

Daily Life and Planning for the Future of Ageing People with Down Syndrome: Results from a National Study on Caregivers

Venusia Covelli¹, Erika Guastafierro², Matilde Leonardi²

¹STORIOSS Research Centre, e-Campus University, Novedrate, Como, Italy

²Neurology, Public Health and Disability Unit, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy

Email: venusia.covelli@gmail.com

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Abstract

Background: Limited research concerns the study of continuity in the future of the physical and social status of elderly people with DS that is when people who take care of them will not be there anymore (“*after we have gone*”). **Objective:** From a biopsychosocial perspective, to investigate the daily life of ageing people with Down Syndrome over 45 years old in order to identify the most important issues in better planning for their future. **Methods:** A cross-sectional Italian national study was carried out. An *ad hoc* questionnaire was administered to formal and informal caregivers of aging people with Down Syndrome. **Results:** 136 family members and health professionals were involved. Most of the people with Down Syndrome live at home, attend a daily center and do many activities. Most of them had never worked and she/he is not at all autonomous. 25% of caregivers declared that, nowadays, there is not planning for the future, and 30.9% of participants who planned their future collected information when it occurred (e.g. when the parents pass away). **Conclusions:** The aging of people with DS requires attention to the planning of their future. In order to better plan, it is necessary to avoid programming “in emergency”, but for time, keeping in mind of the activities developed by the people, their abilities and all of the elements that have allowed them to live well up to a point of their life.

Keywords

Down Syndrome, Trisomy 21, Future Life, Ageing, Elderly, Biopsychosocial Approach

1. Introduction

Down Syndrome (DS) is considered the most common genetic cause of intellec-

tual disability [1] [2]. Despite the well-known comorbidities [3] [4], it was estimated that people with DS will be living as long as the general population [5]. This is due to improvements in medical care and health services [6] [7] who have made that in the last 70 years life expectancy of people with DS has considerably increased by 50 years [8], from an average of 9 years in 1929 [9] to 60 years in 2002 [10] [11]. In comparison to the general population, people with DS start to age prematurely [12] and they can be considered as “old” at the age of 45 [13] [14] [15] [16]. DS is associated with a group of clinical manifestations of “accelerated aging”: early-onset dementia, early-onset menopause, hearing and visual impairments, thyroid dysfunction, obesity, diabetes, sleep apnea, musculoskeletal problems, skin and hair problems [17]. The increase in life expectancy shows a greater decline in cognitive and functional ability in people with DS over 50 age compared to their peers without DS [18] [19] [20].

In addition to a lot of studies that focus on clinical features of people with DS, researchers have also investigated the quality of life of people with DS and their families [21] [22] [23] [24] [25]. As recently reported, changes in clinical conditions tend to limit daily activities and social participation of elderly individuals with DS [26]. In this study conducted in Rome on people with DS (93 of 518 over 45 years old), it was found that limitations in autonomy translated into limitations in social life. This is probably due to the fact that the majority of the sample was living with their family and only a few of them in a small community family house or in a large establishment that could be a stimulus to create social networks. Based on Bertoli *et al.* questionnaire [26], a recent study performed by Matthews and colleagues [27] assessed health, social communication, and daily living skills of adults with DS. The authors described the range of abilities and how increasing age contributes to functional abilities in a sample of 188 individuals who provide care of people with DS from 20 to 69 years old. In people with DS more than 40 years old (49 participants on 188 total sample), levels of independence, communication and social skills were lower than younger people with DS, and tend to decline after age 40 - 45. In Italy, as Bertoli stated, it was hypothesized that the decline was due to the lack of support services after completing school in Rome. This information about independence, communication and social skills is important for family members “in order to plan accordingly for the future to their adult with DS” [27]. Another study, carried out by interviewing 31 people with DS of more than 45 years, consistently with the biopsychosocial perspective, has taken into account the environmental factors, such as social relationships and social assistance, related to the person’s health status that is relevant for the personal functioning of these persons [28]. Family members and health professionals involved with people with DS play an important role in their daily support but, sometimes, they seem to prevent their autonomy development. For this reason, there is a real need, for all people with DS, to provide increased opportunities for engagement in social activities [29].

Unlike the literature on the health conditions of ageing people with DS is remarkable, there is limited research concerned the continuity of their life into the

future. It is important to investigate the future planning for persons with DS to ensure continuity of their status (health and social) despite the loss of their family members, that is when people who take care of them will not be there anymore (“*after we have gone*”). About this, in Italy, a recent law was introduced in response to a need from the families of people with disabilities to ensure a future for their loved ones if there are no longer those who care for them today. Planning for the future is important for everyone, but plans are especially essential for an individual with DS to ensure the continuity of many achievements from the previous years, both at life skills and at health conditions levels.

