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Interface between Intellectual Disability and Mental Health: hermeneutic review

Interface entre Deficiência Intelectual e Saúde Mental: revisão hermenêutica

ABSTRACT

A literature review was conducted aiming to understand the interface between the Intellectual Disability and Mental Health fields and to contribute to mitigating the path of institutionalizing individuals with intellectual deficiencies. The so-called dual diagnosis phenomenon remains underestimated in Brazil but is the object of research and specific public policy internationally. This phenomenon alerts us to the prevalence of mental health problems in those with intellectual disabilities, limiting their social inclusion. The findings reinforce the importance of this theme and indicate possible diagnostic invisibility of the development of mental illness in those with intellectual disabilities in Brazil, which may contribute to sustaining psychiatric institutionalization of this population.

DESCRIPTORS: Intellectual Disability. Mental Disorders, diagnosis. Mental Health. Review. Intellectual Disabilities. Dual Diagnosis. Hermeneutic.

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RESUMO

Realizou-se revisão da literatura com o objetivo de compreender a interface entre os campos da Deficiência Intelectual e da Saúde Mental e contribuir para a mitigação da trajetória de institucionalização das pessoas com deficiência intelectual. Ainda subestimado no Brasil, mas constituindo-se internacionalmente como objeto de investigações e de políticas públicas específicas, o chamado diagnóstico dual alerta à prevalente ocorrência de problemas de saúde mental em pessoas com deficiência intelectual e sua consequente limitação aos processos de inclusão social. Os achados corroboram a relevância da temática e apontam possível invisibilidade dos processos de adoecimento psíquico das pessoas com deficiência intelectual no País, o que pode contribuir para manutenção de percursos de institucionalização psiquiátrica dessa população.

DESCRITORES: Deficiência Intelectual. Transtornos Mentais, diagnóstico. Saúde Mental. Revisão. Diagnóstico Dual. Hermenêutica.

INTRODUCTION

Although the field of Intellectual Disability and Mental Health share the same historical origin – both positioned in defending the rights of populations with a history of institutionalization rights –, each eventually followed their own paths.

All over the world, mental health has become a field of knowledge and practices about the precepts of deinstitutionalization and transformation of a model of care focused on psychiatric hospitals. Its consolidation occurred through the establishment of public health policies based on key conceptual, clinical, legal and ethical-political reforms^{2,34} that reoriented the goals of treatment and composition of a network of services required for new concepts.

In Brazil, mental health has been established as a public policy of the State, made possible by a legal apparatus that guides the reorganization of a service network sensitive to its clinical demands, expanded for the prospect of developing actions in community and social context.

The recent establishment of the Network for Psychosocial Care (RAPS),^a has standardized and made explicit the components and points of attention needed for expanding access and qualification of psychosocial care, among which are the Centers of Support for Family Health (NASF), the Centers for Psychosocial

Care (CAPS), social and culture centers and mental health beds in general hospitals. The refusal of psychiatric hospitals is explicit in the current policy, as a point of attention of RAPS, which we recognize as a step in the transition of the mental health care model.

On the other hand, the constitutive political and theoretical field of intellectual disability stems from the 2000s, with recent conceptual reformulations, including its own nomenclature. This term has been preferably used to as it refer specifically to the intellectual functioning, differing from scenarios of mental disorders. Thus, the deficiency is emphasized as a condition and must be addressed considering the verification of necessary support and changes in surroundings, e.g., people with difficulties in addition can use calculator. This scenario ensures social inclusion of people with Intellectual Disabilities.^{29,b}

The definition of Intellectual Disabilities currently used is that proposed by the American Association on Intellectual and Developmental Disabilities,¹ characterized by “significant limitations in intellectual functioning and in adaptive behavior as expressed in practical, social and conceptual skills originating before the age of 18.” The notion of disability has also been widely recognized, which gains perspective in the International Classification of Functioning, Disability and Health (ICF),³³ a complementary instrument to

^a Portaria 3.088, de 23 de dezembro de 2011. Institui a Rede de Atenção Psicossocial para pessoas com sofrimento ou transtorno mental e com necessidades decorrentes do uso de crack, álcool e outras drogas, no âmbito do Sistema Único de Saúde. *Diário Oficial União*. 26 dez 2011 [cited 2013 Nov 20]. Available from: <http://www.brasilsus.com.br/legislacoes/gm/111276-3088.html>

^b Sassaki RK. Inclusão social: os novos paradigmas para todos os grupos minoritários. São Paulo; 1997 [cited 2012 Sept 2]. Available from: www.entreamigos.com.br/temas

the International Classification of Diseases instrument (ICD-10) that, beyond the medical perspective, includes a corporate and environmental perspective.

