ISSN 0021-2571 (print) · 2384-8553 (online) | Coden: AISSAW 56 (No. 2) | 133-256 (2020)

# ANNALI
## DELL'ISTITUTO SUPERIORE DI SANITÀ

Volume 56 No. 2
2020

A SCIENCE JOURNAL *for* PUBLIC HEALTH

www.iss.it

Ann Ist Super Sanità 2020 | Vol. 56, No. 2

ANNALI
dell'Istituto Superiore di Sanità
A SCIENCE JOURNAL FOR PUBLIC HEALTH

**Publication**
*Annali dell'Istituto Superiore di Sanità* is published quarterly and in special issues.
Freely available online at www.iss.it/annali1 - www.annali-iss.eu

**Annali dell'Istituto Superiore di Sanità is indexed in**
- CAB
- CHEMABS
- EMBASE/Excerpta Medica
- FSTA
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- SCOPUS
- WEB OF SCIENCE

The Journal Impact Factor is 2.172

**Annali Editorial Office**
Scientific Communication Service
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Viale Regina Elena 299, 00161 Rome, Italy
Tel.: +39 06 49902945 Fax: +39 06 49902253
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Papers to be presented for publication should be submitted online to www.annali-iss.eu.

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**Publishing support**
Il Pensiero Scientifico Editore, Rome
Via San Giovanni Valdarno 8, 00138 Rome, Italy
www.pensiero.it

**Subscription information & terms**
Il Pensiero Scientifico Editore
Tel.: +39 06 86282324 Fax: 06 86282250
E-mail: abbonamenti@pensiero.it

Year 2020
Italy individual subscription € 57,00 | Italy institutional subscription € 67,00.
Other countries € 67,00
Each quarterly issue € 21,00

ISSN 0021-2571 (print), 2384-8553 (online)
Coden: AISSAW 56 (No. 2)

Reg. Stampa - Tribunale di Roma, n. 482 del 29 ottobre 1985 (cartaceo); n. 121 del 16 maggio 2014 (online)

Printed in June 2020 by Ti Printing s.r.l.
Via Case Rosse 23, 00131 Rome, Italy

Ann Ist Super Sanità 2020 | Vol. 56, No. 2

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A SCIENCE JOURNAL FOR PUBLIC HEALTH

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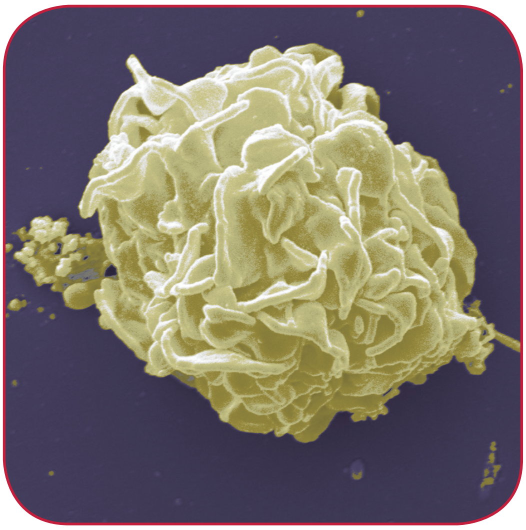

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# Editorial

# A focus on the rights to self-determination and quality of life in people with mental disabilities

**Francesca Cirulli and Aldina Venerosi**

*Centro di Riferimento per le Scienze Comportamentali, Istituto Superiore di Sanità, Rome, Italy*

At world level, health systems have not been able to respond effectively to the burden of mental disorders and there is an important gap to be filled between the need for treatment and its delivery [1]. The pandemic we are currently facing has additionally put mental health on the spot as a sector much neglected so far and most in need for innovative and multi-strategy approaches [2].

Mental health and mental disorders include not only individual traits, such as the ability to manage one's thoughts, emotions, behaviors and interactions with others, but also social, cultural, economic, political and environmental factors determined by national policies, such as social protection, living standards, working conditions, and community social supports, among others. Community-based mental health and social support services need to innovate themselves in order to encompass a recovery-based approach emphasizing the promotion of human rights and quality of life. Employment, housing, educational opportunities and participation in community activities ultimately support individuals with mental disorders and psychosocial disabilities to achieve their own aspirations and goals [1, 3].

The ground-breaking work initiated by the charismatic psychiatrist Franco Basaglia led to a cultural shift in Italy, culminating in the Law 180/1978, which imposed the closure of mental hospitals, restoring dignity to people with mental health problems, and promoting the role of therapeutic communities. Since then, there has been an increasing coverage of evidence-based interventions indicating that, in order to implement community-based mental health, we need to build a recovery model based upon the establishment of interdisciplinary mental health teams supporting individual self-determination. The delivery of "integrated and responsive care" meeting both mental and physical needs, promoting the right to employment, housing and education plays a fundamental role for the inclusion of people with psychosocial disabilities in their services and programs. In the current issue of the journal, the monograph "Life planning for people with neurodevelopmental and intellectual disability: effective support, quality of life, and community engagement" highlights the most advanced examples of good practices towards this aim [4]. As suggested, the availability of person-centered actions, even providing a health budget directly managed by individuals and their families, appears as a promising strategy for addressing person's rights to self-determination [5]. The health budget is defined by the Italian National Observatory on the condition of people with disabilities as a "quantitative and qualitative tool for defining the economic, professional and human resources necessary to trigger a process aimed at restoring centrality to the person, through an individual global project". Certain individuals and groups in society may be placed at a significantly higher risk of experiencing mental health problems. Thus, standing for the rights of people with serious intellectual and neurodevelopment disabilities [6] requires a major effort in terms of tailoring the socio-health services to individual needs with a life-span vision to support the main life transitions. This can be achieved, for example, using constructs such as "Quality of Life" (QoL) that since 2002, the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) proposed as reference frame of all therapeutic and rehabilitative interventions providing assessment and analysis tools, useful for guiding the modulation of individual supports and to suggest guidelines for innovation at the macro-system level. The QoL framework should play a prominent role in education and training of mental health professionals [7].

