

Caregivers' Perception of Health Status and Aging in People with Intellectual Disability in São Paulo, Brazil. Is it different from general population?

Percepção de cuidadores sobre o estado de saúde e envelhecimento de pessoas com Deficiência Intelectual, em São Paulo, Brasil. É diferente de população em geral?

Percepción de los cuidadores del estado de salud y envejecimiento en personas con Discapacidad Intelectual en Sao Paulo, Brasil. ¿Es diferente de la población en general?

Laura M. F. F. Guilhoto
Maria Regina Leondarides
Leila Regina de Castro
Simone Sena
Cristina Almeida
Daniela Karmeli
Elizabete Macedo
Juliana Righini
Angela Alves
Ester Tarandach
Maria Fernanda Prezia
Esper A. Cavalheiro

ABSTRACT: We performed a survey of observed changes during last five years answered by caregivers of 195 people with mild to moderate intellectual disability (age 35-60 years) in domains: daily activities; neurological and psychic/psychiatric functions. There were statistically significant differences ($p < 0.05$) among individuals with intellectual disability (with and without Down syndrome) and healthy controls with referred deterioration in all areas.

Keywords: Aging; Intellectual disability; Down syndrome; Caregiver; Survey.

RESUMEN: *Se realizó un estudio de los cambios observados durante los últimos cinco años respondidas por los cuidadores de 195 personas con discapacidad intelectual leve a moderada (edad 35-60 años) en los dominios: las actividades diarias; las funciones neurológicas y psíquicas / psiquiátricos. Se encontraron diferencias estadísticamente significativas ($p < 0,05$) entre las personas con discapacidad intelectual (con y sin síndrome de Down) y controles sanos con el deterioro reportado en todas las áreas.*

Palabras clave: *Envejecimiento; Discapacidad intelectual; Síndrome de Down; Cuidador; Encuesta.*

RESUMO: *Uma pesquisa foi realizada sobre mudanças observadas por cuidadores, durante os últimos cinco anos, em 195 pessoas com deficiência intelectual leve a moderada (idade 35-60 anos), nos seguintes domínios: atividades diárias, funções neurológicas e psíquicas. Houve diferença estatisticamente significativa ($p < 0,05$) entre os indivíduos com deficiência intelectual (com e sem síndrome de Down) e controles saudáveis com deterioração referida em todas as áreas.*

Palavras-chave: *Envelhecimento; Deficiência intelectual; Síndrome de Down; Cuidador; Questionário.*

Introduction

Intellectual Disability (ID) is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) as a clinical condition characterized by below average intellectual functioning, with limitations in at least two areas of adaptive associated skills (communication, self-care, home life, social adaptation, health and safety, use of community resources, determination, academic functions, leisure and work), beginning before age 18 years (The AAIDD, 2010). It is observed nowadays an increase in life expectancy of people with ID due to several factors, including the improvement of health situation of these individuals.

Living conditions have improved for the general population, and people with ID currently have a greater degree of social inclusion, based on initiatives in the educational area in the labor market.

Although these positive outcomes, there are reports of premature aging and multimorbidity in some subgroups of people with ID, especially in those with Down Syndrome (DS) (Dewinter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012; Hand, 1994; Perkins, & Moran, 2010). Several authors reported signs of early aging in this population (Esbensen, 2010; Lott, & Head, 2005). It is speculated whether other causes of ID also present a premature aging process caused by biological factors or even environmental issues, such as lack of public policies of care for this population with ID.

Aging in Brazil

In recent decades, some research projects have detailed health conditions of the elderly in large cities of Latin America. The project Health, Welfare and Aging (SABE), coordinated by the Pan American Health Organization (PAHO), has been aiming to collect information on the living conditions of the elderly (60 years-old or older) in urban metropolitan areas in seven countries in Latin America and the Caribbean - including the city of Sao Paulo - and to access differences with respect to health status, access and utilization of health care, among others (Barbosa, Souza, Lebrão, Laurenti, & Marucci, 2005).

