


A study on admitting children and adolescents into institutions for people with disabilities


Estudo sobre o acolhimento de crianças e adolescentes em instituições para pessoas com deficiência

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Abstract

This study seeks to investigate the care institutions for people with disabilities in São Paulo State and analyze the admission of children and adolescents to these services. This is a qualitative descriptive study with a cross-sectional sample. In its first stage, this study mapped the institutions in different free-access registers of public and contracted services, tied to federal, state, or municipal management in the areas of childhood, social assistance, and health. In its second step, data were collected by reading the medical records of a specific institution. As a result, this study points to the lack of a single typification or specific regulation, the absence of deinstitutionalization practices, and the lack of coordination with the intersectoral network. Results also show that the recurrent institutionalization of children and adolescents in these institutions and describes the characteristics of this practice: the occurrence of transinstitutionalization, hospitalizations via judicial determination, and lack or precariousness of territorial services and intersectoral actions. Finally, this research points to the need for implementing substitutive networks and developing intersectoral actions of care for children and adolescents and highlights the key relevance of further developing knowledge about the institutionalized population. **Keywords:** Mental Health; Public Health; Institutionalization; Child Advocacy; Child.

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Resumo

Este artigo tem como objetivo investigar as instituições de acolhimento para pessoas com deficiência no estado de São Paulo, assim como analisar o acolhimento de crianças e adolescentes nestes serviços. Trata-se de pesquisa qualitativa, de caráter descritivo e corte transversal. Na primeira etapa de coleta de dados, o estudo realizou um mapeamento das instituições em diferentes cadastros, de livre acesso, dos serviços públicos e conveniados, ligados à gestão federal, estadual e municipal nas áreas da infância, assistência social e saúde. Na segunda etapa, a coleta de dados ocorreu por meio da leitura de prontuários em uma instituição específica. Como resultado, o estudo indica ausência de tipificação única ou regulamentação específica, assim como a falta de práticas de desinstitucionalização e desarticulação com a rede intersetorial. Os resultados revelam, também, que a internação de crianças e adolescentes é recorrente nessas instituições e retratam características desta prática: ocorrência de transinstitucionalização, internações via determinação judicial e falta ou precariedade de serviços territoriais e de ações intersetoriais. Por fim, é apontada a necessidade de implantação de redes substitutivas e desenvolvimento de ações intersetoriais de atenção para crianças e adolescentes. Além da fundamental relevância de aprofundamento sobre a população institucionalizada.

Palavras-chave: Saúde Mental; Saúde Pública; Institucionalização; Defesa da Criança e do Adolescente; Criança.

Introduction

The concept of abnormality in childhood begins to be structured in the 19th century in France from the “discussion of the notion of mental retardation, as constituted by Esquirol even before 1820, under the name of idiocy” (Bercherie, 2001, p. 130). The concern around describing, classifying, and curing idiots propelled the entry of psychiatry into the field of childhood. Thus, “abnormal” children, rather than emerging from mad children, do so from the “figure that nineteenth-century alienism, from the emergence of embryology and the respective notion of development, helped to produce: the idiot” (Lobo, 2018, p. 19).

Note that the formulations on the causes and reversibility of idiocy introduced the notions of instinct and development in childhood psychiatry (Lobo, 2008), fostering the establishment of practices and institutions to control and correct abnormal persons. Abnormality, unlike the disease, represents a deviation from the norm, taking a status of dangerousness that must be contained, observed, and educated (Foucault, 2006).

By the end of the 19th century, idiocy is considered one of the categories of abnormality and ceases to encompass all childhood deviations (Lobo, 2008). The concept of abnormality, forged from the figure of the idiot, is disseminated into the field of childhood and then to the entire social body. Thus, “psychiatry becomes an instance of society in defense against the dangers that undermine its inner core, these dangers are incorporated into the figure of the scientifically identified abnormal” (Nascimento, 2020, p. 32; our translation).