The health budget methodology places the emphasis on co-planning, co-management and co-financing, as well as on the evaluation of the processes and projects to be set up and implemented also through public-private partnerships [5, 8]. In order to achieve this goal, individual plans must be set up by multidisciplinary teams and shared with the person and his/her family, while appropriate administrative tools have to be developed for the direct management of financial and welfare

*Address for correspondence:* Aldina Venerosi, Centro di Riferimento per le Scienze Comportamentali e la Salute Mentale, Istituto Superiore di Sanità, Viale Regina Elena 299, 00161 Rome, Italy. E-mail: aldina.venerosi@iss.it.

resources. The principles of "integrated and responsive care" and the potential for public-private partnership in mental health have been perfectly exemplified by Social Farming (SF) experiences promoted in many regions of Italy and which represent a phenomenon widespread throughout Europe. Rural areas are a perfect place to promote health and build social interventions in mental health. It should be remembered that the European Commission has recently underlined the key role of rural areas – which represent a large part of the European territory and of the population of the Member States – in facing the current and future challenges of society in terms of the supply of public goods, sustainability and improvement of social well-being for the inhabitants of rural and urban areas. Access to the natural environment and outdoor spaces has begun to be considered vitally important for mental health, reducing the effects on stress, lowering anxiety and promoting physical activity, with cascading effects on immune functioning and general physical health. Natural environments – including urban green spaces – also provide opportunity for social engagement and are indeed increasingly recognized for their role in contrasting isolation and loneliness and promoting social integration. By providing de-institutionalized care, SF is increasingly recognized as an innovative way to respond to the cultural shift from institutional psychiatry to community-based mental health care, in line with the recommendations of the WHO's Mental Health Action Plan. SF has the potential to foster the farming sector and to generate informal care being able to promote and generate social services to local communities. In 2015, the first Italian National law on SF was approved by the Italian Parliament [9], providing a framework to support cooperation among health services, farmers, social cooperatives and voluntary associations. The current challenge is to use this legislative framework to exploit SF as a means to envision and develop future strategies for the evolution of the National Health Service in terms of its capability for health delivery and social inclusion and to conjugate this with economic sustainability.

In conclusion, one step further needs to be taken, steered towards the re-orientation of services and the strengthening of local community actions to offer a wide spectrum of welfare solutions depending on the local context, individual desire and skills [8]. This challenge requires a significant innovative impulse in the area of social and health care as well as in civil society itself. As a first step, we need to reorient and facilitate administrative procedures, for example, to promote a health budget approach, avoiding the prevailing of bureaucracy over the needs of personal care. Overall, greater emphasis should be placed on satisfying individual needs, such as housing, friends, social networks, education, and employment alongside clinical care and treatment. Furthermore, social innovation models oriented towards a more participative welfare should promote human and social capital, avoiding "dependence traps" and social isolation.

In Italy, a specific legislation has been produced on this topic, which is based upon the principles of person-centered care, community welfare, and the promotion of a greater control from the end users [10]. A similar welfare system and a convergent definition of the strategic 'pillars' of the regional welfare scheme are shared across Italian regions. Access, assessment, planning, and monitoring are the main steps of the path governing individual care and they may represent the means to align the social and health programs, as well as resources within the local environment, which is where the implementation of the individual path takes place. However, implementation of current local and national legislation is lagging behind. Thus, national policies capable to harmonise, boost and monitor person-centered approaches in the mental health field are urgently needed.

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DOI: 10.4415/ANN_20_02_02

# Levels of physical activity, nutrition and body composition in the workplace: reports from a distribution company

**Gabriele Mascherini**[1], **Elena Ermini**[1], **Alfredo Guerrisi**[1], **Vittorio Bini**[2] **and Cristian Petri**[1]

[1]*Dipartimento di Medicina Sperimentale e Clinica, Università degli Studi di Firenze, Florence, Italy*
[2]*Dipartimento di Medicina, Università degli Studi di Perugia, Perugia, Italy*

**Abstract**

***Introduction.*** Lifestyle factors, as eating habits and physical activity, are associated with health and productivity of workers. The aim of this study is an assessment of lifestyle of the employees of an international company of household items.

***Methods.*** 291 (170 female, 121 male) employees underwent body composition assessment and completed two questionnaires (International Physical Activity Questionnaire and National Institute for Research of the Food and Nutrition).