Based on these considerations and recent suggestions [27], the present study aimed to investigate the daily life of ageing people with DS over 45 years old in order to describe and identify the most important aspects we have to take into account when we are planning for their future. Within the biopsychosocial perspective, the present research is based on the WHO’s International Classification of Functioning, Disability and Health (ICF) that focuses on a person’s living conditions and the role of environmental factors in the creation of disability [30]. The ICF biopsychosocial perspective, conceptualizing the disability as a difficulty of functioning, might potentially represent a significant framework in government policies or clinical practice addressed to ageing persons with DS [31]. Since there are no questionnaires based on the bio-psycho-social perspective, the study has foreseen the construction of a specific instrument (DOQuest) for the evaluation of functioning and disability of ageing people with DS according to ICF’s biopsychosocial approach. Family members and health professionals were involved to observe the presence of health facilities and policies that represent facilitators for a positive experience of ageing.

2. Methods

This study is part of a larger project entitled “DOSAGE: Functioning and disability measure of Ageing people with Down Syndrome: the creation of an instrument for a national and European implementation”, coordinated by Neurological Institute Carlo Besta IRCCS Foundation in Milan, aims to construct a questionnaire (DOQuest) for the evaluation of functioning and disability of ageing people with DS according to ICF’s biopsychosocial approach. The study was approved by the Institute’s ethics committee and all participants signed an informed consent form.

2.1. Participants

Throughout two main associations of family members of people with DS in Italy, Anffas Onlus and AIPD, 136 family members and the health professionals who provided care for people with DS over 45 years were enrolled. Inclusion criteria are family members who take care of a person with DS over 45 years old (parents, siblings, other informal caregivers); health professionals who interact regularly with persons with DS over 45 years old (physician such as geriatrician,

neuropsychiatrist; social health worker; psychiatric rehabilitation technician; occupational therapist; psychologist; psychiatrist; professional educator; social worker, etc.). Exclusion criteria: family members who take care of a person with DS under 45 years old; health professionals who interact regularly with persons with DS under 45 years old; participants who did not provide informed consent to participate in research.

2.2. Instrument

The questionnaire (DOQuest) was made *ad hoc* on the basis of focus group and systematic literature review results published elsewhere [16] [32], and of a pilot study [28]. DOQuest is composed by 136 questions, organized into 6 sections that are inspired by the ICF classification [30]. The first five sections are about people with DS: 1) demographics information; 2) health status and quality of life; 3) social activities and participation; 4) environmental factors, social network and care network; 5) planning of the future. The last section collected demographics information about family members and health professionals. A pilot version of DOQuest was previously submitted to 38 participants (family members or health professionals).

2.3. Data Collection

DOQuest was widespread in Italy by ANFFAS Onlus and AIPD that invited by email all their association's local sections to collect it. Each local association's section collected the disclosure document and its signed informed consent before filling out the questionnaire. Data collection was carried out between May 2015 and September 2015. Participants (family members or health professionals) had the opportunity to choose whether to complete the questionnaire: 1) on paper, by printing the questionnaire and informed consents sent via email, and sending it filled into the coordinator center by post; 2) online, by filling in the questionnaire via the appropriate link. Data collected were analyzed using SPSS 18.0 statistical software package (IBM, Armonk, NY, USA). The questionnaires were collected with the help of 45 local sections of ANFFAS and AIPD associations in over 15 Italian regions. The irregular distribution of the collected data did not allow the possibility of comparing the results by geographical area.

3. Results

3.1. Data on Living Condition of Persons with Down Syndrome

136 questionnaires were collected, of which 68 were filled out by family members and 68 by health professionals. Sociodemographic characteristics of the sample are presented in **Table 1**. The questionnaires have referred to 136 people with DS above the age of 45 years, 61 females and 75 males, with an average age of 53.3 (**Table 2**). Information about where the persons with DS lived was also collected. As shown in **Table 2**, the majority of them were living at home with a family member (66.1%) and 72.8% participated at a daycare center (59.9% is a

Table 1. Socio-demographic characteristics of family members and health professionals.