The care provided to “abnormal” children was provided in specialized (mostly asylum-like) institutions, based on the need for medical-pedagogical intervention in an adequate establishment. Note, however, that theoretical distinctions between madness and idiocy failed to “mean the hospitalization of both in different establishments—they remained together to constitute the so-called ‘mentally ill,’ definitive objects of psychiatry” (Lobo, 2008, p. 261; our translation). Thus, “crazy,” “delinquent,” “weak,” and “idiot”

children have shared the same spaces of exclusion (such as psychiatric hospitals, specialized clinics, and shelters for people with disabilities) for decades. We should, then, highlight that the fields of mental health and disability (especially intellectual disability) share a long history of socially excluding children and adolescents.

In Brazil, during the colonial period, self-care practices and specialized knowledge ignored childhood. At that time, charity (mostly foster care institutions) aided the “needy” without any specific care practice or action for children with disabilities or mental health-related issues.

The transition to a republican government was marked by numerous changes in the political and social context and in moral conceptions and values. The Brazilian political elite was at the forefront of the development project in the country, allied with hygienist medicine to establish new government and population control strategies. According to Ribeiro (2006, p. 30), “medical science becomes powerful and influential in society, receiving from it and its constituted political powers the ‘authorization’ to discover, propose, and impose health and balance norms that would benefit that society” (our translation). At this juncture, childcare significantly changes because medicine, supported by positivist and evolutionary theories, deemed it as the primordial period for intervention and behavioral adequacy. Thus, the assistance to “abnormal” or “irregular” children comes to be considered as fundamental to form a healthy society. According to Lobo (2018, p. 84), children “came to be considered the future of the country, which, in turn, needed good citizens; therefore, it became necessary to prevent future social burdens (...) and deviant conduct” (our translation). Thus, “child psychiatry emerges from a process of social protection, to which the prophylactic interests of psychiatrists and the disciplinary requirements of social apparatuses converged” (Cervo; Smith, 2014, p. 445; our translation).

The theoretical productions of French psychiatry on mental deficiency, of North American psychiatry on delinquency, and of European eugenic and hygienist ideals greatly influenced the concept

Brazilian psychiatrists adopted of abnormality and the model of care for children considered abnormal; a model marked by philanthropic asylum institutions. Thus, at the beginning of the 20th century, the notion was spread on “the importance of assistance to children and adolescents, mainly because they represented a differentiated future for the Brazilian nation,” at the same time, “a set of measures was engendered based on a hygienist logic of normative-legal inspiration, which greatly expanded the offer of closed institutions for the care of children and adolescents, mostly under the tutelage of the philanthropic field” (Brasil, 2005, p. 7; our translation).

Therefore, the beginning of the history of abnormal child care in Brazil is marked by an emphasis on institutionalization as “the institutionalized surveillance of childhood establishes a disciplinarization in which guardianship and coercion are taken as protective measures.” (Cervo; Silva, 2014, p. 446). Thus, “children and adolescents who were rejected, orphaned, disabled, delinquent, abnormal, defective, and alienated became targets of an intense institutionalization that took place through asylum establishments destined for them” (Lobo, 2018, p. 84; our translation), such as orphanages, reformatories, asylums, etc. Thus, the “culture of institutionalization” established itself in Brazil at the end of the 19th century and lasted until the mid-1980s (Rizzini, 2005).

The effects of institutionalizing children and adolescents become the object of studies only from the second half of the 20th century onward, pointing to “a consensus around the idea that institutionalization itself opens a favorable field for the configuration of various risk situations” (Parra; Oliveira; Maturana, 2019, p. 157; our translation). This long institutional permanence proved to be a damaging factor to these individuals’ physical and mental health and their socialization process (Rizzini, 2005) since institutional environments can hinder the “physical, intellectual, emotional, and social development of children separated from their families and placed in institutions due to inadequate stimulation or motivation, the lack of a

consistent involvement or contribution of caregivers, lack of rehabilitation, and other deprivations.” (HRW, 2018, p. 5; our translation). Institutionalization has also had lasting consequences, contributing to the chronification and worsening of pre-existing health conditions and loss of skills.