In Brazil, this project was coordinated by the Faculty of Public Health and School of Nursing of the University of São Paulo, and funded by the Research Foundation Support of São Paulo (FAPESP) and the Brazilian Ministry of Health. This group interviewed 2143 people in Sao Paulo city from January 2000 to March 2001 through a questionnaire and standardized sampling process. It turned out that women made up the majority of the population sampled and 13% lived alone, and this figure increased with age. The Mini Mental State Examination indicated 18% of depression and 7% of cognitive impairment in the studied population, according to the Geriatric Depression Scale. The vast majority of seniors (81%) had no difficulty in basic activities of daily living, and among those who had, most had difficulties in one or two activities.

It was concluded that health conditions are worrisome, as the inadequacy of the social security system for the general aging population (Barbosa, *et al.*, 2005).

Another project in Sao Paulo city, called “Epidoso”, performed by the Aging Research Center of Paulista School of Medicine, Federal University of Sao Paulo (EPM/UNIFESP), the first longitudinal study of elderly in Latin America, evaluated the health and living conditions of residents next to the institution’s community, in Vila Clementino, a district of middle class, looking for associated variables with healthy aging and risk factors for mortality (Ramos, 2003; Ramos, Rosa, Oliveira, Medina, & Santos, 1993). This study found that few variables maintained an independent and significant effect on the risk of death, namely: gender, age, previous hospitalization and positive screening for cognitive impairment and dependence in daily activities. However, the only potential risk factors in this study that could diminish the risk of death were cognitive status and the degree of dependence on daily activities (Ramos, 2003).

Aging and Intellectual Disability

The Seneca project, developed in Catalonia, Spain, from 2003 to 2008, consisted of a longitudinal study whose main objectives were to evaluate service needs of people with mild and moderate ID aged over 40 years in this region and to describe the behavioral profile that can accompany the aging process, and to present concrete proposals for the improvement of public policies (Novell, Nadal, Smilges, Pascual, & Pujol, 2008). This study found that people with ID age prematurely and, except for persons with DS and other syndromes, premature aging of people with mild to moderate ID is a result of lack of health promotion campaigns, poor access to services, quality of health and social care. Another longitudinal study is being conducted in Ireland by the University of Dublin, with the purpose of making a national assessment on aging population with ID and it is called IDS-TILDA (abbreviation of “Intellectual Disability Supplement - The Irish Longitudinal Study on Aging”) (Trinity College Dublin, 2016). In the first stage of this research, the data of 753 people with ID over the age of 40 years were reviewed, corresponding to about 9% of the population with ID in that country in this age range.

Information on the presence of 12 chronic diseases was analyzed using a standardized protocol applied in face to face interviews with people with ID and/or their caregivers.

Many, particularly in younger age groups, reported having good health, but there were significant concerns in terms of heart problems (including risk factors), epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer and thyroid disease. Regardless of ID level, most of these people were dependent on professionals to access social or employment programs. Multimorbidity, defined in this study as two or more chronic health conditions was observed in 71% of the sample, with women at higher risk. The multimorbidity rate was high (63%) even among those aged 40-49 years. Eye diseases and mental illnesses were more often associated with a second health change, and the pattern of most prevalent multimorbidity was mental/neurological pathology. Most adults with ID interviewed in this study had leisure activities, although with some limitations (McCarron, *et al.*, 2013; Trinity College Dublin, 2016).

Besides these initiatives there were some similar reports in other nations, but in Brazil there are no studies regarding the aging process in people with ID (Bigby, 2008; Hand, 1994; Strydom, Chan, King, Hassiotis, & Livingston, 2013).

The present study aims to analyze the perception of caregivers regarding health status of adult people with ID comparing them to control subjects of the same age in São Paulo city, the largest in the country. The hypothesis studied is that individuals with ID have worse health conditions perceived by caregivers than typical individuals of the same age.

The Study Group is composed by professionals of 10 nonprofit organizations in the great São Paulo area which provide outpatient services for people with ID and by one representative person of the families of people with ID. It aims to promote better comprehension of the process of people with intellectual disability in this area (Cidade de Sao Paulo).

Methods

In this study, approved by the Ethics Committee of UNIFESP, adults with mild to moderate ID aged 35 to 60 years and their families attending the participating organizations were invited to take part in the study as well a group of control people without ID of the same age range with a subset of this composed only by siblings of the subjects with ID.