Total sample (N = 136)	Mean (range)	N (%)
Data collection		
Northern Italy		86 (63.3)
Central Italy		44 (32.3)
Southern Italy		6 (4.4)
Family Members (N = 68)		
Mean age (range)	64.7 (39 - 92)	
<i>Female</i>		46 (67.6)
Relationship with the person with DS		
Parents: Mean age (range)	78.6 (67 - 92)	19 (27.9)
Siblings: Mean age (range)	59.9 (39 - 82)	42 (61.8)
Family members: Mean age (range)	59.8 (39 - 78)	7 (10.3)
Education		
Primary school		9 (36.8)
Secondary school		11 (16.2)
High school		23 (33.8)
Degree		9 (13.2)
Master degree/higher		16 (23.6)
Marital status		
Single		8 (11.8)
Married		44 (64.7)
Cohabitant		3 (4.4)
Divorced		3 (4.4)
Widow		10 (14.7)
Work conditions		
Employee		31 (45.6)
Not employee		2 (2.9)
Retired to work		35 (51.5)
Health Professionals (N = 68)		
Mean age (range)	45.6 (23 - 63)	
<i>Female</i>		55 (80.9)
Education		
Secondary school		2 (2.9)
High school		20 (29.4)
Degree		34 (50.1)
Master degree/higher		12 (17.6)
Marital status		
Single		13 (19.1)
Married		42 (61.8)
Cohabitant		4 (5.9)
Divorced		9 (13.2)
Employment		
Educators		52 (76.5)
Social health operators		7 (10.3)
Nurses		4 (5.9)
Psychiatric Rehabilitation Technicians		2 (2.9)
Social workers		2 (2.9)
Something else		1 (1.5)

Table 2. Data of persons with Down syndrome.

Total sample (N = 136)	N (%)
Mean age (range) 53.3 (45 - 67)	
<i>Female</i>	61 (44.9)
<i>Educational level</i>	
No one	58 (42.6)
Primary school	37 (27.2)
Secondary school	36 (26.5)
High school	1 (0.8)
Not specified	4 (2.9)
Total	136 (100)
<i>Did he/she attend "special schools"?</i>	
No	66 (48.5)
Yes, primary school	50 (36.8)
Yes, secondary school	8 (5.9)
Yes, high school	2 (1.5)
I wouldn't know	10 (7.3)
Total	136 (100)
<i>Legal guardianship/protection</i>	
Guardian <i>ad litem</i>	73 (53.7)
Guardian or guardian of the person	39 (28.7)
None	22 (16.1)
Curator or guardian of the property	2 (1.5)
Other	
Total	136 (100)
<i>Economic income*</i>	
Disability pension and attendance allowance	34 (50.3)
Reversibility of the maternal/paternal board	17 (25.1)
Attendance allowance for civil disability	8 (11.5)
Disability pension (age 18 - 65)	6 (9.4)
Salary	1 (1.6)
Inability pension	1 (1.0)
Contributory pension	1 (1.1)
Welfare benefits (more of 65 age)	0 (0.0)
<i>Where do they live?</i>	
At home with their families	90 (66.2)
Social health community for people with disabilities (CSS)	24 (17.6)
Nursing home for people with disabilities (RSD)	9 (6.6)
Family home	5 (3.7)
Nursing home (RSA)	3 (2.2)
Flexible care residence (RAF)	3 (2.2)
Protected apartment	2 (1.5)
Total	136 (100)
<i>Has he/she always lived in the place you have just indicated above?</i>	
No	75 (55.1)
Yes	61 (44.9)
Total	136 (100)

Continued

<i>What are the reasons of his/her change of residence?</i>	
The caregiver who used to help him/her passed away (one or both parents, siblings, formal caregiver)	31 (41.2)
The person or the people that used to assist him/her couldn't do it anymore (e.g. old age parents, or misunderstandings between siblings)	24 (32.0)
His/her family changed residence	5 (6.7)
His health condition has got worse and there was urgent need for greater medical nursing assistance.	4 (5.3)
The facility that sheltered him/her was no longer welcome.	2 (2.7)
The person with DS has asked for a move (for example to live on his/her own or with his/her partner or in a foster home).	2 (2.7)
I wouldn't know	2 (2.7)
Other	5 (6.7)
Total	75 (100)
<i>Participation at a day care center</i>	
Yes	99 (72.8)
No	37 (27.2)
Total	136 (100.0)
<i>The kind of facility he/she is attending is...</i>	
Social care center	59 (59.6)
Educational center	22 (22.2)
Rehabilitative nursing	17 (17.2)
Professional center	1 (1.0)
Total	99 (100.0)

*Multiple responses.

social care center). Half of the sample had changed residence during their life because the caregiver who used to help them passed away (41.2%) or the person that used to assist them couldn't do it anymore (32.0%).

3.2. Health Condition

The second part of the questionnaire investigated the quality of life and the health status perceived by the family members and operators about the person with DS (Table 3). Of 136 responders, the 47.1% believed that the person with DS has good health, and 58.1% believed that their quality of life was good. Regarding the health status specifically, we founded several comorbidities (they reported an average of 6.3 comorbidities) and the frequent pathologies are intellectual disability, dry skin, soliloquy, cataracts, hypothyroidism, hearing loss, obsessive-compulsive disorders, refractive problems, gingivitis, flat foot valgus, hallux valgus, keratosis, depression, alopecia areata, mitral valve prolapse, osteoporosis, scoliosis, epilepsy, aortic insufficiency, and autoimmune hepatitis. Family members and health operators refer that the persons with DS usually take medicine for these pathologies (they take an average of 1.7 drugs/medications): hypothyroidism (15.6%), keratosis (10.4%), respiratory infections (6.1%), dry skin (6.1%), epilepsy (5.6%), depression (5.6%) and autoimmune hepatitis (4.3%).