***Results.*** The weight status of the sample is at the upper limits of normal weight. Products based on cereals are consumed about once a day, fresh meat 3.0 (0.0-12.0) per week, fresh fruit (5.0, 0.0-25.0) and vegetables (6.0, 0.0-14.0) less than one serving a day. No vigorous physical activity is performed (0.0, 0.0-240.0 min/week), moderate is performed 30.0 (0.0-450.0) min/week and only 106 subjects were aware of the number of daily steps.

***Conclusions.*** Job duties can have an influence on the daily habits. Workplaces have great potential to change personal lifestyle choices and a preliminary assessment should be performed in order to propose a tailored intervention.

**Key words**
- workplace
- physical fitness
- nutrition assessment
- overweight
- sedentary lifestyle

## INTRODUCTION

A significant proportion of current healthcare spending is attributed to non-communicable chronic diseases such as diabetes, cardiovascular disease and cancer [1-3]. An incorrect lifestyle, in terms of unhealthy diet and physical inactivity, is associated with the possibility of becoming overweight or obese: all of these are recognized risk factors associated with chronic non-communicable diseases [4, 5].

An unhealthy lifestyle reduces physical function, which negatively affects work performance, decreases quality of life and increases the use of analgesic drugs. Therefore, these factors can hinder individual opportunities to extend workers' active working time and at the same time increase the number of days of absence from work due to illness, reduce productivity and can lead to a premature loss of experienced workers [6].

Lifestyle-related risk factors are changeable, but achieving a substantial change in daily habits is difficult. Workplaces have great potential to change personal lifestyle choices: people of working age spend much of their active time at work [7].

Employers are responsible for the health and safety of their employees, but at the same time, they are interested in reducing employee turnover, increasing productivity and thus ensuring that the worker has a regular commitment [8].

Shift workers are a particular category at risk for chronic diseases. They are particularly exposed to weight gain, type II diabetes, coronary heart disease, stroke and cancer [9]. Shift workers are more prone to physical inactivity and unhealthy diets [10].

It has been shown that an appropriate initiative to promote a healthy lifestyle in the workplace has increased health, increased productivity and had a good cost-effect ratio [11, 12].

The aim of the present study is that of a preliminary assessment of the lifestyle, in terms of physical activity and nutrition, and the resulting body composition of the employees of an international company of household items on the Italian territory.

## MATERIALS AND METHODS

### *Study population*

In order to investigate lifestyle and resulting body composition in a large distribution company specialized in the DIY sector, a group of employees are voluntary enrolled in the study during a medical evaluation

*Address for correspondence*: Gabriele Mascherini, Dipartimento di Medicina Sperimentale e Clinica, Università degli Studi di Firenze, Via delle Oblate 4, 50141 Florence, Italy. E-mail: gabriele.mascherini@unifi.it.

performed within the workplace. The subjects were enrolled consecutively in the period May-November 2018 and the inclusion criteria in the study were to be an employee of the company that requested the study.

After receiving written informed consent, all subjects underwent a voluntarily assessment of body composition and were required to complete two questionnaires. One regarding the daily physical activity (International Physical Activity Questionnaire, IPAQ) and the other about eating habits (National Institute for Research of the Food and Nutrition, INRAN). The study was carried out in conformity with the ethical standards laid down in the 1975 declaration of Helsinki and was approved by the local ethical committee.

### *Procedures*

#### *Questionnaire*

#### International Physical Activity Questionnaire (IPAQ)

The purpose of the questionnaire was to provide common instruments that could be used to obtain internationally comparable data on health-related physical activity [13]. The question asked the time spent being physically active in the last seven days. It consists in four sections:

1. Vigorous physical activities: minutes per week. These activities refer to activities that take hard physical effort and make you breathe much harder than normal.
2. Moderate activities, but not walking: minutes per week. These activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.
3. Walking: minutes per week and number of daily steps. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.
4. Time spent sitting, including reading, watching television, studying and playing video games: minutes per day.

#### National Institute for Research of the Food and Nutrition (INRAN)

Questionnaire assesses eating habits in relation to the frequencies of weekly consumption of food groups [14]. Food groups were: cereals and derivate, packaged cereals, fresh meat, preserved meats, fresh fish, milk or yogurt, cheese, fresh fruit, dried fruit, vegetables, legumes, eggs, dessert items, sweetened beverages and alcohol.

#### *Body composition analysis*

The study of body composition attempts to partition and quantify body weight or mass into its basic components. Over the past century, many techniques and equations have been proposed, but all have some inherent problems: to date, there is no universally applicable criterion or "gold standard" methodology for body composition assessment [15]. The methodology used for the assessment of body composition was in accordance with our previous study [16], and taking into account the integration of anthropometry, circumferences, skinfold thickness, and a whole body bioelectrical impedance analysis.