Professionals of Study Group with the support of doctors and researchers linked to the area, developed and applied a questionnaire on demographic data and 43 questions related to physical, neurological, psychiatric areas and leisure activities, in order to detect perceived changes in these fields noted by caregivers in the last 5 years (Guilhoto, & Cavalheiro, 2014).

Table 1 summarizes the main topics of the questionnaire. Subjects of control groups answered the same questionnaire after signing an informed consent, as well as caregivers of people with ID. Data analysis was performed with descriptive statistics, being considered statistically significant at 5% ($p < 0.05$).

1. Social Data	I- Demographic / socio-economic	Personal, geographic, economic, nonprofit organization etc.
2. Clinical data	II- Diagnosis / etiology	Down syndrome, other genetic diseases, neonatal asphyxia etc.
	III- Clinical history	Associated diseases and drugs
		Antecedents
		i.) Personal: education, previous diseases ii.) Family: diseases, disability
3. Areas	I. Physical	Daily activities / functionality: walking, swallowing, bathing, hygiene habits, sphincter control, fatigue, oral changes, weight, appetite, feeding, dressing, taking medications, transport autonomy
	II. Neurological	Recent and late memory deficits, impairment in speech, understanding, thinking, hearing, vision, smell, pain and sensitivity, sleep, daytime drowsiness, epileptic seizures
	III. Psychological /psychiatric	Apathy, mood, anxiety, obsessive-compulsive symptoms, aggression, sexual behavior
	IV. Social	Social habits, group activities, habits

Table 1. Summary of questionnaire topics regarding social and clinical data and areas of perceived changes by caregivers during the last 5 years in people with intellectual disability

Results

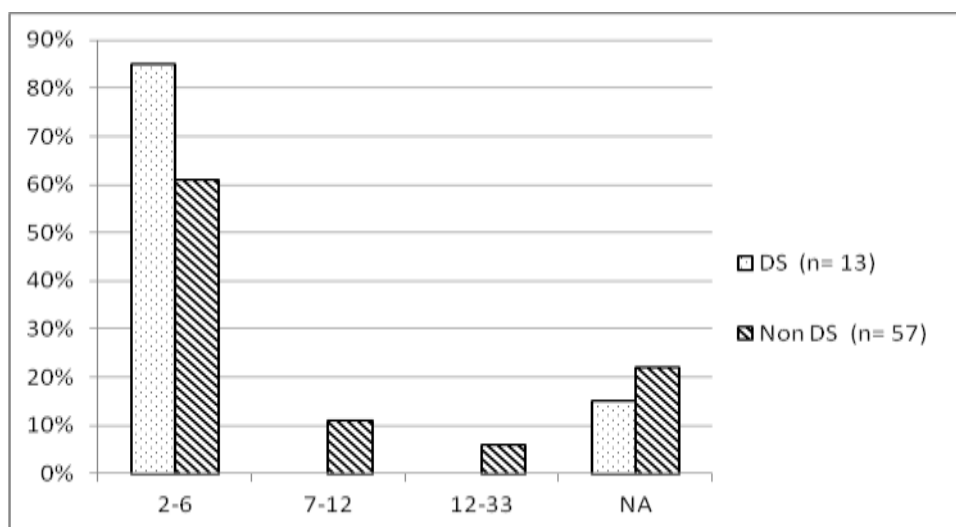
Demographic aspects

In this study out of 298 available people with ID in the age range of 35-60 years it was possible to evaluate 195 questionnaires answered by caregivers of individuals with ID (53% men), 39 of them with DS (20%) and 156 without, with a mean age of 45.4 years (SD=6.9; with DS, 41.3 years, SD=5.7; without DS, 46.5 years, SD=7.3).

The control group consisted of 77 people (62% women; mean age 46.8 years, SD=7.3) without ID in the same age group (35-60 years), with a subset of this consisting of 25 siblings (68% women; mean age 47.9 years, SD=7.7) of the subjects with ID.

About in half (52%) of this population with ID it was declared to have attended regular school at some point in their educational history, 56% of individuals without DS and 38% of those with DS.

