Indicators for assessing the integration of people with intellectual disabilities in Psychosocial Care Network

Indicadores de avaliação da inserção de pessoas com deficiência intelectual na Rede de Atenção Psicossocial

Luciana Togni de Lima e Silva Surjus[1], Rosana Teresa Onocko-Campos[2]

ABSTRACT The article presents indicators to assess the inclusion of people with intellectual disabilities in Psychosocial Care Network, built with the participation of the mental health service professionals. The results indicate the existence of previous barriers of access to mental health services when the finding of disability; of itineraries characterized by institutionalization, which take admission as the first access to treatment; and of lower investment in discussions on therapeutic projects by care teams. The proposed indicators are presented as a knowledge device of the necessary questioning of the psychosocial care to be addressed to people with intellectual disabilities.

KEYWORDS Health evaluation. Indicators. Mental health. Intellectual disability.

RESUMO *O artigo apresenta indicadores para avaliação da inserção de pessoas com deficiência intelectual na Rede de Atenção Psicossocial, construídos de forma participativa junto a profissionais de serviços de saúde mental. Os resultados indicam prévias barreiras de acesso aos Centros de Atenção Psicossocial quando da constatação da deficiência; itinerários marcados pela institucionalização, tendo a internação como o primeiro acesso ao tratamento; e menor investimento em discussões sobre projetos terapêuticos pelas equipes de cuidado. Os indicadores propostos se apresentam como um dispositivo de revelação da necessária problematização da atenção psicossocial às pessoas com deficiência intelectual.*

PALAVRAS-CHAVE *Avaliação em saúde. Indicadores. Saúde mental. Deficiência intelectual.*

[1] Universidade Federal de São Paulo (Unifesp) – Santos (SP), Brasil.
lucianasurjus@gmail.com

[2] Universidade Estadual de Campinas (Unicamp), Faculdade de Ciências Médicas (FCM) – Campinas (SP), Brasil.
rosanaoc@mpc.com.br

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Introduction

According to Minayo (2009), indicators are consisted of numeric, symbolic or verbal expressions created to measure, define parameters, or reveal some aspect about a phenomenon.

The construction of mental health indicators is still considered restricted when compared to other health areas either because the difficulty in establishing consensus for definition of parameters or the complexity of the object itself, which is consisted of subjective questions, of delicate objectification, and systematization required by an evaluation process (ONOCKO-CAMPOS; FURTADO, 2006; FURTADO *ET AL.*, 2013).

In the last decade, the access to some evaluation processes systematizing (OLIVEIRA *ET AL.*, 2014) with focus on Psychosocial Care Network services (Raps) (BANDEIRA, 2002; KANTORSKY *ET AL.*, 2009) has been possible, by means of Centers for Psychosocial Care (Caps) (WETZEL, 2005; SURJUS; ONOCKO-CAMPOS, 2011; GLANZNER, 2011, PITTA *ET AL.*, 2015); Therapeutic Home Services (FURTADO, 2006); Primary Health Care services; as well as by the use of psychiatric medication (ONOCKO-CAMPOS *ET AL.*, 2012; ONOCKO-CAMPOS, 2012). Some of the most recent studies are based on evaluation approaches of fourth generation (GUBA; LINCOLN, 2011), whose difference would be the structuring of inclusive and participatory processes (FURTADO, 2001; WETZEL, 2005; ONOCKO-CAMPOS; FURTADO, 2006; KANTORSKY *ET AL.*, 2009).

As for persons with intellectual disabilities (PCDI), there are scarce data on the Brazilian epidemiological situation, employment conditions, health and social inclusion, being data oriented to school inclusion procedures. The few existing studies reveal a reality of exclusion, abuse, neglect and institutionalization within psychiatric hospitals, many of them in poor conditions and operated by non-governmental bodies (MARTORELL *ET AL.*, 2008).

Although not clearly established as a matter to become a problem in Brazil, two censuses on the population living in Brazilian psychiatric hospitals revealed a large number of PCDI internees. In the States of Rio de Janeiro (GOMES *ET AL.*, 2002) and São Paulo (BARROS; BICHAFF, 2008), such population showed the second highest percentage by diagnostic category among the residents of psychiatric hospitals – 26.4% and 30.5%, respectively, only overcome by the psychoses.

In an assessing research regarding Caps of Campinas (SP) (ONOCKO-CAMPOS; FURTADO, 2006), it was noteworthy the need to better understand the phenomenon of PCDI insertion in Caps III, which, despite their non recognition as adequate demand for the structuring of those services, they showed at the time the third highest percentage of the population served, by diagnostic categories, adding up to 8.3%.