#### Anthropometry and skinfold thickness

Body Mass Index (BMI, kg/m2) was calculated from body mass and height. Skinfold measurements are widely utilized to assess Body Fat Mass (FM). The same operator pinches the skin at the site to raise a double layer of skin and the underlying subcutaneous adipose tissue, but does not pinch the muscle. The calipers (Holtain, Limited Tanner/Whitehouse Skinfold Caliper) are then applied 1 cm below and at right angles to the pinch, and a reading is taken in millimetres (mm). The mean of three measurements were taken in seven different anatomical sites around the body (triceps, biceps, sub-scapula, suprailiac, pectoral, abdominal, anterior thigh) [17]. The sum the seven sites (total skinfold) and their conversion into a percentage (FM %) in kilograms of body fat were calculated. To convert the skinfold values from millimetres to a Fat Mass percentage, the average of the reported values was calculated using three different equations, as stated in the literature [18-20].

#### Whole-body bia

Whole-body impedance (BIA 101 Sport Edition, Akern, Florence, Italy) is generated in soft tissues to oppose the flow of an injected alternate current and is measured from skin Ag/AgCl electrodes placed at fixed-distance (5 cm) on the hands and feet. The device emits an alternating sinusoidal electric current of 400 mA at an operating single frequency of 50 kHz (± 0.1%). The bioelectric parameters measured are Resistance (RZ, Ω) and Reactance (XC, Ω). RZ reflects the amount of body water and has a reverse relationship with the opposition to an alternating current, while XC is the capacitive component of cell membranes: therefore, changes in impedance measurements reflect changes in hydration and cell mass [21]. These parameters were normalized according to a subject's height (RZ/h and XC/h, in Ω/m) in order to consider the different conductor lengths. Additional parameters were: Phase Angle (PA in degree, as ratio between RZ and XC or between intra-and extracellular volumes), Body Cellular Mass (BCM in kg), Total Body Water (TBW in L and %), Extra Cellular Water (ECW, % TBW and L), and Intra Cellular Water (ICW, % TBW) and Resting Metabolic Rate (RMR, kcal).

### *Statistical analysis*

Data are expressed as median (minimum-maximum value). The Shapiro-Wilk test was used to assess the normal distribution of data. Due to their asymmetric distribution the Mann-Whitney's U-test was used for comparisons of continuous variables and the Chi-square test with Yates' correction or Fisher's exact test were used for comparisons of categorical variables.

Correlations were tested by Spearman rho coefficient analysis. All calculations were carried out with IBM-SPSS® version 25.0 (IBM Corp., Armonk, NY, USA, 2017). A two-sided p-value < 0.05 was considered significant.

## RESULTS

291 employees have been evaluated (170 female and 121 male). 71.1% were generic sales staff, 22.8% technical office staff, 5.2% settlor and 1.5% visual merchandising employees with no difference between sexes and 26.5% are smokers.

The weight status of the sample is at the upper limits of normal weight, the males have a significantly higher value than the females ($p < 0.001$) and their median value places them in the overweight condition *(Table 1)*. Body composition analysis shows average parameters in the normal range, however the high standard deviation of these values describes a high inter-individual variability.

Eating habits report that 6.5% follow a diet, 18.2% have a food intolerance and 36.1% take a food supplement. 7.9% do not have breakfast and 10% do it at the bar. Regarding lunch, only 59.5% can consume it at home, in addition, however, 25.8% of employees take advantage of the canteen. Therefore 14.7% must be organized differently (5.2% goes to the restaurant, 5.2% to the bar, 1.7% to fast food and 2.7% skip the meal). The dinner habits are more standardized, 97.9 % consume it at home, while the remaining 2.1% is often at the restaurant. Females are more used to making mid-morning and mid-afternoon snacks than their male counterparts (females 46.5%, males 33.9%; $p < 0.05$).

The results concerning the weekly frequency of consumption of the food groups is shown in *Table 2*, no differences between the sexes were found. Products based on cereals are consumed about once a day, fresh meat 3.0 (0.0-12.0) times per week, fresh fruit (5.0, 0.0-25.0) and vegetables (6.0, 0.0-14.0) less than one serving a day.

The results relating to the physical activity questionnaire are shown in *Table 2* and no differences were found between the sexes. No vigorous physical activity are performed 0.0 (0.0-240.0) min/week, moderate 30.0 (0.0-450.0) min/week, only 106 subjects were aware of the number of daily steps (10000.0, 0.0-23000.0).

### *Relationship between job duties and lifestyle habits*

The job does not affect the likelihood of smoking; however, it influences the habit of making mid-morning and mid-afternoon snacks and the place of consumption of lunch. Visual merchandising employees and technical office staff make snacks more regularly ($p = 0.004$), generic sales staff can often have lunch at home (72.6%) while visual merchandising employees use the canteen in 75% of cases. There are no correlations between the work task and body composition or between the work task and the frequency of consumption of certain foods. It also does not affect the amount of moderate and vigorous physical activity during the week. However, it influences the number of steps (or in any case its knowledge) and above all the hours spent sitting: generic sales staff are those who are less seated during the day (4.00, 0.0-20.0 hours/day; $p < 0.05$) and make the largest number of steps (10000.0, 1000.0-23000.0 steps /day; $p < 0.001$).