The field of concepts and assistance for intellectual disability originates in social movements of people's struggle with disabilities, legitimized by the International Convention on the Rights of Persons with Disabilities – New York, USA, 2007 enacted in Brazil with an equivalent constitutional amendment,^c which states that:

“people with disabilities are those who have long-term physical, intellectual or sensory impediments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The great vulnerability of the population with intellectual disability in terms of violation of rights, deprivation of minimum support services and propensity to institutionalization is of particular concern due the lack of information on epidemiological data, and of publications to guide public policies and guidelines. The existing data are fragmented in most countries, especially among those of low and middle income where, paradoxically, there is a higher prevalence of intellectual disability.^{18,35}

Only beginning with the processes of deinstitutionalization, with the closing of psychiatric hospitals in various countries of the world, was care redirected for community-based mental health services, as well as the creation of social support institutions for people with intellectual disabilities.⁵

Specifically in the field of health, inequities can be observed between people with intellectual disabilities when compared to the general population.^{18,32} Besides the higher predisposition to develop other problems such as cerebral palsy, epilepsy, impaired communication, vision and hearing, and mental disorders,^{11,22} people with intellectual disabilities face significant barriers to care of their health,¹⁹ intensified by the difficulty of access to services, constituting a “cascade of disparities” as termed by Krahn.¹⁶

On the other hand, regarding the mental health scenario, it is estimated that more than a third of people with intellectual disabilities have associated diagnoses of mental disorders,^{5,8,9,24,28} a prevalence that has been justifying the international debate on the subject. In Brazil, despite major advances in reorientation of mental health care model, care for people with intellectual disabilities was not placed equally on the agenda in the field of public health policy.

This study aimed to understand the interface between the fields of intellectual disability and mental health and contribute to the mitigation institutionalization of people with intellectual disabilities.

METHODOLOGICAL PROCEDURES

Considering the unusual connection between various fields and the lack of production about on the proposed problematization, it was considered necessary to synthesize the usual and distinct strategies of literature review, seeking dialogue between different actors and productions that highlight the complexity of the subject and its necessary debate. For both, the propositions of Gadamer¹⁴ and Ricoeur²⁶ subsidized the way for a hermeneutics review to attain the desired goals (Figure).

For Gadamer¹⁹ Hermeneutics is a philosophical stance rather than a methodology. A method of construction of knowledge that recognizes the historicity of the researcher and the highlight of the object of study from the ‘fusion of horizons’ – past-present in the search for answers to current issues, not yet understood. The highlight moment of the object – without resorting to the usual “extract” – could allow his understanding without denying its production context,²⁰ besides containing its own principle of application. According to the author, questions emerge from an ‘effectual history’, which has an effect on the historical researcher and for whom the object is highlighted, creating sense that draws on the traditions that have dealt with similar issues.

We find, therefore, in the turning to the tradition, the possibility of effecting the hermeneutic circle of understanding, in which preconceptions can be revisited. The hermeneutic exercise started from our recognition of belonging to the tradition of Brazilian public mental health, and the transformation of our prejudices into issues – the only possible starting point for understanding, according to Gadamer.

Challenged by our professional experience, working daily with mental health services and intellectual disabilities, supervision of technical teams and in the development of evaluative research about Psychosocial Care Centers,^{21,23,31,d} we identified the presence of an important population with intellectual disabilities inserted in services based on the diagnosis of psychiatric comorbidities or on the grounds of lack of access to more appropriate offers.

Questions emerged from the experience that guided our research in available literature: the demand of people with intellectual disabilities for mental health services

^c Decreto nº 6949 de, 25 de agosto de 2009. Promulga a convenção internacional sobre os direitos das pessoas com deficiência e seu protocolo facultativo, assinados em Nova York, em 30 de março de 2007. *Diário Oficial Uniao*. 26 ago 2009:3.

^d Surjus LTLS. Narrativas políticas: o olhar dos usuários sobre os CAPS de Campinas [master's dissertation]. Campinas: Universidade Estadual de Campinas; 2007.

