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INTEGRATED VIEW OF SUPPORT PROCESSES ON AUTISM SPECTRUM DISORDER

VISÃO INTEGRADA DOS PROCESSOS DE SUPORTE RELATIVOS AO TRANSTORNO DO ESPECTRO DO AUTISMO

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ABSTRACT

Autism has been treated in a fragmented way by different research areas, and integrative studies are needed. Little is known about the effects of public policies on each other, as well as the effects of their lack of coordination. The objective of this work is to develop a broader and more integrated approach to the support processes offered to people with autism, contributing to the progress of public policies and research related to the issue. Through bibliographic review, an integrated model of processes was developed that can holistically follow people with ASD throughout their lives. The main processes identified are: Diagnose early; offer multidisciplinary treatment; provide inclusive formal education; prepare individuals to work; refer professionals to the job market; adjust the work environment; monitor the adaptation process; provide assistance and accompany the elderly. The paradigm according to which the needs of people with ASD are met universally, through integrated support processes, is still far from being realized. The present work, far from exhausting the question, aims to make it more evident.

Keywords: Autism. Autism spectrum disorder. Support processes. Public policy.

RESUMO

O autismo tem sido tratado de forma fragmentada por diferentes áreas de pesquisa, sendo necessários estudos integrativos. Pouco se sabe sobre os efeitos das políticas públicas entre si, bem como os efeitos de sua falta de coordenação. O objetivo deste trabalho é desenvolver uma abordagem mais ampla e integrada dos processos de apoio às pessoas com autismo, contribuindo para o avanço das políticas públicas e pesquisas relacionadas ao tema. Por meio de revisão bibliográfica, foi desenvolvido um modelo integrado de processos que pode acompanhar

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holisticamente as pessoas com TEA ao longo de suas vidas. Os principais processos identificados compreendem: Diagnosticar precocemente; oferecer tratamento multidisciplinar; fornecer educação formal inclusiva; preparar indivíduos para trabalhar; encaminhar profissionais para o mercado de trabalho; ajustar o ambiente de trabalho; monitorar o processo de adaptação; prestar assistência e acompanhar os idosos. O paradigma segundo o qual as necessidades das pessoas com TEA são atendidas de forma universal, por meio de processos de suporte integrados, ainda está longe de se concretizar. O presente trabalho, longe de esgotar a questão, visa torná-la mais evidente.

Palavras-chave: Autismo. Transtorno do espectro do autismo. Processos de suporte. Políticas públicas.

1. INTRODUCTION

Among the various developmental disorders, autism spectrum disorder, ASD, has stood out for its high prevalence, which reaches over 1% in several studies (Baio et al., 2014; Christensen et al., 2019; Sun et al., 2019). A person with autism may have several problems associated with communication, socialization, repetitive and stereotyped behaviors and hardships related to his sensory apparatus, in a wide spectrum of manifestations (Klin, 2006; Posar; Visconti, 2018; Seltzer et al., 2003).

The difficulties of people with autism and their families are significant, since ASD is a condition for life, and can be incapacitating, or even be associated with severe comorbidities, which requires individualized care (Karst; Van Hecke, 2012; Lin; Huang, 2017; Mcstay; Trembath; Dissanayake, 2014). On the other hand, people with autism, receiving adequate support, can in many cases continue their studies, exercise professional activity and start a family, or at least acquire higher levels of autonomy and quality of life (Austin; Pisano, 2017; Rast; Roux; Shattuck, 2019; Robertson, 2009; Smith et al., 2015; Wehman et al., 2013). The objective of this work is to contribute to the development of a better support network through a broader and more integrated approach to the support processes offered to people with autism, contributing to the progress of public policies related to the issue (Roux; Shattuck, 2019; Robertson, 2009; Smith et al., 2015; Wehman et al., 2013). Providing appropriate treatments and care services to this entire population has been a challenge for the community.