### *Relationship between lifestyle habits and body composition*

The results about correlation between body composition and lifestyle habits were report in *Table 3*. In the sample of workers examined, the higher consumption of certain foods appears to influence body composition,

**Table 1**

Body composition of total sample. The differences were report between genders. Data are expressed as median (minimum-maximum values)

| | Total (n = 291) | Female (n = 170) | Male (n = 121) | p value |
|---|---|---|---|---|
| **Age (years)** | 42.9 (21.0-66.0) | 43.0 (21.0-58.0) | 39.0 (22.0-66.0) | 0.049 |
| **BMI (kg/m²)** | 24.5 (14.6-39.3) | 23.3 (14.6-39.3) | 25.6 (17.5-37.7) | < 0.001 |
| **Rz/h (Ω/m)** | 285.6 (188.2-439.1) | 326.6 (216.7-439.1) | 248.9 (188.2-352.6) | < 0.001 |
| **Xc/h (Ω/m)** | 33.2 (21.9-53.6) | 34.7 (23.3-53.6) | 31.3 (21.9-51.8) | < 0.001 |
| **PA (°)** | 6.6 (3.9-9.2) | 6.1 (3.9-8.8) | 7.2 (5.4-9.2) | < 0.001 |
| **FFM (kg)** | 53.4 (33.8-92.2) | 48.4 (33.8-67.6) | 66.7 (49.2-92.2) | < 0.001 |
| **TBW (L)** | 39.1 (25.1-67.8) | 35.4 (25.1-49.9) | 48.9 (34.3-67.8) | < 0.001 |
| **ECW (L)** | 17.1 (11.7-26.1) | 15.8 (11.7-20.9) | 20.2 (13.6-26.1) | < 0.001 |
| **BCM (kg)** | 29.9 (16.5-64.1) | 26.5 (16.5-39.5) | 39.4 (26.7-64.1) | < 0.001 |
| **FFM (%)** | 78.0 (50.9-96.5) | 75.4 (50.9-96.3) | 80.5 (65.6-96.5) | < 0.001 |
| **TBW (%)** | 57.1 (37.3-80.3) | 55.2 (37.3-72.1) | 59.1 (48.2-80.3) | < 0.001 |
| **ECW (%)** | 43.0 (28.8-58.1) | 45.3 (34.5-58.1) | 40.6 (28.8-48.6) | < 0.001 |
| **ICW (%)** | 57.0 (41.9-71.2) | 54.8 (41.9-65.5) | 57.0 (41.9-71.2) | < 0.001 |
| **RMR (kcal)** | 1622.1 (1256.0-2609.1) | 1556.9 (1256.0-2609.1) | 1777.2 (1330.6-2416.8) | < 0.001 |
| **FM (%)** | 20.2 (6.9-36.9) | 23.2 (11.4-36.9) | 16.4 (6.9-30.3) | < 0.001 |
| **Σ7 skinfold (mm)** | 132.2 (37.8-285.8) | 144.6 (49.2-285.8) | 112.5 (37.8-270.8) | < 0.001 |

Legend: BMI = Body Mass Index; Rz/h = ratio between Resistance and height; Xc/h = ratio between Reactance and height; PA = Phase Angle; FFM = Fat-Free Mass; TBW = Total Body Water; ECW = Extra Cellular Water; BCM = Body Cellular Mass; ICW = Intra Cellular Water; RMR = Resting Metabolic Rate; FM = Fat Mass; Σ7 skinfold = Sum of 7 skinfold.

**Table 2**
Frequencies of weekly consumption of food groups and physical activity questionnaire divided between genders. Data are expressed as median (minimum-maximum values)

| | Total (n = 291) | Female (n = 170) | Male (n = 121) | P value |
|---|---|---|---|---|
| **Cereals and derivate** | 7.0 (1.0-32.0) | 7.0 (1.0-32.0) | 7.0 (1.0-30.0) | 0.38 |
| **Packaged cereals** | 5.0 (0.0- 21.0) | 6.0 (0.0-20.0) | 5.0 (0.0-21.0) | 0.15 |
| **Fresh meat** | 3.0 (0.0-12.0) | 3.0 (0.0-12.0) | 3.0 (0.0-7-0) | 0.98 |
| **Preserved meat** | 2.0 (0.0-11.0) | 2.0 (0.0-10.0) | 2.0 (0.0-11.0) | 0.39 |
| **Fresh fish** | 1.0 (0.0-7.0) | 1.0 (0.0-7.0) | 1.0 (0.0-5.0) | 0.71 |
| **Milk or yogurt** | 4.0 (0.0-15.0) | 5.0 (0.0-15.0) | 4.0 (0.0-10.0) | 0.31 |
| **Cheese** | 3.0 (0.0-15.0) | 3.0 (0.0-15.0) | 2.0 (0.0-11.0) | 0.58 |
| **Fresh fruit** | 5.0 (0.0-25.0) | 5.0 (0.0-21.0) | 5.0 (0.0-25.0) | 0.39 |
| **Dried fruit** | 1.0 (0.0-10.0) | 1.0 (0.0-10.0) | 1.0 (0.0-10.0) | 0.13 |
| **Vegetables** | 6.0 (0.0-14.0) | 6.0 (0.0-14.0) | 5.0 (0.0-14.0) | 0.18 |
| **Legumes** | 2.0 (0.0-7.0) | 1.5 (0.0-7.0) | 2.0 (0.0-7.0) | 0.25 |
| **Eggs** | 1.0 (0.0-7.0) | 1.0 (0.0-7.0) | 1.0 (0.0-5.0) | 0.17 |
| **Dessert items** | 4.0 (0.0-21.0) | 3.0 (0.0-15.0) | 4.0 (0.0-21.0) | 0.90 |
| **Sweetened beverages** | 1.0 (0.0-21.0) | 1.0 (0.0-10.0) | 1.0 (0.0-21.0) | 0.75 |
| **Alcohol** | 1.0 (0.0-14.0) | 1.0 (0.0-14.0) | 1.0 (0.0-14.0) | 0.53 |
| **Vigorous (min/week)** | 0.0 (0.0-240.0) | 0.0 (0.0-180.0) | 0.0 (0.0-240.0) | 0.92 |
| **Moderate (min/week)** | 30.0 (0.0-450.0) | 17.5 (0.0-300.0) | 40.0 (0.0-450.0) | 0.13 |
| **Walking (min/week)** | 60.0 (0.0-800.0) | 60.0 (0.0-800.0) | 60.0 (0.0-600.0) | 0.20 |
| **Number of daily steps*** | 10000.0 (0.0-23000.0) | 10000.0 (0.0-19000.0) | 10000.0 (7.0-23000.0) | 0.57 |
| **Sitting position (h)** | 5.0 (0.0-20.0) | 5.0 (0.0-20.0) | 4.0 (0.0-20.0) | 0.08 |