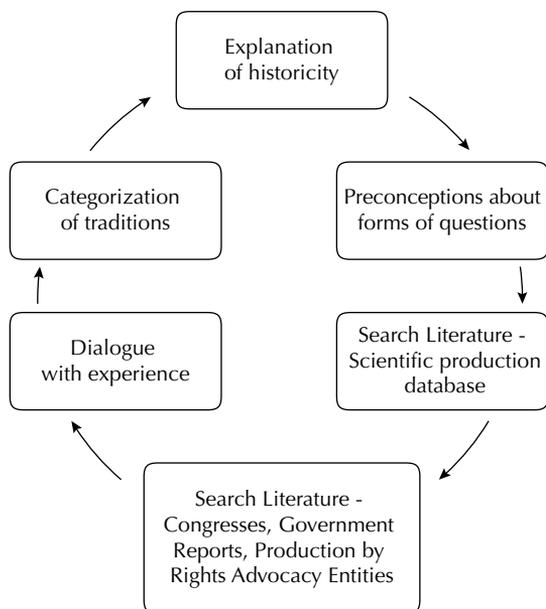


Figure. Flowchart proposed to operate a hermeneutics review.

is a result of the lack of other resources of assistance or expresses the vulnerability of these individuals to the development of mental health problems. What are the traditions that have been concerned with this issue? Has the interface between the fields been put into practice in the planning of public policies in progress?

Upon reflection upon the importance of tradition, Gadamer¹⁹ alerts us to the fact that traditions always speak in multiple voices, which would impose upon us the challenge of being attentive to the weaker voices, silenced and erased in history.²² Nevertheless, moving back to the initial question, the return to traditions that have been concerned with similar issues should, in our case, also consider and dialogue with productions considered non-scientific or “gray”.

Although it lies outside the field of disease, it has enabled people with intellectual disabilities to benefit from the establishment of public policies for social assistance, employment, housing and education. A process of care on the fringe of public health policies appears to have been established with assistance coverage almost completely guaranteed by services provided by charities and non-governmental organizations.

Therefore, the sites of organizations and associations, central to the historical development of actions for people with intellectual disabilities, as well as government documents and reports were also included with information sources in the searches in order to build a diverse and plural review.

Our search started from the Pubmed database under the keyword “intellectual disability and mental disorder”, full expression, with the inclusion criteria of original research and review articles, in English and Portuguese, full open access texts, published between 2000 and 2011, considering that it is a more recent production. Publications were excluded that were restricted to causes of intellectual disability related to children and adolescents and substance abuse.

For the proposed dialogue, books published in international conferences and forums were included, as well as manuals organized by associations for protecting the rights of people with intellectual disabilities and government documents.

Of the articles analyzed, 17 were recovered in the PubMed database^{3,4,8-13,15,17-19,24,27,28,30,32} seven comprised the gray literature.^{c,d,e,f,g,h,i}

Through dialogue between the findings and the authors’ experience, we proceeded to the free categorization of the main traditions that have been dedicated to investigate and understand the interface between the two fields, considering the diversity of interests and commitments that may involve the forces of different voices.

To proceed to the questioning of intellectual disability in interface with the mental health field in Brazil, it is necessary to make clear the points to be careful among which we can point out: (i) the study should not be understood erroneously as supporter of a contemporary trend of psychiatrization/psychologizing of life and human suffering; (ii) the clarification that the proposed discussion begins with the identification of an already present demand in mental health services, and not the proposition of a new demand for the same ones; and (iii) that it is not intended to deny the specificity of the phenomena in question, nor relabel intellectual disabilities to the status of disease, but to recognize that the challenge of inclusion should consider the impact of mental health problems in possibilities for social inclusion of people with intellectual disabilities, an issue that may be underestimated.

^a Martorell A, Mateos JLA. Discapacidad intelectual y salud mental: guía práctica. Madrid: Consejería de Familia y Asuntos Sociales; 2003.

[†] Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual (ES). Transtornos de La salud mental um las personas con discapacidad intelectual: declaración FEAPS. Madrid; 2007.

⁸ Barros S, Bichaff R. Desafios para a desinstitucionalização: censo psicossocial dos moradores em hospitais psiquiátricos do Estado de São Paulo. São Paulo: FUNDAP/Secretaria de Estado da Saúde; 2008.