This evinces that the practice of institutionalizing children and adolescents failed to produce its intended effects, such as furthering development, alleviating symptoms, and controlling behavior. On the contrary, the practice ruptured affective bonds and decreased autonomy, resulting in a huge contingent of institutionalized subjects. Thus, although asylum institutions for abnormal children—such as specialized clinics, shelters for people with disabilities, and psychiatric hospitals—were created to offer protection and care, we find in them “reports of mistreatment, unnecessary prolongation of hospitalizations, and inadequate and distorted therapeutic proposal” (Oliveira; Valença, 2020, p. 9; our translation). These institutions also often faced overcrowding (Lobo, 2008) and violated children and adolescents’ rights in institutional environments.

From the 1980s onward, especially after the redemocratization of Brazil and the promulgation of the 1988 Federal Constitution, a reordering in the legal and assistance field determined the replacement of asylum practices by social policies of social inclusion and deinstitutionalization in several areas.

Regarding childhood, the Statute of the Child and Adolescent (ECA) (Brasil, 1990) defines this population’s specific rights and establishes a doctrine of integral protection. This law seeks to hinder the practice of institutionalizing children and adolescents in nursing homes and establishes guidelines for the elaboration of public policies, interrupting the dispersion of private and philanthropic assistance during most of the 20th century. Thus, “institutional care has undergone significant changes... particularly in the period following the approval of ECA” (Rizzini, 2005, p. 31; our translation).

ECA establishes the right to family and community coexistence and regulates institutional admission as a provisional and exceptional

protective measure. Thus, if determined, the measure should ensure community participation and family tie preservation and promote the return to families or integration into a surrogate family. Care services for children and adolescents are currently linked to the Unified Social Assistance System (SUAS) and classified as high complexity services within the National Social Assistance Policy. Thus, whether public or private, reception services must align themselves with the rights established by ECA, the guidelines of the National Social Assistance Policy and the National Plan for the Promotion, Protection, and Defense of the Right of Children and Adolescents to Family and Community Living (Brasil, 2006), and the recommendations in the Technical Guidelines on Reception Services for Children and Adolescents (MDS, 2009b) and the National Typification of Socio-Assistance Services (MDS, 2014).

Admission services must then admit 20 children or adolescents at most and meet a heterogeneous demand, being, therefore, prohibited of providing exclusive care based on the specific characteristics of children and adolescents, such as health conditions (the case of disability, for example). Thus, as the Technical Guidelines 3 indicates, “specializations and exclusive care should be avoided – such as adopting very narrow age groups, directing care only to a certain gender, exclusively serving or refusing to serve children and adolescents with disabilities or living with HIV/AIDS” (Brasil, 2009, p. 68; our translation). When necessary, specialized care “should be ensured through an articulation with the service network” to guarantee children and adolescents with disabilities or specific health needs “access to treatments, medications, specialized services, and health equipment, as well as the necessary support to the family” (p. 46; our translation).

In the field of disability, the ratification of the United Nations Convention on the Rights of Persons with Disabilities (Brasil, 2007), the National Plan for the Rights of Persons with Disabilities (Brasil, 2011a), and the Statute of Persons with Disabilities (Brasil, 2015) are fundamental legislative frameworks to acknowledge and guarantee rights

and replace asylum practices by social inclusion policies. Decent housing, for example, is established as a right of persons with disabilities and can be achieved “within the family... or in housing for independent living” (Brasil, 2015; our translation).

To disrupt the logic of isolation and segregation of people with disabilities in nursing homes, the National Social Assistance Policy established Inclusive Residence as an institutional admission service to house “young people and adults with disabilities who do not have the conditions for self-sustainability, temporary or permanent family safeguard, or who are in the process of disconnecting themselves from long-term institutions” (Brasil, 2014, p. 454; our translation). Inclusive Residence constitutes, therefore, a substitute service for asylum institutions and aims to “favor the progressive construction of autonomy, social, and community inclusion and the development of adaptive capacities for daily life” (p.45; our translation).