The state, together with the private sector and civil society are three major forces that act in offering support to people with ASD and their family groups, constituting a support network associated with autism (Freitas, 2016; Leopoldino, 2017a; Shepherd; Waddell, 2015). The state apparatus offers its own assistance services, publishes regulations on health, education and other sensitive issues for people with autism and encourages research, among several other activities (Freitas, 2016; Shepherd; Waddell, 2015; Singh et al., 2009). The private initiative complements the offer of various services, expanding the support offered in areas such as education, health, care



for the elderly, among other possibilities, within the rules established by governments (Douglas; Benevides; Carretta, 2017; Johnson; Danis; Hafner-Eaton, 2014). Civil society, in turn, works mainly through representative entities, collecting and reporting complaints, carrying out a wide range of partnerships with public and private institutions, developing its own assistance services and promoting mutual help between people with autism and their families (Leopoldino, 2017a; Shepherd; Waddell, 2015).

It can be said that the current support network has much to improve in the vast majority of countries, and one of the inefficiency factors is the fact that working with support processes in isolation. Health, education, access to work and other issues are continuously dealt with in an uncoordinated way by academia and public managers, negatively affecting the results of policies that are put into practice. The following sections present an integrated view of the various existing support processes, and their main interactions, without the intention of exhausting the material.

2. AUTISM AND RELATED PUBLIC POLICIES

The high prevalence of autism and the great impact of the emotional and financial burden that ASD causes on families and the state are among the main motivators for state action in the construction of specific public policies related to the issue (Christensen et al., 2019; Mcstay; Trembath; Dissanayake, 2014; Sun et al., 2019). However, the implementation of these policies is not trivial due to the complexity of needs and the magnitude of the resources that are needed. The financial charges are substantial, as they involve the monitoring of qualified professionals throughout the life of each person with autism (Buescher et al., 2014; Cimera; Cowan, 2009; Horlin et al., 2014).

The real needs of families are varied and change throughout the lives of their members with autism (World Health Organization; The World Bank, 2011; Robertson, 2009). Early in life, diagnosis is demanded as early as possible, as well as multiprofessional behavioral therapies that stimulate development and socialization, access to inclusive and effective education (Anderson; Liang; Lord, 2014; Araújo; Leite; Da Solidade, 2019; Brugha, et al., 2020; Crane et al., 2018; Daniels; Mandell, 2014; Karst; Van Hecke, 2012; Koegel et al., 2011; Koegel et al., 2014). In the transition to adulthood, attention is required to professional development processes, supported not only in technical training, but in vocational preparation. Additionally, means are needed to effectively and sustainably support the engagement of people with autism in the labor market (Hedley et al., 2017; Leopoldino, 2015; Lin; Huang, 2017; McLaren et al., 2017; Rast; Roux; Shattuck, 2019; Robertson, 2009; Sales; Viana, 2020; Smith et al., 2015; Taylor; Henninger; Mailick, 2015; Wehman et al., 2014). For people with ASD who are leaving the labor market, or



for those who are unable to work, their care needs must be met, including when they are elderly (Rasga; Vicente, 2017; World Health Organization; The World Bank, 2011). Taking this context into account, policies are sought that enable the greatest possible degree of autonomy from early childhood, that encourage the participation of people with autism in professional life in adulthood, and that in times of need and old age of these individuals, offer due care.

As for the adaptation to the needs of autistic people, the construction of public policies must meet a series of requirements, or assumptions, listed by Leopoldino (2017b), here enunciated: Contemplate all stages of life of individuals with ASD, cover the families of autistic people, encompass health, social assistance and education professionals who deal with autistic people, be focused on social inclusion in its various dimensions, turn to gain as much autonomy as possible and to be discussed widely with society, people with ASD and their families (Silva; Chaves, 2014; Orsmond et al., 2013; Friedman; Warfield; Parish, 2013; Karst; Van Hecke, 2012; World Health Organization; The World Bank, 2011; Knapp; Romeo; Beecham, 2009; Ganz, 2007).

