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Country Profile: Intellectual Disability in Brazil

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Review

Introduction

Globalisation has led to an expansion in knowledge about the lives of people with learning disabilities (LD). Yet, there are still countries which remain largely silent within theoretical and practice discourse on LD. Brazil is one such country, probably in part, due to a history of political regimes which suppressed or discouraged knowledge-sharing outside of Brazil, and partly due to geographical and language barriers. However, Brazil is now one of the most rapidly developing countries in the world, with an emerging major economy and such barriers are quickly being eroded. The aim of this paper is to learn and draw inspiration from diversity by profiling the lives of people with LD in a country which has, hitherto, been largely invisible in international discussions on LD. To this end, the paper will begin with a brief introduction to Brazil emphasising particular aspects (demographic, historical, political and religious) which have undoubtedly had an impact on the lives of people with LD in terms of attitudes towards individuals and services provided. Current patterns of living/service provision will be outlined amidst the historical trajectory of care, with a critical and comparative appraisal of the current position of people with LD. The paper will end with some future challenges and opportunities.

Socio-demographic context

Brazil spans approximately 8.5 million square kms (45% of South America) (Paim *et al.*, 2011). A federal republic, with 26 states, 5563 municipalities and a Federal District (containing Brasília, the country's capital), Brazil is made up of 5 geographical Regions (North, Northeast, Center-West, Southeast and South). The current population stands at over 205 million (IBGE, 2014; World Bank, 2014). According to the 2010 census by the Brazilian Institute of Geography and Statistics (IBGE, 2015), around 24.8% of the

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2
3 population are aged 0 to 14 years, 68.5% 15-64 years and 7.4% are 65 years or more,
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5 although recently the number of older people living longer has increased whilst the
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7 overall growth rate of the population has reduced. Forty-seven point seven percent of
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9 the population is classified as white, 7.6% as black, 43.1% as brown, 1.1% as yellow
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11 (Asian) and 0.4% Indians. The population is mainly Catholic (64.6%) with 22.2%
12
13 reporting to be evangelical Christians, 2% stating that they belong to the Spiritualist or
14
15 other religions and 8% saying they are without religion. Brazil's Gross Domestic
16
17 Product (GDP) was estimated to be 1.799 trillion US dollars in 2015 (see CEPR, 2014;
18
19 International Monetary Fund, 2015) which is 3.78% of the world's GDP and ranks
20
21 Brazil as the 7th largest world economy. Development within Brazil has been much
22
23 more rapid in the South and South-East regions. In particular, the Southeastern region
24
25 (covering only 11% of Brazil's territory but accounting for 43% of the population and
26
27 56% of GDP), contrasts with the relative poverty of other regions, especially the North
28
29 and Northeast. Approximately 45.6 million people living in Brazil are classified as
30
31 having some kind of disability (2010 Census, IBGE, 2014) though this includes
32
33 acquired impairments associated with old age. Of these, 1.4% have a 'declared' learning
34
35 or mental disability, depending on the type of assessment instrument used.
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43 Brazil operates under a presidential regime, governed by the 1988 Constitution of the
44
45 Federative Republic of Brazil with the State made up of three branches: Executive,
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47 Legislative and Judicial (Brasil 2010). Under Brazilian law, states and municipalities
48
49 legislate on the basis of the Constitution, but have relative autonomy. Over the last 30
50
51 years, Brazil has adopted a re-democratised, capitalist, international economy (Dore,
52
53 2009) and whilst the national government has sought to minimize socio-economic
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55 inequalities across Brazil through constitutional funds, corruption via partisan political
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3 and economic policies at federal, state and municipal levels of government persists
4
5 (Nunes, 2003), necessarily impacting on the poor and people with disabilities. Attitudes
6
7 towards people with LD in Brazil, as in any country, may be regarded as the product of
8
9 historical social construction (see McClimens and Richardson, 2010). The Brazilian
10
11 experience of this is now discussed.
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16 17 **16th to early 20th Century**