In the field of mental health, the replacement of the asylum model by the psychosocial model of care is determined by Law No 10.216/2001, which reorients mental health treatment by substitute services in psychiatric hospitals. The National Mental Health Policy establishes the psychosocial care network (Brasil, 2011b), recommends care by intersectoral actions between territorial and community-based services, and sets the Therapeutic Residential Service (Brasil, 2000) as an alternative housing for residents of psychiatric hospitals to support mental health users without sufficient family and social support and ensure them an adequate living space.

Therefore, the 21st century witnessed numerous advances in childhood and public policies toward acknowledging and guaranteeing human rights. Deinstitutionalization, established as a guideline of national social assistance and health policies, “has as its starting point the affirmation of subjects’ citizenship and dignity.” (Braga, 2019, p. 211; our translation). Thus, in the last two decades, substitute centers and services in networks linked to the SUS and SUAS have been implemented to care for

peoples’ mental health and disability. Regarding housing services specifically, current data point to 243 Inclusive Residences (Brasil, 2022b) and 813 Therapeutic Residences (Brasil, 2022a) in Brazil.

However, the process of deinstitutionalizing and replacing the current care model occurs gradually. The country has closed asylum institutions and implemented a substitutive network. In this context, research to evaluate the services and care practices carried out in the field of childhood are fundamental to monitor and improve public policies. This means that “evaluative processes acquire a political function of serving as an instrument to boost substitute practices to the hospital-centered model” (Costa; Colugnati; Bonzati, 2015, p. 3244; our translation) as they can “reverse or minimize obstacles, as well as enhance the provided care.”

In Brazil, the institutionalization of adults and children with disabilities is a historical phenomenon, which remains to this day (Almeida, 2012; Cubas, 2016; HRW, 2018; Paula, 2008; Ricardo, 2011; São Paulo, 2017). National data on services linked to SUAS contain 125 admission services for people with disabilities that are not classified as Inclusive Residences (Brasil, 2022b). According to Leite (2011, p. 71), “the demand for sheltering still persists, especially when we refer to the specificity of children and adolescents who have disabilities and/or mental disorders and who, therefore, have different needs and require specialized care and treatment” (our translation).

Thus, this study aims to evaluate admission institution actions toward people with disabilities and analyze the practice of admitting children and adolescents into these services in the state of São Paulo. The belief of the “need to build concrete efforts in the area of health to improve the practice of rights and respect for socially marginalized, discriminated, and stigmatized populations” (Malvasi; Dantas; Manzalli, 2022, p. 3) anchors this research, which ultimately aims to show the factors contributing to maintaining institutionalization and subsidize intersectoral policies and deinstitutionalization and social inclusion actions.

Methodology

A mixed approach with a descriptive character and a cross-sectional section was adopted in this research. Its methodological procedures were developed to map and characterize institutions and collect information about the admission of children and adolescents. Notably, this study only encompasses the admission services not typified as Inclusive or Therapeutic Residences.

The surveyed institutions are unrelated to the state, constituting mostly of social entities, private foundations, and non-profit associations in Brazil. Thus, the information on these services is very fragmented across different areas of activity, forms of funding, and linkage to the State. The diversity of contracts, certifications, and concessions and the lack of information integration across public agencies cause the inexistence of a single registry capable of gathering data on these institutions and the served population. According to Paula (2008, p. 23), “we do not even know the exact number of existing institutions and, much less, information according to their types or the quantitative and qualitative characterization of the served population, as well as the forms of agreement, subsidies, and existing aids” (our translation). The Public Ministry of the State of São Paulo corroborates this scenario, commenting on “the impossibility of specifying where such services are located in the current public care policies as a result of them not effectively fitting the typification of the equipment of the social assistance or health network” (São Paulo, 2017, p. 5; our translation). In view of this, dimensioning all these institutions depends on the intersectoral commitment of public and private actors. Thus, a convenience institution sample was investigated in this research.