However, even if the assumptions are followed, we will have ineffective policies if we do not take into account the integration between the various actions, the leadership in conducting and coordinating the processes and the availability of funding for their implementation and maintenance (Cimera; Cowan, 2009; Johnson; Danis; Hafner-Eaton, 2014; Kreutzer; Niendorf, 2017; Singh et al., 2009). Commonly, autism has been treated in a fragmented way by different research areas, and integrative studies are necessary, as the effects of policies on each other are little known. In this sense, this research seeks to fill the gap in the approach to support processes related to ASD, proposing a more integrated and effective approach.

3. METHODOLOGY

This text is the result of qualitative and bibliographic research on the issue of support processes offered to people with autism (Marconi; Lakatos, 2010; Polak; Dinis, 2011). Since few texts deal directly with the integration of management processes related to TEA, data collection was done by exploring the existing literature, over a year, in a continuous research process, with the construction of a database of texts categorized by different subjects, including access to education, health issues, public policies and quality of life. The identification of support processes started with those related to the professional life of people with autism (Leopoldino, 2015; Leopoldino; Coelho, 2017), realizing the need to understand the other related processes. In order to meet these demands, support processes prior to and after the entry of people with autism into the labor market were added to the model, and the main integrations between the processes were



identified.

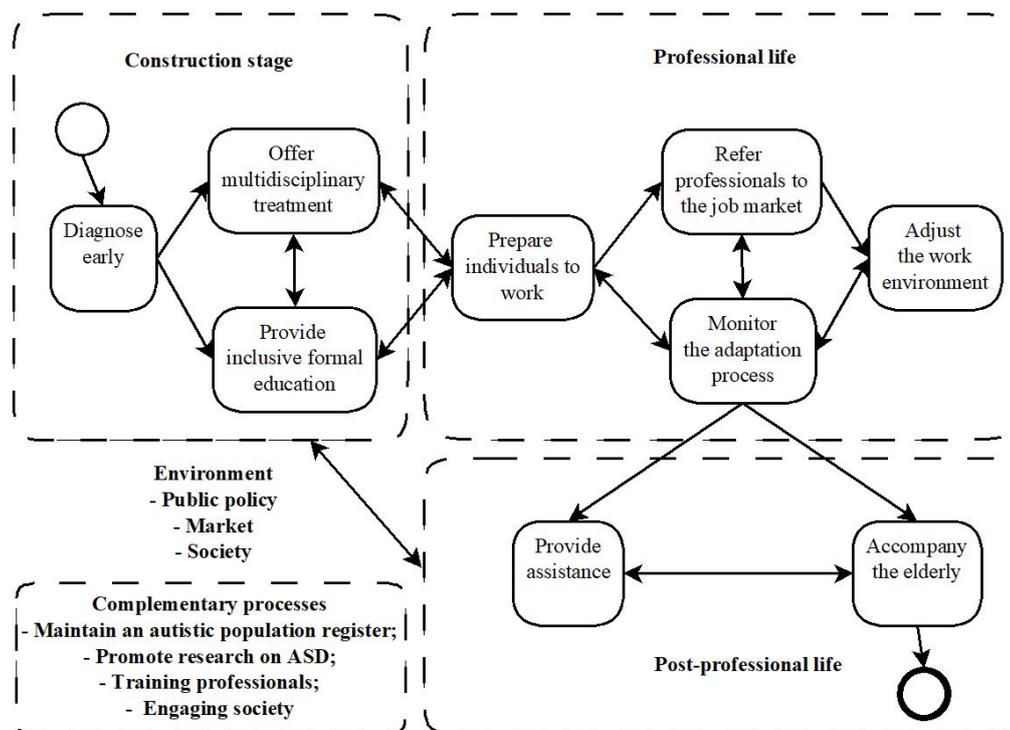
Dozens of articles, theses, dissertations were consulted and the search was carried out in an exploratory way, ending with saturation (Marconi; Lakatos, 2010). The main search engines used were academic Google, SciELO and the national library of theses and dissertations in Brazil (Biblioteca Nacional de Teses e Dissertações, BDTD).