*106 subjects answered the question concerning the numbers of daily steps

in particular:

- packaged cereals reduces ECW (R = -0.139, p = 0.018);
- preserved meats reduces FFM % (R = -0.117, p = 0.046);
- dried fruit reduces TBW equally between the intra and extra cellular compartment (R = -0.127, p = 0.031);
- vegetables reduce ECW (R = -0.127, p = 0.031);
- legumes redistribute water by increasing the intracellular compartment (R = 0.139, p = 0.017) and reducing the extracellular compartment (R = -0.139, p = 0.017).
- Vigorous (R = -0.184, p = 0.002) and moderate (R = -0.127, p = 0.030) physical activity is reduced with increasing age, relationships with body composition are:
- moderate activity increases TBW (R = 0.132, p = 0.024) and FFM (R = 0.126, p = 0.031) and reduces FM (R = -0.129, p = 0.028);
- time spent sitting reduces RMR (R = -0.139, p = 0.018).

## DISCUSSION

Goetzel, *et al* [22] study on the general working population suggests that workplace health promotion can improve health outcomes and productivity.

The results of the present study show that the average condition of the employees of this company is in a condition of general overweight, despite the young age. The differences in body composition between the sexes are physiologically normal; however, the males appear to have greater parameters than the female counterpart. There is a high variability of body composition parameters, attributable to the habits that each individual adopts independently of one another, this is an aspect that characterizes the study of lifestyle.

Eating habits are not in line with international guidelines, if we compare these results with the guidelines of healthy and correct nutrition, it is possible to detect a reduced consumption of fruit, vegetables, milk, cereals, eggs and legumes. Above the guidelines are preserved meat, cheeses, dessert items and sugary drinks [23].

Also, the physical activity performed does not appear to be in line with the recommendations, the sample is described with a level below the recommendations since the 150 minutes of moderate/vigorous physical activity are not reached. The number of daily steps seems to be in line, but it must be reported that only 106 out of 291 was aware of this value.

Job duties can have an influence on the daily habits. In fact, this study shows how some workers manage to carry out the five daily meals more regularly (including snacks) and in more healthy places such as, for example, lunch at home on a regular basis. Also, physical activity of each person is largely influenced by the job

**Table 3**
Spearman's rho correlation between body composition and lifestyle in terms of eating habits and physical activity level