The first stage of data collection consisted of mapping admission institutions for people with disabilities in São Paulo State. Thus, different registers of public and affiliated services linked to federal, state, and municipal management in the

areas of childhood, social assistance, and health were used in this study in view of the dispersion of information on the surveyed institutions. Thus, the database used to map institutions consisted of the following public documents as our primary collection source:

- National Registry of Health Establishments (CNES);
- SUAS Census;
- Registration of the Certification of Beneficent Social Assistance Entity in Health and Social Assistance (CEBAS);
- Registration of social entities affiliated with the State and Municipal¹ Secretariats of social development, health, and people with disabilities²;
- Registration of social entities registered in the State and Municipal¹ Councils of Social Development, Health, Rights of Children, and Adolescents and Persons with Disabilities³
- Civil Inquiry 033/17 (São Paulo, 2017)

However, most used registers display only general identification data on institutions and it is impossible to find, in some cases, their target audience or provided type of care. Thus, a second stage was performed to collect mapping and characterizing information. In it, data were collected on websites or during institutional visits and recorded in a form with the following categories: municipality, target audience, and purpose; financing and agreement with the public sector; number of received people; number of residents under the age of 18 years; and number of residents above 18 years of age.

In the third data collection stage, the medical records of a specific institution were read to gather information about children and adolescents’ psychosocial profile and institutional paths to admission. For this, our information collection form was based on the instrument used in the Census of Residents of psychiatric hospitals of

¹ Municipality of São Paulo

² When available for public access on the Secretariat websites

³ When available for public access on the Council websites

the state of São Paulo (Cayres et al., 2015), which recorded sociodemographic (place and date of birth, municipality of residence, schooling, family income, tutors' schooling) and clinical characteristics (diagnosis, syndromes and associated diseases, date and reason for admission, used medication) and information about the care provided in the services of the network for children and adolescents (referral service, care received, lawsuits).

The information collected in forms was systematized and coded, forming our research database. With this material, our analysis used statistical studies to both generate descriptive statistics of variables and linear regression techniques and correlation and factor analysis to find patterns and relationships between variables and categories.

This research was approved by the Research Ethics Committee of the School of Public Health at Universidade de São Paulo and by Plataforma Brasil – CAAE: 02769018.1.0000.5421. Information was strictly collected from medical records, thus avoiding contact with the surveyed population. Moreover, results were shown in such a way as to preserve the data identifying the researched institutions and admitted subjects and guarantee the secrecy, privacy, and confidentiality of this information.

Results and discussion

This study found 28 institutions for people with disabilities in eight municipalities in São Paulo State, with 1851 admitted people in the surveyed services. This result is relevant since, although this study only covered a sample of institutions, it shows an important contingent of people institutionalized in these services within the state of São Paulo. This study also shows that, among the total admitted population, at least 193 were children or adolescents and 606 had been admitted during their childhood or adolescence, corroborating results of previous research indicating the admission and institutionalization

of these individuals despite legislative advances regarding care and attention in mental health and disability (Almeida, 2012; Cubas, 2016; HRW, 2018; Paula, 2008; Ricardo, 2011). According to Rizzini and Almeida (2011, p. 70), “the naturalization of the (often permanent) confinement of children and adolescents with disabilities must be overcome. Data point to their long institutional permanence, despite it constituting a violation of the rights of these children and adolescents” (our translation).

This study also shows that at least 16 institutions simultaneously served adults, children, and adolescents. The institutionalization of these populations in the same institutional space dates back to the asylum scenario and represents a violation of rights since the admission of children and adolescents must occur in specific services for them.