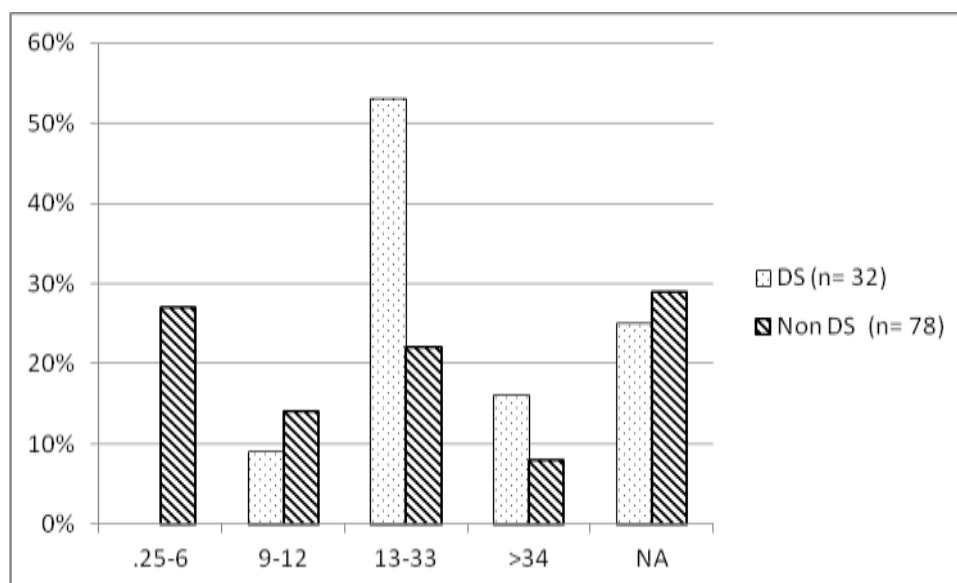
From those, in DS group, 85% attended regular schools from 2 to 6 years compared to 61% in non DS group. In non DS group 11% remained in regular schools for a period ranging from 7-12 years and in 6% for 12-33 years, compared to none with DS for both periods. In about 1/5 (non DS) to 1/6 (DS) of the subjects a detailed time period in regular schools was not available for the caregivers (Graph 1). Although an expressive number attended regular school, 15% of the total had been set in special classes in regular schools at some period of academic life.



Graph 1. Time in years of attendance in regular schools of people with intellectual disability. DS=Down syndrome; NA= not available

Most (75%) of the evaluated people, mainly in the group with DS (91%) compared to non DS (70%), were referred to have attended special schools at some stage of life. Those with DS, 9% stayed in this setting for 9 to 12 years, 53% for 13 to 33 years and 16% for a period ranging from 34 to 44 years, and 25% did not have the exact time information.

Those without DS, 27% studied in these specialized institutions from 3 months to 6 years, 14% between 9-12 years, 22% between 13-33 years and 8% between 34-40 years and 29% did not know the exact time spent there (Graph 2).



Graph 2. Time in years of attendance in special schools of people with intellectual disability. DS=Down syndrome; NA= not available

Most individuals with ID (64%, $n = 124$) was legally banned, especially in the group with DS ($p < 0.001$). Of these, 83% had total ban, with no difference between groups with and without DS. Only 17% of individuals with ID reported to be formally employed. A minority (13%) received financial welfare from disability from Brazilian government (eligible only for population under poverty), being more frequent in those without DS ($p = 0.038$), and 25% received a pension or social security retirement benefit.

Affective relationship (dating) was reported by 24% and active sexual life by 8% of responders (i.e. caregivers), none of those taking care of people with DS.

The majority reported that individuals with ID had never consumed alcoholic beverages (85%) or tobacco (95%) and no individuals with ID were reported to be using illicit drugs.

Deterioration referred by caregivers in people with ID in the last 5 years

In individuals with ID, there was report of decline in physical aspects in the last five years in the following areas: walking (21%); swallowing (11%); oral health (11%); willingness for motor activities (21%); weight (32%) and appetite (13%) maintenance. Neurological/sensorial changes were cited in this period in: recent (12%) and late (4%) memory; speech (10%); vision (14%) and hearing (12%).

In relation to psychiatric aspects in the last five years there were reports of apathy onset especially within family environment (18%), mood changes (19%), anxiety (15%) and aggression (21%).