18 Portuguese colonialism began in the 16th Century with sugarcane exports, aided by West
19
20 African slaves (Bello 1966; Fausto 1999). The Gold Rush largely replaced this market
21
22 in the 17th century, resulting in a second influx of people from Portugal as well as
23
24 French and Dutch emigres. In the First Empire (1822-1831), there is no record of care
25
26 for people with disabilities. Rather, the Brazilian Constitution (Art 8 s1) of 1824
27
28 enacted a form of legal exclusion of people with disabilities who had no political rights.
29
30 People with LD were mainly cared for by Catholic organisations during this era;
31
32 individuals with disabilities were generally abandoned by their families (Ohry, 2004).
33
34 During the Second Empire (1840-1899), two large residential institutions, the Imperial
35
36 Institute of Blind Boys (1854) and the Institute of the Deaf-Mute (1857) were instigated
37
38 by the State Januzzi, 2004). Both probably housed people with LD, since some students
39
40 were dismissed for “instructional disability as a result of severe physical and mental
41
42 diseases” (Araújo, 1993 quoted in Januzzi, 2004 p13). There are also reports in the mid-
43
44 19th century of religious orders from Portugal educating abandoned children including
45
46 those with disabilities, and an historical register documents two institutions for people
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48 with disabilities in Brazil (from 1874 to 1898) although it is unclear as to how these
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50 were financed (Januzzi, 2004).
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3 Given Brazil's history of colonialism and slavery it is perhaps unsurprising that 19th
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5 century theories including 'degeneration' (i.e. 'cumulative hereditary psychiatric
6
7 decline' resulting from inter-marriage between the 'superior' conquering races (whites)
8
9 and 'inferior' conquered races - indigenous Indians and black African slaves)
10
11 (Gobineau, 1853 and Moreau, 1976 cited in Block 2007) and eugenics were as much a
12
13 part of the Brazilian medical and academic discourse on LD as they were in Europe (see
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15 Rodrigues, 1899 cited in Block, 2007, p.184).
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21 However, Brazilian anthropologists and sociologists (see Roquette-Pinto, 1927) began
22
23 to critique racialist constructions of LD with what might be termed a social causation
24
25 theory - that 'degeneration' is caused by environmental factors linked to poverty
26
27 including poor sanitation and hygiene, inaccessibility of clean water and preventable
28
29 illnesses (see Penna, 1918). Block (2007) demonstrates how Brazilian clinicians and
30
31 educators from the early 1900s to the 1920s used slogans such as "sanitation-eugenics,"
32
33 advocating new educational technologies and better living conditions as a challenge to
34
35 perceiving people with LD as a social threat. This more progressive attitude was
36
37 influenced by Guggenbuhl's and Seguin's methods of education (see Trent, 1994)
38
39 including early intervention, repetitive tasks, the use of concrete objects rather than
40
41 abstract concepts, vitamin and mineral rich diets, and positive physical and social
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43 environments.
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50 Despite the progressive work outlined above, Brazil had only seven state schools for
51
52 people with LD in the period 1889-1920 (Januzzi 2004). Military dictatorships from
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54 1889, characterised by brutality, led to containment policies including involuntary
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56 institutional admittance - 16 institutions were recorded in 1929 (Januzzi 2004). By
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3 1930, influential Brazilian scientists were denouncing rural migrants and immigrants as
4 burdens on Brazilian society and, since diagnosis of LD was usually based on
5 observation in relation to region, class and racial stereotypes (see Block, 2007, pp. 186-
6 187), it is not hard to imagine how numbers of people labelled as having ‘low
7 intelligence’ began to rise. Medical professionals were divided between biological-
8 determinists, advocating technological fixes (Block, 2007, p. 186) including
9 institutionalisation and sterilization (Diwan, 2007), and ‘medical-pedagogic’ theorists
10 who sought solutions such as special education classes (Block, 2002). Block (2007)
11 argues that the absence of a consistent theoretical and service framework had the
12 positive consequence of watering down innate “pathological” inheritance theories.
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27 **The Antipoff era (1929-1974)**