In addition to these results, this research found three main operating characteristics common to the surveyed services. The first of these is the absence of a single classification and specific regulation aimed at institutions for people with disabilities, i.e., we observed that institutions differ from each other regarding their objectives, legal provisions, forms of financing, and public agreement.

Regarding service classification, this study notes that the surveyed institutions are typified in different ways, such as:

- Specialized hospital⁴;
- General Hospital⁵;
- Institutional admission service;
- Institutional Admission Service for Children and Adolescents (SAICA);
- Diagnosis and Therapy Support Unit⁶

We also observed discrepancies regarding the legal nature of the institutions, which range from:

- Private association;
- Religious organization;
- Individual Limited Liability Company;

4 Hospital aimed at providing health care in a single specialty/area.

5 Hospital aimed at providing care in basic specialties by specialists and/or other medical specialties.

6 Isolated units whose activities help to determine diagnoses and/or complement patients' treatment and rehabilitation.

- Private Foundation and Limited Liability Company

This research also shows disparities regarding available goods and resources. Institutions often have different simultaneous forms of financing, such as: agreements with the public sector; acceptance of funds, inputs or products; volunteer work; allocation of funds by parliamentary amendments; Continuous Care Benefit for patients; and private investments. A previous study also described this scenario, indicating that “funding for institutions comes from various sources, including from states and municipalities, religious groups, private foundations, and individuals, including from foreign countries” (HRW, 2018, p. 16; our translation). Note that the judiciary power contributes to this plural State funding by determining admission in such institutions.

We should also add that this study portrays unequal care capacities (ranging from 6 to 560 admitted people) and asymmetrical human resources frameworks. Thus, we found no standardized care practices during admission. Each institution develops them according to its typification and form of financing. According to Paula (2008, p. 25), “the predominance of the religious-charitable character or that of a health unit and the fact that it is or considers itself a public, philanthropic, or private entity is what determines the real differences” (our translation). Therefore, the heterogeneous structure of these institutions hinders the establishment of care guidelines and the deinstitutionalization and social inclusion processes of admitted subjects.

The second characteristic common to these institutions is their asylum functioning, which this study found in the lack of social and community participation for the admitted and the perennial character of their hospitalization. Surveys in the last two decades describe similar results and point to the absence of deinstitutionalization practices, with rare cases of dehospitalization and family return (Almeida, 2012; HRW, 2018; Paula, 2008; Ricardo, 2011; São Paulo, 2017). A survey conducted

in São Paulo, for example, describes death as the main reason for severance (São Paulo, 2017).

We also found the weakening of family ties and the restriction to the institutional space after admission. Our analysis of the data collected in medical records on the occurrence of visits and outings during a year (2018) showed a proportion of five times more visits than outings. Departures also have a greater frequency interval since the number of months without visits, on average, is 6.7, against 10.8 months without outings. The total number of visits in three consecutive years – 2016, 2017, and 2018 – points to a relevant occurrence: a 22% reduction in the number of visits, from 12.6 visits per patient in 2016 to 9.8 in 2018. Thus, we observed that hospitalization in the researched institutions restricted family contact to the institutional environment and reduced family members’ visits during the length of hospitalization.

The results of research such as Paula (2008), Ricardo (2011), Almeida (2012), São Paulo (2017), and HRW (2018) also indicate that institutions maintain little dialogue with the intersectoral network. The analyzed records show that admitted subjects attend no education, social assistance, leisure, or culture equipment and that health and rehabilitation care practices (occupational therapy, physiotherapy, psychiatry, psychology, nutrition, dentistry, etc.) are mostly carried out within the institution.

Thus, we claim that admission to these institutions (as in psychiatric hospitals) restricts subjects to the institutional space, weakening family and community bonds and impeding the exercise of citizenship. Thus, Almeida (2012, p. 85) classifies the asylum network for disability as “the fusion of shelter devices and psychiatric hospitals, in which we find an interconnection between the practices of asylum originating from the field of Social Assistance and Health” (our translation).