We describe below the findings in each of the areas analyzed in this population with ID compared to the control group of subjects in the same age range.

Comparison of people with ID and control groups

There were statistically significant differences ($p < 0.05$) among reported changes in individuals with ID (with and without DS) and controls in the past 5 years in the areas: 1) physical: walking, chewing/swallowing, bathing, hygiene after bathroom use, excessive tiredness, oral health, weight change and autonomy in transport; 2) neurological: speech and comprehension of sentences; 3) apathy, mood changes, presence of obsessive compulsive symptoms; 4) leisure: refusal to participate in social activities in groups.

In some areas there was difference between control subjects with only one group of people with ID, either DS (taking medications, attention, poor sleep and daytime sleepiness) or those without DS (sphincter control of urine and feces, dressing up, routine activities, anxiety/impulsivity and aggression) (Table 2).

Table 2. Activities referred as in decline in the last five years with statistical differences ($p < 0.05$) among people with ID and controls of the same age

Reported changes in the studied areas (vs. controls)			
Physical	Neurological	Psychiatric	Leisure
<ul style="list-style-type: none"> • <u>Walking</u> • <u>Chewing / swallowing</u> • <u>Bathing</u> • <u>Hygiene after bathroom use</u> • Urine control (NDS) • Fecal control (NDS) • <u>Excessive tiredness</u> • <u>Oral health</u> • <u>Weight Change</u> • Dress up (NDS) • Take medication (DS) • <u>Autonomy in transport</u> 	<ul style="list-style-type: none"> • Attention (DS) • <u>Speech</u> • <u>Understanding of sentences</u> • Poor nocturnal sleep (DS) • Daytime sleepiness (DS) • Reasoning routine situations (NDS) • Vision (NDS) • Sensitivity to pain (DS) • Seizures (NDS) 	<ul style="list-style-type: none"> • <u>Apathy</u> • <u>Change in mood</u> • Anxiety / impulsivity (NDS) • <u>OCD</u> • Aggressiveness (NDS) 	<ul style="list-style-type: none"> • <u>Refusal in social activity</u>

DS: Down syndrome; NDS: not Down syndrome; OCD: obsessive compulsive disorder. Variables with underlined results were different from controls of siblings in both groups, DS and NDS

Comparison of subjects with ID and control subgroup of siblings

Addiction habits (alcohol, tobacco and illicit drugs) were more frequent in the control group of siblings ($p < 0.001$). Decline in physical, neurological and psychiatric areas, although reported in the last five years in a subgroup of the 198 individuals with ID, were not confirmed in all of them as statistically different ($p < 0.05$) in the control group of 25 siblings of the same age range (35-60 years).

Compared with this subset of siblings, there was only statistical difference in the following reported activities in both groups of patients with ID (with and without DS): hygiene after bathroom use, autonomy in transportation and obsessive compulsive symptoms. There were differences with siblings in only one of the groups of individuals with ID in walking, chewing/swallowing, fatigue, weight and appetite changes, sensitivity to pain (people with DS) and also delayed memory, speech, vision, seizures, anxiety and impulsivity (without DS) (Table 3).

Table 3. Activities reported to decline in the last five years with statistical differences (p<0.05) among people with ID and a control subgroup of siblings in the same age

Reported changes in the studied areas (vs. subgroup of controls of siblings)		
Physical	Neurological	Psychiatric
<ul style="list-style-type: none"> • Walk (DS) • Chewing / swallowing (DS) • <u>Hygiene after bathroom use</u> • Excessive tiredness (DS) • Weight change (DS) • Appetite change (DS) • <u>Autonomy in transport</u> 	<ul style="list-style-type: none"> • Late Memory (NDS) • Speech (NDS) • Vision (NDS) • Sensitivity to pain (SD) • Seizures (NDS) 	<ul style="list-style-type: none"> • Anxiety / impulsivity (NDS) • <u>OCD</u>

DS: Down syndrome; NDS: not Down syndrome; OCD: obsessive compulsive disorder. In underlined variables results were different from controls of siblings in both groups, DS and NDS

Differences within groups with ID

Both groups of people with ID (with and without DS) differed statistically (p<0.05) when compared in few variables. Vision changes were less referred in people without DS and in this group, more epileptic seizures were reported in the last five years. On the other hand changes in pain sensitivity were referred only in the group with DS.