^b Sistema Único de Saúde. Conselho Nacional de Saúde. Relatório Final da IV Conferência Nacional de Saúde Mental – Intersetorial; 2010 Jun 27/Jul 01. Brasília (DF); 2010.

[†] Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Linha de cuidado para a atenção às pessoas com Transtornos do Espectro do Autismo e suas famílias na Rede de Atenção Psicossocial do SUS. Brasília (DF); 2013.

We propose the following categorization of findings in different fields of knowledge, yet with clear connections between themselves, but with different emphases, considered in this review as in main “traditions” from which originate productions on the theme, namely, Psychiatry and Public Health.

PSYCHOLOGY – DOMINANCE OF SCIENTIFIC AND PRODUCTION CONCEPT OF DUAL DIAGNOSIS

The majority of findings are concentrated in this tradition, including scientific articles selected from searches on PubMed. The main issue which arose from significant concerns about the prevalence of mental disorders, or more broadly, of mental health problems in people with intellectual disabilities, with the concept of dual diagnosis, the expression of a new field of knowledge that falls on the “in between” – in the simultaneous occurrence of the phenomena of intellectual disability and mental disorder, objects often defined by their own differentiation.

If the historical separation between these fields led to the identification of specific care needs for each of these populations and conformation of knowledge and implementation of support services, a distorted view may also have been produced collaterally that these two phenomena could not coexist.²⁴

Although the dual diagnosis is not recognized in any of the diagnostic classifications, it has been used in international scientific literature to name some associations about people who “accumulate” different psychiatric diagnoses, such as mental illness and drug addiction or intellectual disability associated with mental disorders,²⁷ marking this dual condition as a new territory.

Advancing on the concept of comorbidity, notwithstanding that dual diagnosis seems to have arisen as an artifact to explain the occurrence of simultaneous phenomena that concentrated distinct efforts for their comprehension and consolidation of models of care, its proposition could also indicate the limitations of offers of health care oriented by diagnostic classifications, always insufficient for the complexity of the health-illness process. Specifically, with regard to mental disorders and intellectual disabilities, however, dual diagnosis appears only as a psychiatric subspecialty, and a field of identity of struggles for health care as a right.

Although there are many studies on the prevalence of mental disorders in people with intellectual disabilities, the variability of the terminology used both to conceptualize intellectual disability as well as mental disorder hamper the comparability of publications.³⁰

The lack of representativeness of the samples, the inability of the interviewer, the person’s own difficulties in understanding and saying what he/she feels, inadequate evaluation methods and limited diagnostic systems have been identified as factors that hinder the psychiatric diagnosis in people with intellectual disabilities, mobilizing efforts towards their qualification.²⁷

Diagnostics systems designed for use in the general population, such as ICD-10 and DSM-IV, have been considered inappropriate mainly due to the difficulty in obtaining subjective reports of symptomatology. New systems have been adapted or developed and are being used in epidemiological research in the UK, European Union and United States, such as The Diagnostic Criteria for Adults with Learning e Disability (DC-LD),⁸ Diagnostic Manual-Intellectual Disability (DM-ID)¹² e Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD).^{9,11}

Despite the recognition of the difficulties to establish reliable criteria for epidemiological studies, researchers discovered a prevalence between 30.0% and 40.0% of mental disorder in people with intellectual disabilities. Based on a biopsychosocial explanatory model, some authors have alerted to the buildup that people with intellectual disability would be considered having risk factors for the development of mental disorder.^{8,11,12,30}

Some genetic alterations and their predisposition to specific psychiatric disorders such as the case of Down syndrome and depression were identified; the alteration of thyroid function – one of the causes of intellectual disability and the consequent changes in behavior; and a iatrogenic due to the use of psychotropic drugs. Low self-esteem, low stress tolerance, common situations of abuse and hyper or hypostimulating environments, have been identified as psychological and social risk factors for the development of mental disorders in this population.^{3,9,17,18,j}

To the extent that the limitations of intellectual disability intensify, psychopathological symptoms are less elaborate and more difficult to assess. On the other hand, some patterns of behaviors common to people with intellectual disabilities, such as the existence of imaginary friends and talking to oneself, are sometimes mistakenly identified as symptoms and these patients are medicated with no indication that justifies such approach.^e

One aspect highly considered in the scientific field b manuals of associations defending the rights of citizenship is the recognition of the “eclipsing” effect of intellectual disability.²⁵ This concept refers to the frequent attribution of symptoms to the mental condition of intellectual disability disorders, becoming “eclipsed” psychopathology and consequently its necessary attention.