4. SUPPORT PROCESSES FOR AUTISTIC PEOPLE

Support processes for people with autism aims to meet the complex and lasting needs of a relatively large population. Therefore, they are not exclusive to the State, or to society, demanding the integration and complementary action of different public, private and third sector entities. There are basically two types of support processes for people with autism: those that have a direct influence on the lives of people with autism, called in this text primordial, and those that, despite their importance, have an indirect impact, which are named here as secondary.

Having essential character, the primordial support processes accompany individuals throughout their life, and comprise the stage of building bonds, knowledge and autonomy, the whole professional life, and must be offered after the period of professional activity, as can be seen in figure 1.

Figure 1: Support processes



Source: Literature review

The so-called secondary processes have the function of supporting the primary processes,



and help their smooth functioning. The main support processes identified were: Maintain an autistic population register; promote research on ASD; training professionals and, finally, engaging society.

4.1 Primary Processes

The primary processes of support for people with autism cover the three major stages of their lives: the construction stage, the professional life and the one that occurs after the end of the professional activity. The main interactions between the processes and life stages of people with ASD are shown in Figure 1, while some of their performance indicators can be seen in Table 1.

The **construction stage** comprises the first years of formation and the process of developing autonomy, family ties and first contacts with the outside world. The participation of parents, as well as the support of public policies are essential at this stage. Within this context, the main related support processes are: Diagnose early, offer multidisciplinary treatment and provide inclusive formal education.

The importance of **diagnosing ASD cases early** is already well documented in the literature. Autistic diagnosed in the early years of childhood tend to show better results in behavioral therapies, due to their greater brain adaptability, and the higher difficulty in diagnosing adults (Brugha, et al., 2020; Crane et al., 2018; Daniels; Mandell, 2014; Koegel et al., 2014). Even without a definitive diagnosis, multidisciplinary interventions can be carried out in order to stimulate individuals, improving their skills. Additionally, the importance of post-diagnostic support is emphasized (Crane et al., 2018). It is important to highlight that the incorrect diagnosis can lead to the adoption of inappropriate therapies, consuming precious time and resources with insufficient results.

Table 1: Performance indicators of key support processes

Life Stage	Support Process	Support Indicators
Construction stage	Diagnose early	<ul style="list-style-type: none"> • Degree of universality of early diagnosis • Average time on the waiting list for diagnostic services • Average age of first consultation for diagnosis • Mean age at diagnosis • Number of diagnoses per unit of time • Average age of late diagnoses • Number of late diagnoses per unit of time
	Offer multidisciplinary treatment	<ul style="list-style-type: none"> • Degree of universality • Average time on the waiting list for treatments • Number of calls per time period



		<ul style="list-style-type: none"> • Quantification of service hours by time period • Time interval between feedbacks for the family • Years of experience of therapists • Degree of training of therapists • Degree of adequacy of treatments to the needs of autistic people • Percentage of people with ASD with appropriate treatments
	Provide inclusive formal education	<ul style="list-style-type: none"> • Percentage of people with ASD who attend the regular education system • Percentage of people with ASD who are attending regular education • Evasion percentage of people with ASD • Average time that people with ASD spend in the educational system • Average grades of people with ASD in the main subjects
Professional life	Prepare individuals to work	<ul style="list-style-type: none"> • Number and percentage of autistic people with adequate formal vocational training • Number and percentage of autistic people in vocational secondary education • Number and percentage of autistic people in undergraduate university education • Number and percentage of autistic students in graduate school • Number and percentage of autistic individuals with each degree of education • Average time to obtain each degree • Number and percentage of evasion of autistic children in each course
	Refer professionals to the job market	<ul style="list-style-type: none"> • Average time until the allocation of each autistic professional • Relationship between the number of places offered and the number of candidates • Number of people referred in each period • Percentage of referrals that result in employment • Average salary offered • Average workload of vacancies offered
	Adjust the work environment	<ul style="list-style-type: none"> • Degree of satisfaction with the physical environment
	Monitor the adaptation process	<ul style="list-style-type: none"> • Average time autists stay at work • Degree of satisfaction of workers with work • Number of hours worked per unit of storms • Income
Port-professional life	Provide assistance	<ul style="list-style-type: none"> • Quality of life assessment • Main needs • Number of people served • Social spending per individual