Discussion

In our study with individuals with ID aged 35 to 60 years, there was report of decline in physical aspects in the last five years in the following areas: walking (21%); swallowing (11%); oral health (11%); willingness for motor activities (21%); weight (32%) and appetite (13%) maintenance. Neurological/sensorial changes were cited in this period in: recent (12%) and late (4%) memory; speech (10%); vision (14%) and hearing (12%). In relation to psychiatric aspects in the last five years there were reports of apathy onset especially in family environment (18%), mood changes (19%), anxiety (15%) and aggression (21%). Some of these variables were differently reported in control group, especially in that not composed by siblings.

Few differences in the last 5 years were reported between people with DS and with other etiologies for ID. Vision changes were reported more frequent in people without DS probably because in people with DS it is commonly observed earlier visual problems mainly during childhood and adolescence. By other hand changes in sensitivity to pain was referred more often in people with DS which is common in this genetic syndrome that presents with decreased responsiveness to nociceptive stimulation. Although epileptic seizures were more referred in people without DS in the last five years, this is a subject that deserves better elucidation in future papers that might study people of residential community settings which may have more severe clinical presentations.

The deterioration found in some people with ID during the aging process in this study was found in other international papers and even in Brazilian general population older than 60 years in Brazil.

Although the different character of our study (by proxy or with subjectiveness regarding caregiver's opinion and because of the younger age of subjects - less than 60 years) it was possible to show similar frequencies of suggestive symptoms of depression (apathy onset especially in family environment [18%], mood changes [19%], anxiety [15%] and aggression [21%]) and of cognitive impairment (changes in recent [12%] and late [4%] memory, speech [10%]) which were also referred in project SABE in 18% and 7% of their subjects older than 60 years, respectively.

In that project 19% of the studied population had difficulties in daily activities which were also similar to the physical decline in last 5 years referred in our younger population (walking [21%], swallowing [11%], and willingness for motor activities [21%], vision [14%] and hearing [12%]).

Some of these findings, such as cognitive deterioration which may lead to dependence in daily activities, as referred in Epidoso's project predict risk factors for mortality and consist in potential elements of change in the aging process. This was also verified in a longitudinal study of people with ID without DS in UK which demonstrated an up to five times higher incidence of dementia in older people with ID than older adults in the general population (Strydom, *et al.*, 2013). By another hand Epidoso's study in Brazil referred age as a risk factor in the general population, and our group is younger than 60 years which poses greater future impacts (Ramos, 2003).

Only 17% of our studied population with ID had formal jobs and 38% received governmental transfers. These findings are also similar to the general aging population data of SABE's project in São Paulo city which showed social limitations in the population older than 60 years. Epidoso's study found that few variables maintained an independent and significant effect on the risk of death, namely: gender, age, previous hospitalization and positive screening for cognitive impairment and dependence in daily activities. However, the only potential risk factors that could diminish the risk of death were cognitive status and the degree of dependence on daily activities (Ramos, 2003).

In our present study leisure activities constituted also a declared problem with refusal of people with ID to go out for social activities in the last 5 years compared with the control group.

Most adults interviewed in IDS-TILDA had leisure activities, however, they reported to rarely participate in social activities with friends outside their homes and families had limited roles in their lives (McCarron, *et al.*, 2013; Trinity College Dublin, 2016).

Some limitations of this study should be mentioned such as the likely selection of less vulnerable individuals with ID attending these non-governmental organizations, which present with more favorable physical and social conditions. Another important factor is the account of caregivers who, despite their opinion being considered as closest to reality as possible, it contains subjective elements which may be difficult for interpreting.

Planning of preventive measures as well as adequate services for this aging population with ID might decrease individual and collective burden of social, health and economic impacts in this new paradigm of greater longevity associated to high morbidity (Barr, Gilgunn, Kane, & Moore, 1999; Heller, 2008; Lin, JD, Wu, Lin, PY, Lin, LP, & Chu, 2011). New research methods including longitudinal studies should be planned in order to better optimize public and private resources in this field (Hilgenkamp, Bastiaanse, Hermans, Penning, Van Wijck, & Evenhuis, 2011; Starr, & Marsden, 2008).

