzol MJ, Wan M, Murray M, Wong IC, Danckaerts M, Bonnot O, Falissard B, Masi G, Fegert JM, Vicari S, Carucci S, Dittmann RW, Buitelaar JK; PERS Consortium (2014) Paediatric European Risperidon Studies (PERS): context, rationale, objectives, strategy and challenges, Eur Child Adolesc Psychiatry 23(12):1149-60; Kölch M, Ludolph AG, Plener PL, Fangerau H, Vitiello B, Fegert JM. (2010) Safeguarding Children's Rights in Psychopharmacological Research: Ethical and Legal Issues, Current Pharmaceutical Design, 16(22):2398-406; Persico AM, Arango C, Buitelaar JK, Correll CU, Glennon JC, Hoekstra PJ, Moreno C, Vitiello B, Vorstman J, Zuddas A European Child and Adolescent Clinical Psychopharmacology Network; Unmet needs in

monitoring would be essential. Data for Germany fail to demonstrate a general overprovision through exuberant prescription of psychotherapeutic drugs to minors.

- We agree to the conclusion in (20) and it puts the harsh criticism in the previous paragraphs into perspective. However, it is still vague and for example does not define where there is a limit to supporting parents balanced with the best interest of the child, which constitutes the real ethical dilemma of children with mentally ill parents. In Germany, DGKJP supported the efforts to establish networks of early support, which aim for this topic. Nevertheless, in Germany children of mentally ill parents remain an underserved and vulnerable group given too little attention. By now the parliament recognized this as well, so that the delegates passed a cross party resolution about this topic at the end of the legislature.
- The report scathes a 'biased use of evidence in mental health'. We want to stress that especially the German health system, the health insurances and policy-makers increasingly focus on such a term they understand one-dimensionally. Due to this reason, the DGKJP vehemently advocated against the reimbursement system for psychiatry, psychotherapy and psychosomatics (PEPP). This model originated from a simple "pay for performance" notion and reduced evidence to results of economic calculation. DGKJP actively works with its delegates in the scientific advisory board of psychotherapy. The advisory board occupy themselves with the efficacy and maybe harmful effects of psychotherapy treatments from the perspective of a high and differentiated scientific standard. Randomized controlled trials (RCTs), nevertheless, are only one possibility among others for bringing an efficacy proof. Unfortunately, it comes up that worldwide, there are no sufficient numbers of studies about children and adolescents. We undertook own efforts and hold a congress about psychotherapy research every year, by now entwined with the congress about biological research. In German CAP university chairs, diverse therapy studies are conducted, some with state funding. The scientific child and adolescent psychiatry and psychotherapy (note the naming) is a classic example of the breadth of research issues and translational research.
- Besides extended research, there is also a need to extend teaching. To our understanding, it is urgently necessary to make child and adolescent psychiatry to an obligatory subject in the university courses of medicine and of pedagogics, as nearly half of the mental disorders in adulthood already manifest in childhood.

Unfortunately, our subject is one of the few specialist disciplines not adequately represented in our university curricula. We actively commit ourselves to an adequate share of contents concerning the development and disorders of children and adolescents, within the reform of the psychotherapeutic education. In Germany and Europe, Child and Adolescent Psychiatry has always been a discipline which does not only contain psychiatric elements, but also pedagogic, social scientific as well as developmental psychological aspects. Therefore, any criticism of a one-sided biological orientation, also within research, does not apply; nor do we agree that policy-making by our expert association of the field of child and adolescent psychiatry and psychotherapy may neglect children's rights or inclusion. Nevertheless, we acknowledge that further efforts are needed in research and care, so that in the future, further support will be indispensable.

In conclusion, in regards to the report it is important to note:

- Generally it is welcomed that the special rapporteur of the UN focuses on mental health and acknowledges it as an important topic.
- Increased research in the sense of extensive research, encompassing other than biological aspects like research into service provision, social aspects and prevention, is appreciated.
- DGKJP supports the approach to overcome rigid system boundaries.
- In Germany however, many points of criticism do not apply to the care system for mentally disordered children and adolescents, especially concerning participation, overmedication etc.

Berlin, 11.09.2017