| | | Cereals and derivate | Packaged cereals | Fresh meat | Preserved meats | Fresh fish | Milk or yogurt | Cheese | Fresh fruit | Dried fruit | Vegetables | Legumes | Eggs | Dessert items | Sweetened beverages | Alcohol | Vigorous (min/week) | Moderate (min/week) | Walking (min/week) | Sitting position (h) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Age (years)** | R | -0.019 | 0.021 | 0.055 | 0.034 | -0.036 | 0.033 | -0.015 | 0.057 | -0.008 | 0.042 | 0.011 | -0.070 | -0.006 | -0.008 | 0.079 | -0.184** | -0.127* | -0.017 | 0.043 |
| | p value | 0.748 | 0.717 | 0.349 | 0.563 | 0.540 | 0.579 | 0.795 | 0.329 | 0.887 | 0.476 | 0.850 | 0.231 | 0.918 | 0.893 | 0.177 | 0.002 | 0.030 | 0.767 | 0.468 |
| **BMI (kg/m²)** | R | 0.029 | -0.038 | 0.116* | 0.038 | -0.021 | -0.008 | 0.049 | -0.059 | -0.113 | 0.005 | 0.018 | -0.007 | -0.028 | 0.018 | 0.030 | -0.016 | -0.028 | -0.007 | -0.027 |
| | p value | 0.620 | 0.524 | 0.049 | 0.522 | 0.715 | 0.891 | 0.409 | 0.314 | 0.054 | 0.938 | 0.759 | 0.909 | 0.639 | 0.762 | 0.609 | 0.784 | 0.632 | 0.908 | 0.642 |
| **Rz/h (Ω/m)** | R | 0.066 | 0.066 | -0.013 | 0.071 | 0.028 | 0.012 | 0.005 | 0.050 | 0.105 | 0.073 | -0.064 | 0.026 | -0.044 | -0.001 | -0.051 | 0.005 | -0.113 | 0.012 | 0.063 |
| | p value | 0.265 | 0.259 | 0.820 | 0.224 | 0.629 | 0.834 | 0.932 | 0.392 | 0.074 | 0.217 | 0.277 | 0.663 | 0.457 | 0.981 | 0.387 | 0.935 | 0.055 | 0.839 | 0.286 |
| **Xc/h (Ω/m)** | R | -0.035 | 0.119* | -0.020 | -0.018 | 0.024 | -0.084 | -0.021 | 0.039 | 0.086 | 0.125* | 0.047 | 0.024 | -0.098 | -0.047 | -0.049 | 0.004 | -0.003 | -0.022 | 0.038 |
| | p value | 0.557 | 0.043 | 0.738 | 0.761 | 0.685 | 0.155 | 0.718 | 0.503 | 0.143 | 0.033 | 0.429 | 0.678 | 0.094 | 0.428 | 0.402 | 0.950 | 0.962 | 0.709 | 0.518 |
| **PA (°)** | R | -0.089 | 0.038 | -0.008 | -0.110 | -0.009 | -0.063 | -0.017 | -0.011 | -0.038 | 0.043 | 0.140* | -0.019 | -0.037 | -0.038 | 0.017 | 0.002 | 0.107 | -0.050 | -0.049 |
| | p value | 0.128 | 0.522 | 0.886 | 0.061 | 0.878 | 0.285 | 0.778 | 0.854 | 0.520 | 0.463 | 0.016 | 0.752 | 0.535 | 0.523 | 0.772 | 0.968 | 0.068 | 0.396 | 0.408 |
| **FFM (kg)** | R | -0.048 | -0.086 | 0.029 | -0.038 | -0.037 | -0.037 | -0.015 | -0.051 | -0.127* | -0.080 | 0.064 | -0.068 | 0.007 | 0.016 | 0.045 | -0.018 | 0.078 | -0.058 | -0.075 |
| | p value | 0.417 | 0.144 | 0.627 | 0.517 | 0.534 | 0.525 | 0.792 | 0.388 | 0.031 | 0.172 | 0.277 | 0.246 | 0.910 | 0.792 | 0.447 | 0.756 | 0.184 | 0.323 | 0.203 |
| **TBW (L)** | R | -0.050 | -0.094 | 0.029 | -0.037 | -0.037 | -0.034 | -0.011 | -0.055 | -0.127* | -0.087 | 0.058 | -0.067 | 0.013 | 0.016 | 0.047 | -0.018 | 0.074 | -0.055 | -0.075 |
| | p value | 0.392 | 0.111 | 0.617 | 0.533 | 0.527 | 0.563 | 0.849 | 0.348 | 0.030 | 0.138 | 0.323 | 0.257 | 0.829 | 0.789 | 0.422 | 0.763 | 0.210 | 0.352 | 0.200 |
| **ECW (L)** | R | -0.001 | -0.139* | 0.046 | 0.028 | -0.022 | 0.010 | 0.013 | -0.058 | -0.119* | -0.127* | -0.007 | -0.071 | 0.056 | 0.034 | 0.066 | -0.010 | 0.014 | -0.030 | -0.086 |
| | p value | 0.987 | 0.018 | 0.438 | 0.632 | 0.703 | 0.862 | 0.821 | 0.323 | 0.043 | 0.031 | 0.906 | 0.228 | 0.338 | 0.564 | 0.265 | 0.869 | 0.811 | 0.611 | 0.143 |
| **BCM (kg)** | R | -0.066 | -0.056 | 0.013 | -0.069 | -0.040 | -0.047 | -0.022 | -0.046 | -0.115* | -0.052 | 0.094 | -0.058 | -0.003 | 0.009 | 0.031 | -0.012 | 0.096 | -0.066 | -0.071 |
| | p value | 0.262 | 0.345 | 0.821 | 0.241 | 0.494 | 0.421 | 0.715 | 0.439 | 0.050 | 0.375 | 0.110 | 0.326 | 0.965 | 0.876 | 0.602 | 0.833 | 0.101 | 0.260 | 0.229 |
| **FFM (%)** | R | -0.072 | 0.020 | -0.108 | -0.117* | 0.018 | -0.016 | -0.060 | 0.028 | 0.031 | -0.047 | 0.078 | -0.011 | 0.047 | -0.015 | 0.031 | 0.017 | 0.132* | 0.003 | -0.020 |
| | p value | 0.221 | 0.734 | 0.067 | 0.046 | 0.759 | 0.780 | 0.311 | 0.628 | 0.593 | 0.425 | 0.185 | 0.854 | 0.425 | 0.805 | 0.603 | 0.774 | 0.024 | 0.956 | 0.733 |
| **TBW (%)** | R | -0.068 | 0.016 | -0.110 | -0.113 | 0.019 | -0.010 | -0.055 | 0.028 | 0.034 | -0.050 | 0.073 | -0.005 | 0.057 | -0.016 | 0.031 | 0.012 | 0.126* | 0.008 | -0.022 |
| | p value | 0.249 | 0.784 | 0.061 | 0.053 | 0.753 | 0.862 | 0.346 | 0.632 | 0.562 | 0.392 | 0.211 | 0.929 | 0.332 | 0.789 | 0.596 | 0.838 | 0.031 | 0.891 | 0.705 |
| **ECW (%)** | R | 0.091 | -0.036 | 0.009 | 0.108 | 0.012 | 0.060 | 0.016 | 0.012 | 0.039 | -0.038 | -0.139* | 0.018 | 0.036 | 0.036 | -0.016 | 0.000 | -0.109 | 0.051 | 0.052 |
| | p value | 0.120 | 0.542 | 0.875 | 0.065 | 0.843 | 0.309 | 0.783 | 0.833 | 0.503 | 0.521 | 0.017 | 0.766 | 0.541 | 0.545 | 0.783 | 0.997 | 0.064 | 0.386 | 0.380 |
| **ICW (%)** | R | -0.091 | 0.036 | -0.009 | -0.108 | -0.012 | -0.060 | -0.016 | -0.012 | -0.039 | 0.038 | 0.139* | -0.018 | -0.036 | -0.036 | 0.016 | 0.000 | 0.109 | -0.051 | -0.052 |
| | p value | 0.120 | 0.542 | 0.875 | 0.065 | 0.843 | 0.309 | 0.783 | 0.833 | 0.503 | 0.521 | 0.017 | 0.766 | 0.541 | 0.545 | 0.783 | 0.997 | 0.064 | 0.386 | 0.380 |
| **RMR (kcal)** | R | -0.010 | -0.038 | 0.078 | 0.019 | -0.064 | 0.077 | 0.030 | -0.002 | -0.095 | -0.087 | 0.056 | -0.088 | 0.036 | 0.066 | 0.034 | 0.094 | 0.081 | 0.092 | -0.139* |
| | p value | 0.869 | 0.519 | 0.184 | 0.747 | 0.278 | 0.191 | 0.616 | 0.975 | 0.106 | 0.140 | 0.339 | 0.135 | 0.536 | 0.259 | 0.568 | 0.110 | 0.170 | 0.116 | 0.018 |
| **FM (%)** | R | 0.004 | 0.006 | 0.046 | 0.058 | -0.059 | 0.029 | 0.029 | -0.030 | -0.035 | 0.016 | -0.021 | 0.068 | 0.006 | 0.083 | -0.009 | -0.067 | -0.129* | -0.003 | 0.051 |
| | p value | 0.944 | 0.924 | 0.436 | 0.327 | 0.318 | 0.626 | 0.620 | 0.610 | 0.547 | 0.786 | 0.719 | 0.250 | 0.914 | 0.159 | 0.877 | 0.257 | 0.028 | 0.955 | 0.388 |
| **Σ7 skinfold (mm)** | R | 0.030 | -0.031 | 0.084 | 0.021 | -0.067 | 0.033 | 0.020 | -0.056 | -0.046 | 0.013 | -0.072 | 0.069 | -0.019 | 0.063 | 0.024 | -0.042 | -0.097 | -0.066 | 0.047 |
| | p value | 0.609 | 0.604 | 0.153 | 0.722 | 0.257 | 0.580 | 0.732 | 0.342 | 0.437 | 0.820 | 0.222 | 0.240 | 0.741 | 0.287 | 0.688 | 0.480 | 0.099 | 0.263 | 0.426 |