Conclusion

Studies in several countries reported signs of premature aging in individuals with ID, especially those with Down syndrome. In this study, performed in nonprofit organizations of São Paulo city through questionnaires answered by caregivers of people with mild to moderate ID aged 35-60 years, more changes in physical, neurological and psychiatric areas were reported in the last five years compared with control subjects of the same age. Multicentric research within work networks such as nonprofit organizations is fundamental, as it adds different care visions allowing collection of data with greater power of analysis. Long-term longitudinal studies that replicate these findings are necessary, in order to identify and detail risk factors for prevention of disability deterioration in this population.

References

- Barbosa, A. R., Souza, J. M., Lebrão, M. L., Laurenti, R., & Marucci, M. F. (2005). Functional limitations of Brazilian elderly by age and gender differences: data from SABE Survey. *Cad. Saúde Pública*, 21(4), 1177-1185. Available at: <http://www.scielo.br/pdf/csp/v21n4/20.pdf>. Access in: January, 26, 2016.
- Barr, O., Gilgunn, J., Kane, T., & Moore, G. (1999). Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. *J. Adv. Nurs*, 29(6), 1482-1491. Available at: doi: 10.1046/j.1365-2648.1999.01036.x. Access in: January, 26, 2016.
- Bigby, C. (2008). Beset by obstacles: a review of Australian policy development to support ageing in place for people with intellectual disability. *J. Intellect Dev Disabil*, 33(1), 76-86. Available at: doi: 10.1080/13668250701852433. Access in: January, 26, 2016.

Cidade de São Paulo. (2011). Portaria n.º 561, de 20 de maio de 2011. *Diário Oficial do Município*, 21 may.

Dewinter, C. F., Bastiaanse, L. P., Hilgenkamp, T. I., Evenhuis, H. M., & Echteld, M. A. (2012). Overweight and obesity in older people with intellectual disability. *Res. Dev. Disabil.*, 33(2), 398-405. Available at: doi: 10.1016/j.ridd.2011.09.022. Access in: January, 26, 2016.

Esbensen, A. J. (2010). Health conditions associated with aging and end of life of adults with Down syndrome. *Int. Rev. Res. Ment. Retard.*, 39(C), 107-126. Available at: doi: 10.1016/S0074-7750(10)39004-5. Access in: January, 26, 2016.

Guilhoto, L., & Cavalheiro, E. A. (2014). Adult Life and Ageing of Person with Intellectual Disability in Sao Paulo, Brazil: Report from a multicenter Study Group. Annals of 9th Congress of European Association of Mental Health in Intellectual Disability. Utrecht: *EAMHID CENTRAL OFFICE*, 1, 99-99. Available at: <http://www.scielo.br/pdf/csp/v21n4/20.pdf>. Access in: January, 26, 2016.

Hand, J. E. (1994). Report of a national survey of older people with lifelong intellectual handicap in New Zealand. *Journal of Intellectual Disability Research*, 38(Issue 3), 275-287. Available at: doi: 10.1111/j.1365-2788.1994.tb00395.x. Access in: January, 26, 2016.

Heller, T. (2008). Report of the state of the science in aging with developmental disabilities: charting lifespan trajectories and supportive environments for healthy community living symposium. *Disability and Health Journal*, 1(Issue 3), 127-130. Available at: doi: <http://dx.doi.org/10.1016/j.dhjo.2008.04.001>. Access in: January, 26, 2016.

Hilgenkamp, T. I., Bastiaanse, L. P., Hermans, H., Penning, C., Van Wijck, R., & Evenhuis, H. M. (2011). Study healthy ageing and intellectual disabilities: recruitment and design. *Res. Dev. Disabil.*, 32(3), 1097-1106. Available at: doi: 10.1016/j.ridd.2011.01.018. Access in: January, 26, 2016.

Lin, J. D., Wu, C. L., Lin, P. Y., Lin, L. P., & Chu, C. M. (2011). Early onset ageing and service preparation in people with intellectual disabilities: institutional managers' perspective. *Res. Dev. Disabil.*, 32(1), 188-193. Available at: doi: 10.1016/j.ridd.2010.09.018. Access in: January, 26, 2016.