Finally, the third institutional characteristic refers to defining target audiences by diagnosis. As in psychiatric hospitals, institutions are structured around admitted subjects’ “deviations,” i.e., they establish diagnostic criteria for admission

to the institution, reducing “the subject and their complexity into only an object: an affirmed disease” (Braga, 2019, p. 202; our translation).

We found the following distinct definitions of target audience in our surveyed sample:

- People with physical and mental disabilities;
- People with Autism Spectrum Disorder (ASD);
- People with physical and mental disabilities and ASD;
- People with Cerebral Palsy (CP);
- People with CP and ASD;
- People with mental disabilities;
- People with special needs.

We should stress, however, that the asylum functioning of the surveyed institutions avoided the impact of diagnosis on the target audience, which, in some cases, is established in a rather vague way. Instead of providing specialized care, institutions maintain the practice of institutionalizing “abnormal” children and supporting the asylum model of care. Thus, the institutionalized population shows hybrid mental health and disability demands and should, therefore, be the target of public policies in both fields.

The separation between mental health and disability was fundamental for the “identification of specialties in the care of each of these populations and in the conformation of knowledge and implementation of support services” (Surjus; Campos, 2014, p. 536; our translation). Likewise, recognizing the intersection zones between these fields proves to be essential to develop public policies that meet the real needs of this population. Mental disability and ASD are points of intersection between these two fields and represent the main target audiences of the surveyed institutions. Thus, the promotion of deinstitutionalization actions in the surveyed institutions configures an urgent task for both the field of disability (especially mental disability) and that of mental health.

Regarding the practice of admitting children and adolescents in the surveyed institutions, our analysis of the information on this population’s profile evinced distinct institutional trajectories,

followed by children and adolescents, together with their families, up to admission to the researched institution. The recognition of the characteristics of each of these institutional paths constitutes an important result of this study as it highlights the context and operation methods of the services that produced the need for admission.

Trajectory 1 is marked by judicial determination as a reason for admission, representing 30% of infant and adolescent patients. This result agrees with research in psychiatric hospitals, which also describes hospitalizations of children and adolescents via court orders. As a reason, we found complex situations, such as social vulnerability, neglect, lack of access to treatment, precarious family support, and abandonment. Thus, as with psychiatric hospitalizations, admission via court order emerges as a measure to ensure care or access to treatment in complex situations that, in reality, involve demands in several areas in addition to mental health and disability. This finding indicates that the protection and right to health premises for this population can serve as a pretext for arbitrary social control. This means, according to Resende (2008, p. 106), that the judiciary, “when responding to this social provocation, often acts in a diametrically opposed sense to the inclusion and rescue of the life project, (...) imbued with a gigantic deception, in the sense of seeking the forms judged most ‘effective’ and ‘instantaneous’ of ‘recovery’” (our translation).

However, note that, rather than stemming from the isolated action of a field or service, institutionalization arises from the relation between the health system, justice, education, social assistance, etc. Thus, overcoming the institutionalization of children and adolescents in nursing homes necessarily depends on expanding the debate and articulating actions between care networks and the justice system.

This study portrays a second trajectory common to children and adolescents, characterized by multiple hospitalizations and institutional admission. It also found that 16% of the cases were referred by psychiatric hospitals, 14% by SAICAs, and 12% by other institutions admitting people with disabilities. Our analysis of length of stay in referring

institutions showed that hospitalizations last, on average, 31 months in institutions for people with disabilities and 7 months in psychiatric hospitals. Thus, in addition to multiple hospitalizations, children and adolescents already had a long period of institutional experience prior to their admission.

That 14% of cases had been referred by SAICAs is an important finding of this study—also described in other studies (Almeida, 2012; Ricardo, 2011)—as it shows that protective admission measures often result in referrals to nursing home institutions and perennial social exclusion.