Table 3. Health condition.

	Total sample N (136)	N (%)
<i>In general, how do you evaluate the current state of health of the person with DS?</i>		
Very bad		5 (3.7)
Bad		16 (11.8)
Neither bad nor good		42 (30.9)
Good		64 (47.1)
Very good		9 (6.6)
<i>In general, how do you evaluate the current state quality of life of the person with DS?</i>		
Bad		4 (2.9)
Neither bad nor good		31 (22.8)
Good		79 (58.1)
Very good		22 (16.2)
<i>Who is the person in charge of the person with DS healthcare assistance?</i>		
Primary health care: general medical examinations		12 (8.8)
Secondary health care: medical examination with a specialist		29 (21.3)
Free healthcare products like incontinence diapers, crutches, catheter, etc.		1 (0.7)
Rehabilitation service		33 (24.3)
Nursing home admission		15 (11.0)
Psychological and psychiatric assistance through mental health departments (please specify):		15 (11.0)
<i>Comorbidities*</i>		
Dry skin		54 (39.7)
Cataract (H26)		41 (30.1)
Hypothyroidism (E03)		36 (26.5)
Blindness and low vision (H54)		35 (25.7)
Refraction disorder		27 (19.9)
Periodontitis		26 (19.1)
Flat foot (M 21.4)		25 (18.4)
Bunion		24 (17.6)
Keratosis		24 (17.6)
Gingivitis		18 (13.2)

*ICD-10 diagnosis codes related to the ten most frequent comorbidities reported by participants.

3.3. Activities and Participation

In the third part of the questionnaire we investigate the activities and the social participation of the person with DS (**Table 4**). This section demonstrates that people with DS in our sample are very engaged in the activities organized by the centers in which they live or by their families. In addition, we have explored the ability of the use of public transport and we discovered that most of them are not able to use transport independently but only on familiar routes. Regarding their health care, 56.3% of people with DS are not able to take care of their own health and they do not know how to take medicines themselves. From a relational point of view, they easily enter in relation with strangers, but generally (61.4%) they

Table 4. Activities and participations.

Total sample N (136)	Completely/ Moderately	A little/ Not at all	Missing
<i>Learning ability and the application of acquired knowledge</i>			
Is he/she able to read?	N (&) 48 (35.3)	N (&) 88 (64.7)	N (&) 0.0
Does he/she understand what he/she reads?	41 (30.1)	92 (67.6)	3 (2.2)
Is he/she able to write?	42 (30.9)	93 (68.4)	0.7
Is he/she able to do easy calculations?	10 (7.4)	126 (92.6)	0.0
Is he/she able to make decisions that affect his/her daily life	71 (52.2)	65 (47.8)	0.0
<i>The capacity to perform tasks and general requests.</i>			
Is the person with DS able to perform a simple task?	85 (62.5)	51 (37.5)	0.0
Is he/she able to perform articulated tasks within a group?	72 (52.9)	63 (46.3)	1 (0.7)
Is he/she able to complete articulated tasks independently, such as getting up in the morning and prepare himself to go out?	61 (44.9)	75 (55.1)	0.0
Is he/she able to plan his/her own daily routine?	44 (32.4)	92 (67.6)	0.0
<i>Communication skills</i>			
Is he/she able to manage a conversation (to begin, to keep and to end a conversation)?	49 (36.0)	87 (64.0)	0.0
Is he/she able to use a telephone?	29 (21.3)	106 (77.9)	1 (0.7)
Does he/she know how to use the computer autonomously?	21 (15.4)	115 (84.6)	0.0
Is he/she able to read the time on digital watches?	44 (32.4)	87 (64.0)	5 (3.7)
Is he/she able to read the time on analog watches (with hands)?	39 (28.7)	97 (71.3)	0.0
<i>Capacities to take care of him/herself</i>			
Is the person with DS able to look after his/her own health?	25 (18.4)	110 (80.9)	1 (0.7)
To what extent is he/she able to take medicines?	46 (33.8)	85 (62.5)	5 (3.7)
To what extent is he/she able to wash her/himself?	64 (47.1)	71 (52.2)	1 (0.7)
To what extent is he/she able to manage urination and defecation?	97 (71.3)	38 (27.9)	1 (0.7)
To what extent is he/she able to manage menstruation?	10 (7.4)	8 (5.9)	118 (86.8)
To what extent is he/she able to get dressed and get undressed?	101 (74.3)	32 (23.5)	3 (2.2)
To what extent is he/she able to put one's shoes on?	94 (69.1)	41 (30.1)	1 (0.7)
To what extent is he/she able to choose suitable clothing?	57 (41.9)	79 (58.1)	0.0
To what extent is he/she able to use cutlery and eat food?	117 (86.0)	17 (12.5)	2 (1.5)
To what extent is he/she able to take a glass and raise it to his/her lips and then drink the drink?	125 (91.9)	11 (8.1)	0.0
<i>Capacity to manage daily routine/ domestic life (only if he/she live at home)</i>			
To what extent he/she is able to acquire daily goods (for example choose food, drinks, dresses, cleaning products etc.)?	19 (14.0)	102 (75.0)	15 (11.0)
to what extent is he/she able to prepare meals for him/herself and the others (parents for example)?	10 (7.4)	111 (81.6)	15 (11.0)
to what extent is he/she able to do housework (for example cleaning up, do the laundry)?	29 (21.3)	91 (66.9)	16 (11.8)
to what extent is he/she able to assist others (his/her parents for example) if properly educated to do so?	21 (15.4)	98 (72.1)	17 (12.5)