In what recent international studies are concerned, more than a third of PCDI is estimated to carry concomitantly diagnoses of mental disorders, what justifies the international debate on the topic (COOPER *ET AL.*, 2006; COSTELLO; BOURAS, 2006; PICKARD; AKINSOLA, 2010; SALVADOR-CARULLA *ET AL.*, 2000; SURJUS; ONOCKO-CAMPOS, 2014).

Thus, the study here described was developed with the aim of building indicators that may contribute to the evaluation and monitoring of PCDI insertion in Raps.

Methodology

As subproject of the ‘Mental health assessing research: indicators for the evaluation and monitoring of Caps III in the State of São Paulo’, this article adopted as study field the municipalities carrying Caps type III (Caps III), with 24-hour operation, in the State of São Paulo in 2011. The research was financed by the Fundação de Amparo à Pesquisa do Estado de São Paulo (Fapesp) by means of Fapesp Notice named ‘SUS Research: shared management in health’; process no. 2009/53130-3.

The effective integration and participation of social actors in the research contexts is becoming increasingly valued. In the field of service evaluation, and not only as to health services, there are still challenges to ensure such participation due to the diversity of actors to be involved and to the own validation and appropriation by the government of the results being produced by studies conducted under those prospects.

Bearing that concern in mind, the experience presented here was developed from the proposition of a course on evaluation of mental health services that provided reference spaces for assimilation of concepts and knowledge production about their own practice. It aimed the creation of assessment tool based on the direct dialogue with professionals and managers of Caps III in a training space that allowed participants to certification. Moreover, the proposed methodology encouraged the activation of other actors, such as users of the services and their families, of more extended teams, in addition to other services and actors from the territory to which professionals pertained (FURTADO *ET AL.,* 2013).

The course lasted one year and addressed central issues of evaluation processes, embodying themes inherent to the Caps identified in previous study, which concerned to the evaluation of those services in the city of Campinas (ONOCKO-CAMPOS, 2006; SURJUS; ONOCKO-CAMPOS, 2011). The course was organized and conducted in a partnership between Campinas State University (Unicamp) and Federal University of the State of São Paulo (Unifesp), creating two simultaneous working areas that involved students and professors of undergraduate and postgraduate degrees in public health, as well as invited professors.

As the search here addressed is based on indicators, analyzers and evaluation provisions built on a previous research (ONOCKO-CAMPOS; FURTADO, 2006), that material was taken for the purpose of organizing the course planning by its main themes: Caps Design, Management, Attention to Crisis, Professional Training, Group Practice and Therapeutic Project. They were added to other themes that proved to be critical and little in-depth at that time: Territory Work, Intellectual Disability (DI), use of psychiatric drugs and strategy of Autonomous Management of Medication (GAM), Therapeutic Residences and Recovery. So, throughout the course, the evaluation theme was also taken directly in some instances as transversally, through the axes adopted to compose the programming.

Each municipality indicated two participants per Cap III, provided a seat for the equipment coordinator. Seats for mental health articulators from Regional Health Boards (DRS) were also required, and a selection process took place whenever the number of people listed exceeded the availability. A total of 50 professionals and managers took part from all Caps (III) in the State of São Paulo, which, at that time, carried 26 services under activity 24 hours a day, being six in the city of Campinas, five in Santos, three in Santo André and Diadema, two in the cities of Casa Branca and São Paulo each, and one in the cities of Jundiaí, Barretos, Santa Rita do Passa Quatro, Ribeirão Preto, São Vicente and Rio Claro each. Just one Cap refused to participate.

Services were distributed following regionalization criterion, being the work centers organized as follows: Campinas assembled Caps III representatives from the city itself and from those of Ribeirão Preto, Santa Rita do Passa Quatro, Bebedouro, Barretos, Casa Branca, Jundiaí and Rio Claro; Santos assembled representatives from the city itself and from those of São Vicente, São Paulo, Diadema, Guarulhos, Santo André and São Bernardo do Campo.

The methodology applied in the course enabled the special qualification of actors involved in the development of indicators, offering subsidies for a greater mastery of concepts central to the evaluation and participatory processes. Thus, the survey favored the appropriation of a language that sustained it own, generating concrete anticipation of the use of coproduced products. The professionals involved returned to their services by developing the use of discussions and reflections with other workers, users and families with the aim to identify the criteria that could be applied in the evaluation of services. To this end, team meetings and general assemblies of services were useful as field of dissemination and contribution from and to the process.