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29 Helena Antipoff was a Russian-born psychologist who had trained under Claparede in
30 Geneva. Following research in Minas Gerais (a State in Southeastern Brazil) where a
31 large number of children with LD were excluded from public schools due to “the impact
32 of the social environment and of teaching practices” (Campos 2001, p.134), Antipoff
33 sought alternatives for these children, coining the term "excepcional” (exceptional) as
34 an antidote to pejorative labels such as “subnormal”. She argued for both ‘special
35 classes’ in public schools and separate, ‘special schools’. Whilst these interventions
36 now seem contradictory in nature, the aim was to include children with LD both in state
37 schools and in society (Lourenço, 2000). With an emphasis on educating and supporting
38 individuals to self-advocate and live independently, Antipoff formed the Pestalozzi
39 Society School (Sociedade Pestalozzi) in Minas Gerais in 1932. Arguably then,
40 Antipoff’s model, (as well as the absence of a unified theory of LD and the fact that
41 few other services existed) inadvertently helped to prevent a Brazilian movement of
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3 mass sterilisation, persecution and murder which was occurring to varying degrees in
4
5 other countries (Kanner, 1964; Lifton, 1986; Thomas *et al.*, 2006) before and during
6
7 World War II. It may also have helped to prevent the kind of post-war mass
8
9 institutionalisation that, influenced by the rise of welfare states, was common in Europe
10
11 (see Antipoff, 1945). However, this also meant that most people with LD in Brazil
12
13 were living with their families with no specific education or opportunity for social
14
15 inclusion. Whilst the medical model of treatment shifted to Antipoff's social-cultural
16
17 model, there was little practical support to operationalise this. Antipoff's 'Rosário', a
18
19 utopian egalitarian community for 'all exceptional people' including those with LD and
20
21 with high IQs, - arguably a pre-cursor to philosophies of normalisation (Nirje 1969;
22
23 Wolfensberger 1972) - was not replicated throughout Brazil.
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30 Furthermore, Antipoff's democratic views (Antipoff, 1944) contrasted sharply with the
31
32 1930-45 Vargas government which withdrew the educational democratization process
33
34 (Mendes, 2010). Other Brazilian professionals were imprisoned or blacklisted for their
35
36 ideals and immigrant radicals (including Jewish activists) were deported to Nazi
37
38 Germany and their deaths. The government of Minas Gerais did not renew Antipoff's
39
40 contract and she had to hide her Russian/communist influences (Campos, 2001; 2012)
41
42 both in her publications and public interactions (see Block and Cavalcante, 2014).
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44 Eventually moving to Rio de Janeiro, she worked for the Ministry of Health and helped
45
46 to create the Pestalozzi Society of Brazil (Lourenço, 2000).
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52 **The Associação dos Pais e Amigos dos Excepcionais (The Association of Parents**
53 **and Friends of the Exceptional) (APAE)**
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3 Essentially an advocacy organisation for people with LD, APAE was formed by
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5 parents in 1954. In 1956, Kubitschek's State presidency coincided with economic
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7 growth and post-war global civil rights which enabled APAE to grow. In 1960, the
8
9 Pestalozzi Society collaborated with APAE to establish a federal division responsible
10
11 for people with LD within the Ministry of Education and Culture, called the National
12
13 Campaign of Education and Rehabilitation of the Mentally Disabled (CADEME)
14
15 (Block, 2007 p. 190), and, in 1961, the first Law of Directives and Basis for National
16
17 Education (LDBEN) to emphasize education for persons with disabilities was
18
19 established. (Mantoan and Valente, 1998, p. 13). Even during the repressive 1964-85
20
21 military dictatorship movements such as APAE were able to influence Government
22
23 action. For example, mandatory education for all children between 7 and 15 years of age
24
25 was instigated by the 1971 Federal Law No. 5692 (see Mantoan and Valente, 1998 pp.
26
27 11-12), the Ministry of Education and Culture declared 'special education' a priority in
28
29 1972 (Mantoan and Valente, 1998, p. 16), and in 1973 the National Centre for Special
30
31 Education (CENESP) was formed. Special educational classes within public schools
32
33 were now funded by the State (see Cesar, 1992). Set within the political turmoil of the
34
35 times, these movements are a testament to organised and effective public lobbies
36
37 (Mazzotta, 1996). Yet, teachers were poorly trained and paid, and ill-equipped to alter
38
39 their teaching to meet the needs of those with LD.
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47 **Recent and present times**