Continued***Interpersonal interactions and relationships***

Does he/she easily relate to strangers?	92 (67.6)	44 (32.4)	0.0
Does he/she easily relate to the people that live in his community (friends, neighbors, acquaintances, peers, etc...)?	104 (76.5)	32 (23.5)	0.0
Can he/she have a romantic relationship? is he/she able to maintain the relationship?	26 (19.1)	101 (74.3)	9 (6.6)

are not able to create and maintain a romantic relationship. A relevant fact concerns the present and past work experience of our reference sample. As many as 79.4% do not work and have never worked. Only 8.1% have worked in the past and only 5.1% now work. However, they are very engaged in the activities organized by the centers where they live or by their families.

3.4. The Participation of the Person with DS in Social Life and in Activities within the Community Center

In this section, the DOQuest investigates the participation of persons with DS in the activities promoted by the community centers (Table 5). In general, our sample is not involved in voluntary activities (69.9%). Most of the persons with DS do not go to the cinema (47.1%) and do not enjoy any sports (59.6%). Regarding religion and spirituality, 53.7% of persons with DS do not relate with any kind of them. When asked which activities they perform in the community centers he/she is attending, it emerged that the principal activities are music therapy (31.6%) and art and decorative activities (29.4%) while the activities that they perform at home are mostly reading a book or a newspaper (23.5%) and watching television (40.4%).

3.5. Environmental Factors

The fourth section of the DOQuest is regarding the environmental factors (Table 6), in particular the use of support devices or the relational involvement. From a physical point of view, our sample does not need aids for personal use in daily life (84.6%). Specifically, they do not need products of technology, mobility aids for personal indoor and outdoor mobility and transportation (79.4%) and they do not need also any communication devices (72.1%).

On the other hand, from a relational point of view, the majority (84.6%) of our sample feels most comfortable with three or more persons. These persons are especially their mothers (25.0%) or brothers and sisters (41.9%).

3.6. Future Planning

In the last section of the questionnaire, dedicated to understanding the living conditions of people with DS, we explore the future perspective planned for them (Table 7). 25% of family members and health professionals said that there is not planning for the future of persons with DS. A lot of respondents stated that they have not thought of any actions for planning the future of the person

Table 5. The participation of the person with DS in social life and in activities within the community center.

Total sample N (136)	N (%)
<i>The perceived level of independence</i>	
Completely	4 (2.9)
Moderately	57 (41.9)
A little	53 (39.0)
Not at all	20 (14.7)
Not applicable	2 (1.5)
<i>Does the person with DS work? Has he/she ever worked?</i>	
He/she works	7 (5.1)
He/she doesn't work and he/she have never worked.	108 (79.4)
He/she doesn't work, but he used to work in the past	11 (8.1)
He did volunteer work or he/she volunteer in the community	8 (5.9)
I wouldn't know	2 (1.5)
<i>Can the person with DS manage independently his/her savings/finances?</i>	
Completely	0 (0)
Moderately	4 (2.9)
A little	20 (14.7)
Not at all	112 (82.4)
<i>Does the person with DS volunteer in associations or in the community?</i>	
No	95 (69.9)
Yes, habitually	23 (16.9)
Yes, occasionally	8 (5.9)
Actually no more	4 (2.9)
He's not interested about it	4 (2.9)
I wouldn't know	2 (1.5)
<i>Does the person with DS go to cinemas, museums, theatres?</i>	
No	64 (47.1)
Yes, occasionally	35 (25.7)
Yes, habitually	17 (12.5)
Actually no more	8 (5.9)
He's not interested about it	8 (5.9)
I wouldn't know	4 (2.9)
<i>Does the person with DS play any sports?</i>	
No	81 (59.6)
Yes, habitually	17 (12.5)
Yes, occasionally	16 (11.8)
Actually no more	13 (9.6)
He's not interested about it	8 (5.9)
I wouldn't know	1 (0.7)
<i>How does the person with DS relate to religion and spirituality?</i>	
No	73 (53.7)
Yes, occasionally	23 (16.9)
Yes, habitually	19 (14.0)