Trajectory 2 shows, therefore, that a significant portion of children and adolescents underwent readmissions and transfers between various institutions. This phenomenon, known as transinstitutionalization, can be observed in cases in which “the ‘static’ of segregation in a separate and total institution has been replaced by the ‘dynamics’ of circulation between specialized services” (Rotelli; de Leonardis; Mauri, 2001, p. 23; our translation). Thus, in analogy with the allegory of the Ship of Fools, we can say that a portion of children and adolescents navigate between various asylum institutions and that the ultimate destination of this trip will be their chronification and institutionalization. In other words, the flow of referrals and rereferrals between institutions, instead of producing actions and responses consistent with the needs of this population, establishes a “mechanism that feeds the problems and makes them chronic” (Rotelli; de Leonardis; Mauri, 2001, p. 23; our translation).

Trajectory 3 comprises cases referred by public agencies or services (24%) and family members (14%). The main reasons for admission in these cases were due to a lack of territorial services, difficulty in accessing treatment, absence of home care, and difficulty in school inclusion. This trajectory portrays situations in which the lack of territorial services or their precariousness and intersectoral actions contributed to institutional admissions and expose gaps in the implementation of the substitutive network. Thus, the State, despite being the author of public policies, perpetuates the asylum practice due to its lack of investment in a substitutive network and its slowness in implementing it.

Thus, this study points to the consolidation of an intersectoral network in the field of childhood and adolescence as the first task to eliminate practices of social exclusion. The articulation between services of different fields and levels of complexity is fundamental to produce effective responses to children and adolescents’ needs.

Final considerations

The main contribution of the study is showing the continuity of the institutionalization of children and adolescents in institutions that admit people with disabilities. Moreover, this research shows that the admission of children and adolescents into these services results from complex situations determined by factors related to the characteristics of subjects, family contexts, and public service networks in several areas. This study also portrays the information scarcity about children and adolescents in these institutions and considers it crucial and urgent that this theme be taken as an object of investigation since dimensioning the current situation is fundamental to subsidize actions of deinstitutionalization and “readjustment of public services or those provided by private entities (social organizations), so they align with the normative parameters for their proper functioning” (Brasil, 2021, p. 43; our translation). Thus, discontinuing the asylum model depends on implementing substitutive services, strengthening family care practices, developing intersectoral actions, and conducting research to evaluate the functioning of childhood and adolescence protection and care networks.

The process of deinstitutionalization not only requires closing asylums, but also makes it “necessary to dismantle all the mechanisms that erupt in situations of objectification of people, of hospitalization in psychiatric institutions, of institutionalization” (Braga, 2019, p. 207; our translation). In this context, institutionalizing children and adolescents indicates “a complex of formal and informal actions that enforces long permanence as a social practice in the face of the need for a public response to people with disabilities”

(Almeida, 2012, p. 153; our translation). This means that the disability asylum network is a problem that “will not be solved by focusing only on the issue of institutional care. It is linked to macroeconomic and political circumstances that must be faced in parallel so that boarding schools cease to be an attractive option for children” (Rizzini, 2005, p. 36; our translation).

This study, therefore, stresses that it is fundamental that admission institutions for people with disabilities be removed from obscurity, deemed the responsibility of the public power, and included in mental health and disability discussions and actions. Couto (2008, p. 10) also points out that, in childhood and adolescence, overcoming institutionalization in the asylum network for disability “is an ethical and civilizing imperative that does not entail postponement or simplification” (our translation).

Finally, we should mention that this study only had access to a sample of institutions, which is insufficient to describe the entire disability asylum network. This research, then, reaffirms the importance of conducting a census survey that covers all these institutions, as that São Paulo State conducted with psychiatric hospital residents. Another limitation of this research refers to its exclusive use of medical records to collect patients’ profile data since these records contain superficial information about the characteristics of the served population. Thus, we recommend that future studies use, in addition to medical records, other information collection instruments, such as the International Classification of Functioning, Disability, and Health, and interviews with employees and admitted subjects to diversify information sources and include the institutionalized population and workers’ perception on institutions and the demands necessary for deinstitutionalization.

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