		<ul style="list-style-type: none"> • Improvement in quality of life after interventions
	Accompany the elderly	<ul style="list-style-type: none"> • Life expectancy

Source: Author's elaboration

Possibilities for greater social integration, performance in studies and gaining autonomy are opened by **offering multidisciplinary treatment** for people with autism (Braga, 2018; Koegel et al., 2014). Professionals from different specialties such as psychiatrists, neuropsychiatrists, psychologists, speech therapists, occupational therapists and psychopedagogues are just some of the professionals who can be involved. Alternative therapies with scientific evidence can complete treatments, always taking into account individual needs (Araújo; Leite; Da Solidade, 2019; Freire; De Andrade; Motti, 2016).

Access to education is essential, and **providing inclusive formal education** is a challenge. Problems such as the non-universalization of the educational service, lack of teacher training, prejudice from colleagues and shortfall of places are just some of the obstacles encountered in educational systems (Minatel; Matsukura, 2015; Koegel et al., 2011).

Professional life follows the construction stage, providing access to work, greater income, professional relationships and new achievements, promoting better quality of life (Mason et al., 2018; McLaren et al., 2017). However, nothing hinders the continuation of the multidisciplinary treatments that are necessary, or the initiation of new therapies. It is emphasized that not all people with autism will enter professional life, due to the severity of the manifestations of autism and the comorbidities that they may present. The labor market is not always favorable for autistic people in working conditions. There are recurrent reports of difficulty in finding a job, in maintaining it, and the workload and wages offered in general are lower than neurotypic people (Robertson, 2009; Taylor; Henninger; Mailick, 2015; Wehman et al., 2014). The support processes associated with professional life are: Prepare individuals for work; refer professionals to the job market; adjust the work environment and monitor the adaptation process.

Effort to **prepare individuals with autism for the job market** comes from the need to not only provide technical training, but also vocational experiences (Smith et al., 2015; Rast; Roux; Shattuck, 2019; Wehman et al., 2013). With proper preparation, workers with ASD can develop skills and find job options that best meet their needs and that best fit their desires. Universities and high school and technical education, must prepare to collaborate in this process (Sales; Viana, 2020).

Referring professionals to the market fosters more harmonious and lasting work relationships, as it aims at matching the qualifications and expectations of the autistic worker with the demands of efficiency and training offered by the various employers (Leopoldino; Coelho,



2017; McLaren et al., 2017). Inclusive employment agencies, public, private or third party entities can play this role, expanding access to vacancies and establishing a communication network that brings candidates and employers together. The best fit between candidate and vacancy can increase both the amount of hours worked and the remuneration received (Cimera; Cowan, 2009).

Adjusting the work environment is an activity that allows to increase the satisfaction and productivity of the professional with ASD in the work environment. Due to sensory issues, it may be necessary to make changes to reduce noise, echo, odors and the level of ambient lighting, in addition to visual aids, adoption of coaching, among other possibilities (Posar; Visconti, 2018; Wehman et al., 2014). The attitudes of the immediate manager and colleagues are essential for the autistic worker to adapt to the routine of the work environment. It is important that the worker is heard, so that the adjustment is even more effective.

Monitor the adaptation process of each person with ASD at work is to be able to early identify adjustment problems between employees and the tasks they must perform in order to act to solve them (Leopoldino; Coelho, 2017). It is a continuous process throughout professional life. When problems are found, a new attempt at adjustment in the work environment can be made, or a new reallocation in another job opening, or the worker can be referred for new professional training. The following of the adaptation process can also indicate that the worker is on the verge of entering the post-professional life phase, starting a new transition in his life.