^j Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual (ES). Transtornos de La salud mental um las personas con discapacidad intelectual: declaración FEAPS. Madrid; 2007.

According to studies, people with intellectual disabilities, in addition to really suffering more from mental illnesses than people without disabilities, sometimes manifest different symptoms than the general population, often having their suffering trivialized.^{10,12,17,35} Thus, the issue of dual diagnosis has been considered a great challenging due to the intense suffering it causes in people, the difficulty of identifying it and the sensitive probability that these patients remain excluded from access to rights and social inclusion, if not ensured a solid structure of articulated support spaces.^{4,e}

It is possible to search for the limit of access established by the diagnoses in the experience with the various services. When a child admitted in a renowned institution for the disabled, then starts displaying inadequate, e.g., inappropriate behavior, with regard to increased aggression or the expression of sexuality, quickly the presence of a diagnosis of mental disorder is questioned. If confirmed, often the second diagnosis results in imposing the loss of quality services for the families and initiates a long search for access to mental health services. Many services offer concrete barriers to access, limiting the identification of certain diagnoses.

COLLECTIVE HEALTH – THE DEMAND FOR PROPOSALS FOR PUBLIC POLICY AND THE LACK OF INTERFACE BETWEEN THE FIELDS IN BRAZIL

Although the production of family associations in this study has been included in the public health category, by calling for reviews of the policies in place, it is necessary to consider that the published texts were based on the recognition of the high prevalence of mental health problems in people with intellectual disabilities, heavily supported by the findings of the psychiatric literature.

The difficulty of territorialization of care for people with dual diagnosis is due to lack of experience and skill of many mental health professionals with people with intellectual disabilities; by the pace of at which the person with intellectual disabilities includes himself in intense spaces; by the difficulty of management of mental health issues by professional services for people with intellectual disabilities.^f

On the grounds of lack of assistance to this population, some countries in Europe and the UK have been investing in the creation of subspecialty training – mental health in intellectual disability – and the implementation of specialized mental health services,^{3,4} following the example of mental health services targeted to people with problems related to drug use or infant-juvenile population. Such services appear linked to social policies or mental health with a variability in the organization model and articulation between them. In some experiments these services were designed from intersectoral coordination, and in others,

in cooperation from support provided by experienced personnel in specialized mental health services for intellectual disability.⁴ We identified the experience as similar to which was proposed by Campos in Brazil,^{6,7} as a specialized matrix of support, to which is added a welcome intersectoral perspective.

According to Bouras & Holt,⁵ the awareness of professionals and family members to recognize the possibility and vulnerability of mental health problems in the population with intellectual disabilities increases the chance of avoiding their neglect and caring for them in a more adequate way.

In Latin America there is limited information about people with intellectual disabilities in relation to epidemiological data as well as the processes of social inclusion, employment conditions, education and health. The few existing studies are generalized to the reality of other countries and point out a reality of exclusion, abuse, neglect and institutionalization in psychiatric hospitals, many of them in poor conditions and operated by non-governmental agencies.¹⁸

Historically, the care for people with intellectual disabilities emerged in Brazil in the areas of education and health, developed by philanthropic institutions. Even today, the reference of care for people with intellectual disabilities is almost entirely restricted to the same scenario, maintaining a certain welfare and charitable nature, being undeniable the pioneerism of these institutions in investing in this population.

Although it not established as a question in the country, population censuses of residents of Brazilian Psychiatric Hospitals show large numbers of people with intellectual disabilities still waiting for processes of deinstitutionalization.¹⁵

In the states of Rio de Janeiro¹⁵ and Sao Paulo,⁸ the population with intellectual disabilities configured the second highest percentage by diagnostic category among residents of psychiatric hospitals – 26.4% and 30.5%, respectively, surpassed only by psychoses. None of the publications, however, problematized these findings.

In the final report of the Fourth National Conference on Mental Health – Intersectoral^h (2010) one can find 26 resolutions that include the issue of intellectual disabilities, which seemed to indicate the start of an approximation of the fields in three areas: 1) recognition of the need for training mental health care teams in qualified mental health care for persons with disabilities, emphasizing intellectual disabilities; 2) approximation among vulnerable populations to strengthen equitable policies; 3) the claim to the rights guaranteed by the International Convention on the Rights of Persons with Disabilities, which expands the concept of people with disabilities and has the strength of a constitutional amendment in Brazil.