48
49 Approximately 1.40% of the total number (45.6 million) of people with a disability
50
51 have a declared learning or mental disability although this figure has been disputed due
52
53 to the questionable assessment instrument (critiqued as socio-culturally insensitive and
54
55 difficult to understand) used for the 2010 Census. Individuals with LD were also
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3 counted together with people with mental illness and the figure fails to include all those
4
5 who have an undeclared LD. Brazil currently uses the American Association on
6
7 Intellectual and Developmental Disabilities (AAIDD, 2010 p.1) definition of LD:
8
9 “significant limitations in intellectual functioning and in adaptive behavior as expressed
10
11 in practical, social and conceptual skills originating before the age of 18.” The
12
13 International Classification of Functioning, Disability and Health (ICFDH) (WHO,
14
15 2001), which incorporates an environmental aspect to LD, is also used in conjunction
16
17 with the International Classification of Diseases (ICD-10). Brazil lacks individually
18
19 administered measures for LD normed on its own population and is unable to correctly
20
21 implement DSM-V and ICD-10 suggested methodology according to Oakland (2004)
22
23 and Surjus and Campos (2014). A mixed-economy of mainly private, with some state
24
25 funded, LD services exists within Brazil which means that an inconsistent, fuzzy (at
26
27 best) and ‘hit and miss’ (at worst) assessment process exists with many people
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29 presenting with an LD never getting a diagnosis.
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36 As outlined above, support for people with LD in Brazil, including most special
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38 education services, largely originated in social movements led by parent groups, with
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40 support from the Federal Council of Psychologists and other professional associations,
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42 rather than educators. Their persistent demands for educational inclusion for people
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44 with LD culminated in the adoption of the UN Convention on the Rights of Persons
45
46 with Disabilities (UNCRPD) (United Nations, 2006) (ratified in Brazil in 2008) (see
47
48 Kirakosyan (2013) for a fuller account of its implementation). In addition to the
49
50 Convention, Brazil also instigated a Statute of the Rights of Persons with Disabilities
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52 (2015), consistent with the Convention but more detailed to meet the Brazilian social
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54 context. This new Brazilian federal law established a legal framework for people with
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3 disabilities, enabling them to benefit from the establishment of public policies for social
4 assistance, employment, housing and education. The law also created an allowance
5 (*auxílio-inclusão*) to be paid to people with moderate to severe disabilities entering
6 employment, established anti-discrimination law, and created a 10% ‘disabled’ student
7 quota in relation to higher education. An inclusion database (*cadastro de inclusão*) was
8 also set up to collect and disseminate geo-referenced statistics to enable the
9 identification and characterization of people with disabilities as well as barriers faced by
10 them that prevent the enforcement of their rights.
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23 **Responsibility for care**