Lott, I. T., & Head, E. (2005). Alzheimer disease and Down syndrome: factors in pathogenesis. *Neurobiology of Aging*, 26(3), 383-389. Available at: doi: 10.1016/j.neurobiolaging.2004.08.005. Access in: January, 26, 2016.

McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Res Dev Disabil.*, 34(1), 521-527. Available at: doi: 10.1016/j.ridd.2012.07.029. Access in: January, 26, 2016.

Novell, R., Nadal, M., Smilges, A., Pascual, J., & Pujol, J. (2008). *Seneca: Envejecimiento y discapacidad intelectual en Cataluña*. Informe ejecutivo. Federació catalana pro-persones amb discapacitat intel·lectual, dic. Available at: http://www.feaps.org/biblioteca/documentos/informe_seneca.pdf. Access in: January, 26, 2016.

Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *Jama*, 304(1), 91-92. Available at: doi: 10.1001/jama.2010.906. Access in: January, 26, 2016.

Ramos, L. R. (2003). Determinant factors for healthy aging among senior citizens in a large city: the Epidoso Project in São Paulo. *Cad. Saúde Pública*, 19(3), 793-798. Available at: file:///C:/Users/Dados/Downloads/Determinant_factors_for_healthy_aging_among_senior.pdf. Access in: January, 26, 2016.

Ramos, L. R., Rosa, T. E. C., Oliveira, Z., Medina, M. C., & Santos, F. R. G. (1993). Profile of the elderly residents in São Paulo, Brazil: Results from a household survey. *Revista de Saúde Pública*, 27, 87-94.

Starr, J. M., & Marsden, L. (2008). Characterisation of user-defined health status in older adults with intellectual disabilities. *J. Intellect. Disabil. Res.*, 52(6), 483-489.

Strydom, A., Hassiotis, A., King, M., & Livingston, G. (2009). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychol Med.*, 39(1), 13-21. Available at: doi: 10.1017/S0033291708003334. Access in: January, 26, 2016.

Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Res Dev Disabil*, 34(6), 1881-1885. Available at: doi: 10.1016/j.ridd.2013.02.021. Access in: January, 26, 2016.

The AAIDD Ad Hoc Committee on Terminology and Classification. (2010). *Intellectual Disability: definition, classification, and systems of supports*. Eleventh edition. Washington, EUA: American Association on Intellectual and Developmental Disabilities (AAIDD) (259 pp.).

Trinity College Dublin. *IDS TILDA. The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing*. Available at: <http://www.idstilda.tcd.ie/>. Access in: January, 26, 2016.

Recebido em 11/10/2016

Aceito em 30/12/2016

Laura Maria de Figueiredo Ferreira Guilhoto - Médica neurologista. Graduação em Medicina pela Universidade de São Paulo. Mestre e Doutora em Medicina (Neurologia) pela FMUSP. Residência Médica em Neurologia Infantil e formação em Eletrencefalografia, no Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, e Fellowship em Neurofisiologia Clínica, no Rush Presbyterian St. Luke's Medical Center em Chicago, EUA. Pós-doutoramento no Children's Hospital Boston da Universidade de Havard. Atualmente é médica neurologista do Departamento de Neurologia e Neurocirurgia da Unifesp e colaboradora da APAE DE SÃO PAULO.

E-mail: lauraguilhoto@apaesp.org.br; lauragui@gmail.com

Laura Maria de Figueiredo Ferreira Guilhoto, Maria Regina Leondarides, Leila Regina de Castro, Simone Sena, Cristina Almeida, Daniela Karmeli, Elizabete Macedo, Juliana Righini, Angela Alves, Ester Tarandach, Maria Fernanda Prezia, Esper A. Cavalheiro – Participantes do Grupo de Estudos sobre a Vida Adulta e Envelhecimento da Pessoa com Deficiência Intelectual, formado pelas instituições A Alternativa, ADERE, ADID, APABEX, APAE DE SÃO PAULO, APOIE, AVAPE, CARPE DIEM, CHAVERIM, CIAM/ALDEIA DA ESPERANÇA, médicos, pesquisadores e representantes de familiares.