The **post-professional life** of people with autism has received little attention from the academy, but it tends to gain importance as the number of adults diagnosed with ASD increases, as does their life expectancy (Wright et al., 2013). Two primary processes support autistic people in old age: Provide assistance and accompany the elderly.

Financial aid, housing and other issues must be dealt with humanely, with both material and psychosocial support provided (Rasga; Vicente, 2017; Wright et al., 2013). The care offered by the process of **providing assistance** is not exclusive to the elderly and can be made available whenever necessary to citizens with ASD of all ages.

Lastly, the process of **accompanying the elderly** guarantees people with ASD access to all policies associated with aging. Still insufficiently known and researched, adults with autism will need support for old age, since the elderly population with autism only tends to grow (World Health Organization; The World Bank, 2011; Wright et al., 2013).

4.2 Secondary Processes

The so-called secondary processes comprise the continuous and essential activities that assist the primordial processes, but which do not have an immediate impact on the lives of people with



autism. The literature review identified four secondary processes: Maintaining population records of autistic people, promoting research on ASD, training qualified professionals and, finally, engaging society.

Keeping autistic records means being able to access information about who they are, how they live, about their needs, the way they are financially supported and their life trajectory. Such information is essential for the strategic management of inclusion policies, in addition to allowing the crossing of data regarding the influence between different support policies. In the case of registrations that are separate, but that present complementarity, it is recommended to adopt technical data integration procedures, to carry out broader consultations and eliminate inconsistencies (Campos et al., 2000; Halevy; Rajaraman; Ordille, 2006).

Much is still unknown in relation to autism, so **promoting research on ASD** is a way to reduce important gaps in several branches of knowledge. Issues such as the causes of autism, drugs, specific educational software and health management are just some of the fields in which research on autism can make relevant contributions. This process covers both basic and clinical research and those that present themselves as both basic and clinical (Singh et al., 2009). In addition to universities, business groups can be covered by these policies, increasing the speed and scale of the adoption of related innovations. But without funding, equipment or valuing science and researchers, research results tend to take longer and be less frequent (Singh et al., 2009).

The need to **train qualified professionals** to deal with autistic people is a reality. This qualification gap is not restricted to therapists and teachers who deal with children. Dentists, doctors, nurses, teachers and any professional who has to assist people with ASD at different stages of their lives, will need adequate training that understands the technical and human issues of autism (Imran et al., 2011; Nascimento; Cruz; Braun, 2016; Silva; Chaves, 2014).

Engaging society is a necessity in order to obtain the essential support for the implantation and maintenance of supports for people with autism. This involvement encompasses the awareness of the population in general, incentives for associations and social entrepreneurship involving autism and, finally, the creation of job vacancies for people with autism in companies and in the public sector. Society's engagement is strengthened through the participation of various sectors in the construction and execution of policies to be adopted.

Most current research on autism deals with support processes for people with ASD independently. They are worthwhile investigations that address fields such as health, education, the rights of people with ASD, access to employment, among so many relevant topics. However, the search for integrative visions brings new perspectives, in which the synergistic integration of actions by multiple actors increases efficiency, with the prospect of greater success rates and



reduction of time and costs spent.

Such a vision in which the needs of people with ASD are met universally, through integrated support processes, is still far from being realized. The present work, by no means exhausting the question, aims to make it more evident.

5. CONCLUSION

This text aims to contribute to the discussion on the best way to organize autism support processes. Knowledge about the processes presented here can influence the way in which support policies for autistic people are designed and implemented. The reported vision integrates processes usually contemplated in isolation, as well as their main interactions. The use of management indicators added to the support processes leads to a better evaluation of the results presented, in addition to comparative analyzes.

Further research on this issue is needed to explore fields that are still under-worked. Opportunities are shown for the analysis of efficiency in public policies on autism, the study of interactions between the public and private sectors, the influence of the process integration degree for their effectiveness and the analysis of the influence of a process on the others. Alternative models of organization of the support processes can be proposed, enriching the knowledge on the issue.

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