24 Responsibility for policy and services provided for people with LD is technically shared
25 between government structures. The Brazilian federal government seeks to comply with
26 the UN Convention whilst all 26 states and their accompanying municipalities submit to
27 the Federal Constitution, sharing the government’s responsibilities. National
28 programmes include: the ‘family grant’, offering resources to low-income households
29 with a disabled family member; ‘continued provision’ (a benefit equivalent to the
30 minimum wage for people with disabilities and older people with low incomes); and the
31 ‘free pass’, for public transport across municipalities, states and inter-states awarded to
32 all people with disabilities. The ‘My Home, My Life Programme’, stipulated that 10%
33 of low-income housing built should be aimed at disabled people. Finally, persons with
34 disabilities also have tax exemption on the purchase of a car, in consideration that it
35 may need to be adapted after purchase. In theory, funding related to federal policy is
36 divided between each state. In practice, state policies tend to move away from federal
37 government projects, especially the larger states with relatively more autonomous
38 power such as São Paulo. Similarly, municipalities have some autonomy to propose
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3 public policies and specific regulations regarding people with disabilities so long as
4 these do not contradict federal law. There is little consistency or security in funding
5 sources, support varying across states and administrations (Block, 2007, p. 191).
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11 Whilst integration of children with LD into state schools and special needs education is
12 a constitutional right, provision tends to consist of 'information' and 'special classes'
13 taught in Portuguese only (despite 180 indigenous languages spoken in addition to
14 Spanish and German). Pletsch (2014) argues that segregationist and overly protective
15 perspectives advanced by philanthropic-private initiatives on the one hand and inclusive
16 perspectives of the public sector on the other, as well as a lack of clear guidelines
17 concerning pedagogic practices (especially for those with severe LD), in addition to
18 poor teacher training and institutional conservatism (Mantoan and Valente, 1998) have
19 led to inconsistent practice throughout Brazil. For example, students with LD are often
20 excluded from conventional classes (Glat, 1989;; Bueno, 1993) with many receiving
21 little or no academic education in the special classes where they are placed (Mendes,
22 2010). The student might be "promoted" to the 'ordinary' class or, alternatively, be
23 transferred to a 'special school', without grading or certification. Many special schools,
24 whilst having philanthropic/charitable beginnings and funding, are now being supported
25 by regulated public funding and adopting a common curriculum (Moraes, 2012).
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47 Within this context, it is unsurprising that the APAEs and Pestalozzi Societies continue
48 to remain the main and, for many, the only source of social capital for people with LD
49 and their families. APAEs operate on a nonprofit basis and are dependent almost
50 exclusively upon public fundraising. They incorporate an expansive network of schools
51 and services created to assist low-income children and adults with LD including
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3 specialized health and welfare provision (e.g., newborn screening laboratories for LD,
4 prenatal care of pregnant women). Some APAEs (e.g., in Sao Paulo) also provide
5 diagnostic and therapeutic services and conduct research supported by CENESP.
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7 Operating as ‘functional rehabilitation’ services, APAEs further aim to stimulate
8 autonomy and social participation of people with LD by offering various day time
9 activities and experiences including peer counselling, skills training, and job placement
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16 (Federação Nacional das Apaes, 2009, 2011)
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21 Nevertheless, reliant on insecure, small government grants and philanthropic donations
22 that vary across states and regions, the APAEs tend to be housed in congregate,
23 segregated, medium to large-sized, institutional buildings (taking an average of 40 to 60
24 people at any one time). Whilst the starting aim of the APAEs was to support
25 individuals with LD to be employable and independent, similar outcomes to traditional
26 day centres in other countries are evident. That is, the APAEs have tended to become an
27 end in themselves rather than a means to an end with people with LD who entered the
28 centres as small children still attending 40 or 50 years later (Block, 2007), stuck in
29 routines and activities that people of a similar age without LD would have moved on
30 from years before. The engagement with other people with LD, staff and volunteers
31 enjoyed by APAE attendees obscures a reality of social isolation and marginalisation
32 within their communities, and fails to profit from the power of integration between
33 people with and without LD to stimulate social, intellectual and affective development
34 in both groups (Mantoan and Valente, 1998). Critics argue that the term ‘exceptional’
35 has become a pejorative label (*rotulo*) (Charlton, 1998), that adaptive behaviour
36 technologies are not routinely used, and APAEs mainly cater for people with mild LD,
37 having little to offer those with more severe and complex needs. People still largely live
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3 at home with their families with little hope of transitioning to supported living
4 environments. A few self-advocacy groups which formed in the 1990s have had some
5 success in changing institutional policy and service practice. For example, one group
6 successfully challenged policy not to allow (heterosexual) romances and appropriate
7 public expression of these (Block, 2007, p. 192) but such milestones seems to have been
8 few and far between.
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18 Ironically, people with mild LD who escape official diagnosis (ibid, p192) may be able
19 to have a quality of life comparable to others of a similar socio-economic level; they
20 work, marry, have children and do not experience extreme differentiation or exclusion.
21 While the ‘true prevalence’ of learning disability is always much greater than its
22 ‘administrative prevalence’ (e.g., Emerson & Hatton, 2014), McNight (1995) reflects
23 that Brazil’s current ‘net slipping’ differs from the USA (at least) where bureaucratic
24 systems have largely replaced community responsibility with isolated, segregated
25 ‘treatment’ that marginalises individuals with LD. This comparison serves as a good
26 example of how LD is a social construction which shifts from country to country
27 depending on historical and socio-economic influences.
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43 Carvalho (2013) points out that current Brazilian Federal policy on LD needs to be
44 adjusted to ‘fit’ with global movements. For example, whilst the UNCRPD recognises
45 the importance of individual autonomy, independence and freedom to make decisions
46 and choices (Article 19), the Brazilian Civil Code 1 (Brasil, 2014) does not take into
47 account legal capacity of persons with LD. Put simply, Brazil is still adopting a
48 diagnostic (or status approach) to capacity in that a person is judged ‘incapable’ to make
49 a decision simply because they have a diagnosis of LD. This differs from the functional
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3 approach (used, for example, within the UK Mental Capacity Act 2005) in which
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5 capacity is judged more on a decision by decision basis reflecting the person's ability
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7 to: understand the information concerning the decision; weigh up the information;
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9 choose freely; and communicate their choice. There is also no systematic history of
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11 service evaluation in Brazil, hence service outcomes for individuals and their families
12
13 are unclear.
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18 Nevertheless, it is possible to identify positive and emergent perspectives in Brazil. For
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20 example, the ICFDH (WHO, 2001), DSM-V and AAIDD (2010) diagnostic standards
21
22 are slowly starting to be more widely used as potential guides to diagnosis and
23
24 intervention for people with LD in Brazil. Even so, there remain no specific
25
26 governmental programs and services for persons with LD; their education is largely
27
28 still left to NGOs with individualised support tending to remain a goal rather than a
29
30 norm. For those who live in extreme poverty, for example in the favelas and 'rubbish
31
32 dumps', the idea of individual 'anything' is simply a dream. The process of school
33
34 inclusion of children with LD is very slow.. Social inclusion is yet but a dot on the
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36 horizon.
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42 As with any country, Brazil also has a growing older population of people with LD,
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44 including those with dementia (Abrisqueta-Gomez *et al.*, 2004). Caldas and Bererö
45
46 (2007) argue that the concept of ageing needs to be reframed especially when it comes
47
48 to those with LD, since their functional decline requires particular and intensive
49
50 support. Yet, this population receive no assistance from the State, even where they
51
52 depend on their even more elderly parents for their care. Solutions to this growing
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3 problem need to take into consideration the trans-generational culture of Brazil; families
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5 are normatively dependent upon one another.
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8 9 **Challenges for the future**