As one of the mentioned research thematic axes (FURTADO *ET AL.*, 2013; SURJUS; ONOCKO-CAMPOS, 2011), the DI theme was dealt with reasoned on the course methodology, which included immersion field activities in each of the cities involved. In that specific theme, the activities consisted in the identification of the care network to PCDI within the service region, in the visiting to one of the institutions, and in the implementation of critical analysis over the PCDI insertion in the Caps. Such activities produced a preliminary mapping of the institutions chosen for service among the cities involved in the course.

The problematization of the interface between DI and mental health fields was proposed substantiated on the presentation of previous experiences in research and practice scenarios that justified such necessity, confirmed by findings of the hermeneutics review of literature (ONOCKO-CAMPOS; FURTADO, 2006; SURJUS; ONOCKO-CAMPOS, 2011).

The review was presented to participants by means of the exposition through dialogue to each research core. The theme discussion and in-depth analysis, as well as the construction of indicators, were carried out by means of Shared Appreciation Groups (GAP):

> GAP arise from the observation that a program or service cannot be reduced to written documents or to what was advocated by those who have conceived or managed them, but other sources should be taken into consideration, including the word spread informally, not leaving an accurate trace. (FURTADO *ET AL.*, 2013, P. 106; FREE TRANSLATION).

The device was developed in the context of the actions of self-assessment and strengthening of community organisms in Canada and Brazil (LAPERRIÈRE; ZÚÑIGA, 2007). It has been applied in qualitative evaluation research as to increase the participation and involvement of different stakeholders, thus producing evaluation processes that are appropriate and appropriable by the main actors involved in such services, a process favored by most horizontal and collaborative relations with the external evaluators – sometimes generators of mistrust and inhibition of the group under ‘evaluation’, which results in stereotyped responses to what would be ‘desirable’ (FURTADO *ET AL.*, 2013).

Expositions took place in the mornings, being the GAP carried out in the afternoons, in which the participants were divided into small groups; there were six groups in total, being three in Campinas and three in Santos. Every GAP counted on a same leader and rapporteur by group, chosen among university professors, doctoral students, master students, and undergraduates involved in scientific research.

The GAP was carried out in a way that each participant shared experiences on immersion activities previously to every theoretical discussion, propitiating a theoretical and practical dialogue and producing a collective summary of the day. All discussions were recorded by the rapporteur in a file visible to all participants, opened to changes so to become more reliable to the group understanding, being validated in the following meeting.

That material was processed by researchers based on the axes: consensus, dissent or propositions that led to criteria, dimensions or clues concerned to the construction of indicators related to the previously determined thematic axes. The material was resubmitted to the groups at the beginning of the following meeting for validation.

As for DI axis, the course provoked, by means of the dispersion activity, the visitation and mapping of institutions dedicated to PCDI care, the demand analysis and the reception in Caps, as mentioned, and the proposal of indicators respecting that specificity.

The GAP systematization occurred in conjunction with the participants, categorizing their argumentative nuclei. Such systematization generated some questions that became subject of prioritizations, creating the initial indicators to be discussed in a broad consensus-building workshop, from which emerged the proposed indicators *(chart 1)*.

Chart 1. Indicators proposed

Indicator Name	Definition	Interpretation	Data Source	Period	Method of Calculation
Insertion of user with Intellectual Disabilities (DI) in the Center of Psychosocial Care (Caps)	Insertion in Caps of DI user	Measures accessibility to Caps of DI user	- screening - census - record of Outpatient Health Actions (RAAS) - medical record	Biannual	Total number of DI users entered in Caps Number of users diagnosed with DI forwarded to Caps
Individual Therapeutic Projects (PTI) of shared DI users	Joint responsibility for the attention to DI user (construction of specialized network)	Measures the collective PTI construction of DI users entered in Caps	- medical record - team and/or mini team meeting records (reference team)	Biannual	Quantity of DI users sharing PTI with institutions that serve DI diagnosed people Quantity of DI users served by Caps
DI Residents in Residential Therapeutic Services (SRT)	Proportion of DI Residents in SRT	Measures the specificity of work in SRT based on the attendance of DI residents	- Housing census - Caps census - RAAS	Annual Note: not all units carry on SRT	Number of DI users residents in SRT/per year Number of users residents in SRT/per year

Results and discussion

The design of the study, which worked on education, research and extension concomitantly, proved to be quite appropriate to the intended objectives, generating in both fields – Campinas and Santos – good assiduity, interest and involvement of the participants. Immersion tasks were completed with commitment, but facing some difficulty in carrying out the proposed readings. There were also movement and reflection effects in teams of the services involved, based on the themes proposed. Both the course and the research revealed themselves a strategic space for the offer, to mental health, of knowledge accumulated in collective health for the construction of services evaluation.