Continued

Actually no more	13 (9.6)
He's not interested about it	5 (3.7)
I wouldn't know	3 (2.2)
<i>What are the daily activities of the person with this DS within the community center he/she is attending?</i>	
Music therapy	43 (31.6)
Art and decorative activities	40 (29.4)
Sewing class	9 (6.6)
Film viewing and discussing	5 (3.7)
Swimming	4 (2.9)
None	8 (5.9)
He doesn't attend any community center	9 (6.6)
Other	13 (9.5)
<i>What kind of activities does the person with DS do when he/she is at home or in other living situation?</i>	
He/she watches television	55 (40.4)
He/she reads a book/newspaper	32 (23.5)
Perform repetitive gestures, rituals	19 (14.0)
He/she calls friends and relatives.	14 (10.4)
He/she uses the computer	2 (1.5)
I wouldn't know	6 (4.4)
Other	8 (5.8)

Table 6. Environmental factors: data about the physical and social environment the person with down syndrome lives in.

Total sample N (136)	N (%)
<i>Does the person with DS use assistive devices, in his/her daily life (for example continitive diapers, etc.)?</i>	
Yes	21 (15.4)
No	115 (84.6)
<i>Does the person with DS need products of technology, mobility aids for personal indoor and outdoor mobility and transportation (for example, wheelchair, orthopedic shoes, limb prosthesis)?</i>	
Yes	28 (20.6)
No	108 (79.4)
<i>Does the person with DS need communication devices (that help people to communicate and get information for example devices to write and read, hearing aid, glasses, etc.)?</i>	
Yes	38 (27.9)
No	98 (72.1)
<i>Thinking about people involved in the life of the person with DS, how many of them the person with DS feels most comfortable with?</i>	
None	2 (1.5)
One	4 (2.9)

Continued

Two	5 (3.7)
Three or more than three	125 (91.9)
Who are those people?	
Immediate Family: parents, brothers, sisters.	102 (75.0)
Extended family: uncles, aunts, nephews, nieces	12 (8.8)
Acquaintances, neighbors.	2 (1.5)
People that provide support or assistance	15 (11.0)
Friends	3 (2.2)
Other	2 (1.5)
Who is the reference person the person with DS feels most comfortable with?	
Mother	34 (25.0)
Father	2 (1.5)
Both parents	3 (2.2)
Brother/s or sister/s	57 (41.9)
People that provide support or assistance (social worker, psychologist, caregiver etc.)	21 (15.4)
In the past his/her mother/father/health professional but actually no more	14 (10.3)
Other	5 (3.7)
Thinking about the person with DS, does he get any moral, physical, emotional support from animals like pets (dogs, cats, birds, fish, etc.)?	
Yes	36 (26.5)
No	91 (66.9)
I wouldn't know	9 (6.6)

About the assistance network	Completely/ Moderately N (%)	A little/ Not at all N (%)	I wouldn't know N (%)
Are you satisfied with the housing management services and policies offered for people with DS?	47 (63.9)	39 (28.7)	50 (36.8)
Are you satisfied with the public transport services offered in your territory for adults with DS?	51 (37.5)	53 (39.0)	32 (23.5)
To what extent associations and organizations that have something to do with the Down Syndrome has positively affected the life of the person with DS?	100 (73.5)	21 (15.4)	15 (11.0)
Are you satisfied with the social security services or policies offered in your territory for people with DS?	54 (39.7)	66 (48.5)	16 (11.8)
Are you satisfied with the health care services and policies offered in your territory for adults with DS?	67 (49.2)	52 (38.2)	17 (12.5)
Are you satisfied with the education and training services or policies offered in your territory for adults with DS?	51 (37.5)	55 (40.4)	30 (22.1)
Are you satisfied with the labor services and policies offered in your territory for adults with DS?	29 (21.3)	64 (47.1)	43 (31.6)
To what extent the health care assistance offered in your territory is able to provide assistance to the person with DS?	76 (55.9)	48 (35.3)	12 (8.8)

Table 7. Future planning.