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11 In line with the redemocratised government, disabled people have been organizing
12
13 themselves into communities to exert their civil rights with support from academics and
14
15 interested government officials (see Coelho de Amorim, 1995). LD self advocates have,
16
17 since around 2000, also been expressing their difficulties in letters written during the
18
19 country-wide Congresses organized by APAEs. During the 6th Forum: Self Defense
20
21 and Self Advocacy (November 2014) in the Brazilian state of Paraná, the letter written
22
23 by the participants with LD and multiple disabilities detailed the following demands:
24
25 (a) a guarantee of political participation in municipal and state education, health and
26
27 social assistance in the country; (b) access to participation in projects of environmental
28
29 education; (c) a guarantee of the right to education for all; (d) investment in assistive
30
31 technology; (e) educational rights respected in schools and universities with adapted
32
33 curricula and well trained teachers; (f) development of projects to fight prejudice and
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35 violence against persons with disabilities; (g) fulfilment of accessibility laws; (h)
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37 respect of the right to leisure.
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46 The National Programme for Self-Management is represented by people with LD as
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48 well as people with multiple disabilities and is actively participating in activities that
49
50 promote development, social inclusion and citizenship (National Federation of Apaes-
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52 Fenapaes, 2015). The First International Symposium on Disability Studies: Conflicts,
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54 Rights, and Diversity, held in São Paulo in 2013 discussed issues about disability in
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56 Brazil today. Connor (2013) argues that Studies on Disability in Education are
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3 expanding within Brazil with disability regarded as an integral part of the concept of
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5 diversity in schools, as opposed to medical/clinical paradigms. Further advances have
6
7 been made in relation to autism with a federal law in 2012 recognising autism as a
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9 “disability for all legal purposes” in Brazil, ensuring that people with autism could now
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11 claim social benefits (see Rios and Andrada, 2015).
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16 Block (2013) and Watson (2013) highlight the transforming power of activists and
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18 academics within the current and future emancipation of disabled people including the
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20 development of disability studies (de Mello *et al.*, 2016). However, some disability
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22 studies scholars and others protest against “disablism” (Bueno, 2011; Glat and Pletsch,
23
24 2011) and bemoan the failure to address social exclusion of people with LD including a
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26 lack of independent living, continuous social oppression of people with LD through
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28 stigmatization and the politicization of disability, (Carvalho, 2003, 2004, 2006). They
29
30 also argue for research and conference events to build and share knowledge about LD
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32 which in turn will help to change cultural attitudes (Connor *et al.*, 2014). The authors of
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34 this paper worry about continued re-emerging suspicions towards the integration of
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36 people with LD by the general population due to economic vulnerability, insufficient
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38 State commitment to social issues in general and a lack of effective shared solutions.
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40 Without sustained State commitment to funding research as well as changing attitudes
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42 and practice, the original aspirations of Antipoff may not be realised.
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