We believe that such design redeems the sense of collectiveness, allowing workers to know the differences and similarities among services of the various regions of the State of São Paulo, from which we hoped to find more in common than the absolute shared diversity of their practices.

The mapping of the institutions supporting PCDI along the immersion in the field made explicit a range of services consisting, in its entirety, by institutions of philanthropic and special educational character, of very little variation, formed of family associations, and the only public institution presented in the mapping concerned with the long permanence, showing, yet, a gap in political guidelines and a fragmented scenario, of few joints (SURJUS; ONOCKO-CAMPOS, 2013).

It is noteworthy that such perspective became worldwide consolidated from changes arising from the World War II and the birth of the welfare state, with the emergence of family associations willing to protect relatives with disabilities and to administering specific services. Notwithstanding the fact that such movements are overcoming boosters of religious and mystical theories, they ended up generating postures predominantly protective in services and educational models inevitably infantilizers, influenced by a medical culture characterized by the ideal of rehabilitation in specific places, aiming at a hypothetical and future cure (LEPRI, 2012).

Along GAP debates, sensitive questions regarding the appropriateness of PCDI inclusion in Caps arose, leaving the access to service to the discretion of the professional chosen to carry out the initial reception of the day. In some services, the fact that professionals face disability issues seems to anticipate the refusal of the insertion in the services, even before more qualified evaluation of the accessing reasons.

On the other hand, in some institutions supporting PCDI, mental health problems are used as a criterion for access exclusion in a way that such information is recorded in existing protocols. It is striking, however, that description of the cases arriving to Caps reveals a worrying reversal of the proposed route in the structuring of the Raps based on Bill nº 10216/2001, which determines that the hospitalization would be the last resource to be triggered.

It was noteworthy that many of the PCDI have, even today, the internment in psychiatric hospitals as first offer in the field of mental health, being justified by serious situations involving total absence of support by the families and the complete exclusion of social conviviality possibilities. The recurring situation of abuse and the important social vulnerability of people currently included in the Caps are also reported. The incoming of cases from Caps addressed to children and teenagers is perceived as recent by the participants.

The logic that substitutes the asylum model, which relies on Caps as Raps articulator, stays suspended when the professional insecurity, justified by the assistance emptiness of reference services to DI, does not allow him to envisage partners for such attention, highlighting concerns that Caps reproduce social segregation. However, sometimes became clear the movement, previously to the host of that population by Caps, of restricted actions regarding the identification effort of the institutions to which forward that population, there being very little criticism of that culture.

The study of Montobbio and Lepri (2008) reflects the maintenance effects of crystallized conceptions of artificial spaces aiming at the integration, and the consequent reinforcement of bounding the PCDI to eternal infantilization. It reflects the world of formal work as the only consistent way to produce both the processes of PDCI emancipation and the change of social representation about future prospects for that population.

The reproduction of the stereotypical perception of PDCI needs was only revisited by the group of participating professionals when they recognize the symptoms associated to the category of mental illnesses. However, the insertion of that population in Caps has been restricted to social spaces, without major investments in case discussion team meetings or construction of Unique Therapeutic Projects (PTS) (SURJUS; ONOCKO-CAMPOS, 2013).

We recognize that it is not uncommon, in paradigmatic changing processes, the contradictory coexistence of different perspectives regarding the offers of support and care also to people with disabilities as to people with mental disorders, among charitable or tutelary, criminalizing and biomedical conceptions (LEPRI, 2012; FOUCAULT, 2006). It is worth remembering that, paradoxically, in the period in which most progress has been made in different classifications between insanity and idiocy or mental retardation, it was also when the doors of the asylums were definitely opened to PCDI (FOUCAULT, 2006).

It dates back the 1990s, however, the consolidation of a biopsychosocial understanding model, inspired on overcoming successful experiences of mental institutions and special educational institutions that conceive disability as resulting from multiple dimensions – biomedical, psychological, social, cultural and political – related among themselves (LEPRI, 2012). Such dimensions have been materialized by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and by the United Nations Convention on the Rights of Persons with Disabilities (BRAZIL, 2009), which have not yet found enough absorption by professionals working in the field of psychosocial care.