	People with DS that lives at home N (%)	People with DS that does not live at home N (%)	Total N (%)
<i>Has caregiver already made a detailed planning for the person with DS future?</i>			
Yes	48 (35.5)	41 (30.1)	89 (65.6)
No	29 (21.3)	5 (3.7)	34 (25.0)
I don't know	13 (9.6)	0 (0.0)	13 (9.6)
Total	90 (66.2)	46 (33.8)	136 (100.0)
<i>What actions have been taken to plan the future of the person with DS?</i>			
None. They collect information when it is the time	26 (19.1)	16 (11.8)	42 (30.9)
I wouldn't know	20 (14.7)	3 (2.2)	23 (16.9)
Preliminary contacts have been taken with foster homes or others health-related facilities	15 (11.0)	18 (13.0)	33 (24.3)
Some information have been requested to people who have been in the same condition	10 (7.4)	6 (4.4)	16 (11.8)
No one	9 (6.6)	0 (0.0)	9 (6.6)
Person with DS will remain at home with brother or sister	7 (5.1)	0 (0.0)	7 (5.1)
Request of information to people who had faced up to the same problems	0 (0.0)	3 (2.2)	3 (2.2)
Other	3 (2.2)	0 (0.0)	3 (2.2)
Total	90 (66.2)	46 (33.8)	136 (100.0)
<i>Even if no detailed planning for his/her future has been made, where would caregiver like or prefer him/her to stay, and who would caregiver like to look after him/her?</i>			
In his/her relative's house (siblings, aunts and uncles, cousins, etc.)	43 (31.6)	9 (6.6)	52 (38.2)
In a group home with assistance from family members and relatives (brothers, sisters, uncles, aunts, cousins, etc.)	18 (13.2)	18 (13.2)	36 (26.5)
In an assisted-living facility with assistance from family members and relatives (brothers, sisters, uncles, aunts, cousins, etc.)	9 (6.6)	11 (8.1)	20 (14.7)
I wouldn't know	7 (5.1)	5 (3.7)	12 (8.8)
At home with a caregiver	6 (4.4)	0 (0.0)	6 (4.4)
At home with one or more than one roommates	5 (3.7)	0 (0.0)	5 (3.7)
At home but next to a relative's house (siblings, aunts and uncles, cousins, etc.)	2 (1.5)	2 (1.5)	4 (2.9)
Other	0 (0.0)	1 (0.7)	1 (0.7)
Total	90 (66.2)	46 (33.8)	136 (100.0)

with DS because they would collect information when it is the time (30.9%). Some of them instead have taken preliminary contacts with foster homes or other health-related facilities (24.3%). They also prefer to leave the person with DS in his/her relative's house or in a group with assistance from family members and relatives (26.5%) and few of them prefer an assisted-living facility with assistance from family members and relatives (14.7%). Finally, a lot of people with DS expressed the desire to continue their life with their family, together with their friends or with a partner.

4. Discussion

The present study belongs to a wider national Italian research aiming to spread the knowledge of the aging of people with DS and to identify the most important features in better future planning reported by a sample of 136 formal and informal caregivers (family members and health professionals) of people with DS over 45 years old. In accordance with the biopsychosocial perspective, we performed and administered an *ad hoc* questionnaire (DOQuest) which evaluated their health status, current state of their life, activity and participation domains, environmental factors and details about their future planning. Results provided significant information about how to plan their future taking into account their current life.

Most of the sample of people with DS do not have an educational qualification and receive a disability pension and attendance allowance. They live at home with a family member (parents or siblings) and attend a daily center, specifically a social care center; otherwise, people with DS who do not live at home live in a social health community for people with disabilities. Half of the sample changed the place where they live at least once in a lifetime, most often because parents passed away, and this occurrence caused important implications for future planning that future research might investigate [33]. Overall, family members contacted are mainly brothers or sisters and health professionals are most of all educators. This is different from other studies that usually involve parents, especially mothers. Little research focuses on people who were provided care of adult people with DS [27] [28]. Both studies remark on the importance to advise formal and informal caregivers about daily life activities and abilities for the future planning of ageing people with DS.

DOQuest also investigated the quality of life and the health conditions of the person with DS. Overall, family members and health professionals evaluated the perceived health status and quality of life of ageing people with DS as "good". About the perceived mental health status, respondents explained that in their opinion it had worsened gradually or it remained unchanged. In a longitudinal study conducted by Esbensen and colleagues [14], it was specified that people with DS were evaluated over a 9-year period. It was found that personal care skills declined more in adults with less severe intellectual disability while the skills of adults with more severe intellectual disability declined less. In contrast

with these results, the study conducted by a group of researchers coordinated by Fonseca [27] showed that behavioral changes precede or occur concomitantly with cognitive decline and it is confirmed by a lot of studies in this area [34] [35] [36]. Moreover, the respondents of the current study evaluated the perceived level of autonomy of people with DS as “enough” or “quite low”. In a longitudinal analysis of a group of older adults with DS, it was explored that having better family relations may lead to more social connections and a greater maintaining independence in mobility and transportation. However, as we could see further on, the autonomy of our sample in mobility and transportation is very limited [32]. The last part of this section concerns the health conditions and the comorbidities that we could discover in the literature [17].