We also understand in this light the initiatives and concerns expressed by associations of relatives of autistic persons in Brazil, a field clearly placed in the “in between” previously pointed out, with the phenomenon being target of understanding in the spectrum of mental and behavioral disorders, as well as of neuro-developmental disorders, challenging the construction of new knowledge and being sometimes overlooked by the various service networks.

A theme that also appears with some frequency in the report of the Fourth Conference on Mental Health, a line of attention for care of people with autism disorders and their families in the Network for Psychosocial Care of SUS^l is a recent publication proposes the necessary approximation between the fields of mental health and intellectual disability from the perspective of the International Convention on the Rights of Persons with Disabilities, moving forward with the presentation of the program QualityRights^k of the World Health Organization as the first device for action in mental health, under the provisions of that Convention.

FINAL CONSIDERATIONS

Although there remain many obstacles in the process of diagnosing mental disorder, people with intellectual disabilities living with accumulation of risk factors for the development of mental illness. The voices heard by the research seem to converge on the limits of the processes of inclusion of people with intellectual disabilities, aggravated by the occurrence of mental health problems. This often translates into the negligence in maintenance of services both for the support network of people with disabilities as well as for the mental health network.

In Brazil, although public policies coexist in the both fields, questioning regarding the mental health problems of the population with intellectual disability does not seem to occur in either of them, despite the fact that two censuses of residents of psychiatric hospitals warn of the possible and silent destination. Besides vulnerability to mental illness, it is necessary to problematize the consequent marginalization of populations when health services are organized based on diagnostic classifications.

It should be emphasized, however, recent efforts in the direction of public health policies in Brazil with a view to establishing networks of health care, that bring the challenge of expanding the access and quality of care across all of SUS. It also seems historically timely the proposition of inserting the Network for Psychosocial Care and Care for People with Disabilities in the networks prioritized for deployment by SUS.^{l,m}

Notwithstanding the consolidation of such policies that have been put into effect by the establishment of national, state and municipal coordination efforts, driven and legitimized by movements and social control in the field of mental health, the Brazilian Psychiatric Reform continues to face constant challenges, involving several disputes of interests be they conceptual, ethical and/or political for overcoming asylum related problems of psychosocial nature.

In this sense, it becomes imminent to be aware of the silent permanence of psychiatric hospitals or spaces with new appearances despite the expansion of a substitute care network destined for the same purpose: to exclude populations upon which are imposed complex innovations of already known answers, as well as demanding sensitive changes within the scope of locations and social and spaces.

Despite advances in relation to other Latin American countries, there aren't to date directions, by the current policy, concerning the needs or means to support people with intellectual disability policy, except mentioning procedures that qualify for public funding. There is no scientific literature available addressing the effectiveness of proposed policies nor their degree of implementation.

However, the necessary process of connecting the networks follows a slow pace and this frailty seems to fall up on people with intellectual disabilities forgotten behind the walls of the old psychiatric hospitals. We therefore reaffirm the need for opening points of dialogue between managers and professionals of such networks, making them aware of the need for construction of training of access and mental health care for people with intellectual disabilities, as well as for joint processes of deinstitutionalization. To silence this question can mean the reproduction of historical segregation as a blind response to scenarios of lack of assistance and neglect.

^k World Health Organization. WHO QualityRights Project – addressing a hidden emergency. Geneva; [cited 2012 Sept 2]. Available from: http://www.who.int/mental_health/policy/quality_rights/en/

^l Portaria nº 4279 de, 30 de dezembro de 2010. Estabelece diretrizes para a organização da Rede de Atenção à Saúde no âmbito do Sistema Único de Saúde (SUS). *Diário Oficial Uniao*. 31 dez 2010; Seção1:88.

^m Decreto 7508, de 28 de junho de 2011. Regulamenta a Lei nº 8.080, de 19 de setembro de 1990, para dispor sobre a organização do Sistema Único de Saúde-SUS, o planejamento da saúde, a assistência à saúde e a articulação interfederativa, e dá outras providências. *Diário Oficial Uniao*. 29 jun 2011:1.

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