Many developed countries have moved from a model of large institutions and health home care to smaller environments within the community along with the growth of the independent living movement. Countries such as Norway and Sweden, and other Eastern Europeans, have already overcome approaches based predominantly on institutions, deploying community care services that include day treatment centers, adopting home support for people with disabilities resulting from processes of deinstitutionalization, promoting the decentralization of management to local governments and the expansion and diversification of social services and service providers, which, in Brazil, are more noticeable in Raps proposals than in the field of disability.

Some Caps professionals recognize, however, that the population carrying DI is already under the care of Caps, using strategies like specific groups to implement most appropriate proposals, evaluating relational gains from the insertion into service, and offering support to families and questioning them as to what they expect as good results. There is also the identification of the recent search of partnerships with institutions for DI as for actions addressed to egresses from psychiatric hospitals, residents of Therapeutic Residential Services (SRT).

Due to many emerging dimensions in the proposed training course, we consider successful that, in an unprecedented agenda, three indicators have been prioritized regarding the theme disability, among the 17 elaborated, including the various themes worked on evaluation research; quantitatively, the theme was equivalent to the importance given, for example, to the 'therapeutic' project.

Conclusions

Although not encompassing all aspects to be explored, we believe that the indicators here prioritized have the potential of evincing to managers and professionals the matter relevance, rescuing it from the invisibility and silence to what has been reduced in order to contribute to the deepening required to the structuring of more appropriate and effective responses.

Actually, the questioning provoked along the course was, for the vast majority of participants, the first moment of contact with the theme psychosocial care at PCDI, generating a consensus about the need to highlight and denaturalizes the arrival, the insertion and the care of those people in Raps. The confirmation regarding the institutionalization path in psychiatric hospitals reaffirms the responsibility of Caps as articulator of a replacing network to the asylum model. However, in face of a so early questioning, we chose not to set a parameter to what would be expected in terms of PDCI insertion in Caps. Even considering that we could exceed, in the absence of similar studies, the estimate of 40% arisen from researches on the prevalence of PDCI mental health problems, the first indicator proposed had the aim to produce a more qualified approach regarding the demands of that population, potentially producing new evidence. To this end, it proposes the recording of such data, favoring the team to better understand and evaluate the needs for search service, what allows for greater knowledge of reality, and producing information that may encourage future comparative studies.

The inclusion of therapeutic homes as *locus* of PCDI mapping in Raps accrued from the finding that a significant part of the population in the process of deinstitutionalization, often held off from the own care in and of Caps, has DI, fact that is rarely taken into account in the proposing projects of care and inclusion. Here, we suggest that, based on the indicator monitoring built in the proposed time interval, teams may, in addition to the knowledge of the resident specific needs, produce information on the access broadening of that population to the deinstitutionalization processes.

As for the possibility of a partnership with the institutions of PDCI support, one of the indicators was proposed with the aim of highlighting the lack of social support of families, as well as of boosting Caps to search for unknown and possibly under appropriated partnerships. We propose that, regarding such indicator, the rapprochement among most of the cases under monitoring be promoted in a partnership with the care network to the person with disabilities.

Along the course, we realized that the possibility of exchanges among the actors of different units reverberated on the daily life of the services. The ways to deal with certain issues, forms of organization and management of practices were shared, as were the possibilities to carry on the clinic, being the process learning leveraged by participants, who reported stories of major mobilizations and changes caused by the proposed design. Thus, we verified a proactive posture of professionals, more attentive to the context of their practices, as to demands and problematizations concerning PDCI psychosocial needs.

Within the GAP, similarly, the meetings served as an opportunity for greater knowledge and reflection on the own substituting network configuration in each territory or municipality. When, for example, they shared equipments that made up the care network to DI, several participants were surprised to ‘find out’ other services that could compose the care extended to that population, generating other capacities in the working process and clinical proposals. The critical perception about Caps and the unfolding from evaluation looks seem to have grown.

We can affirm that the complexity of the research design was a successful strategy for the effectiveness of the different actors participation, constituting as much a space of generating information for research as of a forum for discussion, appropriation and intervention over the course of service organization, within which one can make use of different possibilities of promoting debate and group interaction. Our study also highlights that mental health professionals and managers can build indicators and consensuses whenever they are well grounded on an appropriate and participating methodology.

Authors

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