The third section of the DOQuest is about the capacity of the person with DS to perform tasks and actions and his/her involvement of typical life situations: they are able to do a simple task but they are not really able to plan their own daily routine. According to these results they are not able to take care of themselves, to take their medicine, to use any type of transportation and to prepare meals for themselves or for the others. In the 9-years study conducted by Esbensen [14], it is possible to see the changes in the functional abilities of people with DS. Specifically, in the period of the study, meal-related activities remain stable while skills in housekeeping improve. On the other hand, skills in personal care and mobility declined during this period. This lack of autonomy in the activities of daily living is probably due to an insufficient training for autonomy carried out by families or health operators [28] [29] [32]. In fact, it is so important to promote autonomy and social integration because adults with DS could develop their capacity to make choices among options, implementing decision and evaluating their effects [37]. In a study conducted in Rome with older people with DS [26] authors found that their quality of life was very poor, frequently characterized by limited autonomy and a dearth of social interactions [23]. In a recent qualitative study, twenty leaders in intellectual disability services in Sweden reported that “a prerequisite for healthy ageing for persons with intellectual disabilities is the opportunity to live according to their preferences and to make independent decisions. At the same time, they depend on individualized degrees of support from staff in order to make the most of this opportunity” ([38], pg. 4).

In the fourth section it is inquired the influence of the environmental factor in the daily life of people with DS. Family members and health operators consider that the persons with DS could have a better quality of life if they could use the services that are currently available for them. The importance of the environmental factors is stressed also in literature, in fact, there is ample evidence that developmental change is influenced by environmental factors such as family environment, social world, the opportunities that are available for individuals and supportive health care. For example, in a study carried out by Temple and colleagues [39] it was highlighted that more years of education predicted lower rates of Alzheimer’s disease in people with DS. In another research [40] it was

demonstrated that family cohesion and good quality of the mother-child relationship could predict growth in communication, daily living skills and socialization skills. So, we could say that family relations' impact on health, functional abilities and behavior problems and the family environment impact on the functioning of people with DS.

In addition, in our study it is considered the quality of the services turned to people with DS and their families. Both family members and health operators seem quite satisfied about social security services, social care services and education and training services.

The fifth part of the DOQuest is regarding the future of the person with DS. Here, family members and health professionals revealed that they have thought about the future but in concrete they have not acted yet or they have taken preliminary contacts with health-related facilities. When they think about the future, family members prefer that the persons with DS stay in their relative's house. This is a really important section of our study because the future perspective of older people with DS it has never been analyzed before. We tried to consider their future not only from an organizing point of view but as a perspective that family members and health operators hope [32] [38].

This study has some limitations. At first the DOQuest instrument is too long to be easily submitted to a very large sample. In addition, there is the necessity to validate the DOQuest to obtain generalizable measures. Another issue is concerning the sample that it is not representative, was selected by convenience so it is not well balanced between the different parts of Italy (the majority of responders live in the northern part of Italy). Despite of this, for the first time, it was possible to collect significant data on persons with DS over 45 years old with a holistic approach in relation to their future planning. In this perspective is really important take into account not only the health condition of persons with DS but also the environmental factors that characterized their lives. We remark that there is a lack of knowledge in the information of daily life activities of ageing people with DS in Italy [28] [32], because a great number of studies have focused on their physical and mental impairment. The aim of this study is also to fill this gap and investigate the involvement of people with DS in social activities. As Matthews and colleagues [37] recently stated, more quantitative data are required to accurately describe the abilities and potential of adults with DS (pg. 1389). Through the DOQuest it will be possible to collect important data, at the national and international level, for policymakers about how to prepare broad-spectrum interventions that are tailored to the actual and future needs of elderly people with DS. Validation of DOQuest is needed and future research will focus on this aim.

5. Conclusions

In conclusion, the results suggest two important essays: 1) it is important to plan the future of ageing people with DS in good time, and not only when it is neces-

sary and unavoidable, so as to favor the continuity of skills acquired in adulthood avoiding a deterioration of their quality of life; 2) in concomitance of any change in their life (e.g. change of residence or level of independence due to a worsened health condition) it is mandatory to take into account not only their health conditions but also all the aspects that characterized their existence in a biopsychosocial view in order to better plan their present and future life. Henceforward, we invite to consider the disability of these people from a social and relational point of view and they cannot be treated just from a medical point of view. Following this direction, the information about the life contest and the environmental factors are really very important in order to plan tailored social-healthcare intervention.

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Conflicts of Interest

No potential conflict of interest was reported by the authors.

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