Legend: BMI = Body Mass Index; Rz/h = ratio between Resistance and height; Xc/h = ratio between Reactance and height; PA = Phase Angle; FFM = Fat-Free Mass; TBW = Total Body Water; ECW = Extra Cellular Water; BCM = Body Cellular Mass; ICW = Intra Cellular Water; RMR = Resting Metabolic Rate; FM = Fat Mass; Σ7 skinfold = Sum of 7 skinfold.
*Correlation is significant at the .05 level (2-tailed). **Correlation is significant at the .01 level (2-tailed).

function, some job duties require prolonged sitting position (for example at the cash desk, or for an office worker on the computer), the tasks of others involve moving within the stores and in some cases also moving loads (sales staff). Therefore, even if it has been observed that the work task does not influence the personal choice of certain foods, it is possible to demonstrate that in any case it involves a modification of the energy balance that could influence the resulting body composition.

The relationships studied in the present work between lifestyle and body composition show interesting associations, the current habits of employees in the workplace should undergo some changes in order to achieve health improvements. In fact, if those who have a sedentary job organize lunch with preserved meat, they will see a reduction in RMR due to reduced physical activity and a reduction in FFM for the choice of food: this will create a vicious circle that will lead to a worsening of the worker's condition over the years. In addition, it is known that over time the vigorous activity naturally tends to decrease, therefore, it is necessary to set one's habits early towards a moderate activity, to have habits consolidated later on. The other relationship found in this work confirm the recommendations on proper nutrition: favor fresh fruit and vegetables, dried fruit, cereals and legumes during the week.

Workplaces, as physical and social settings, have great potential for promoting health and wellbeing [24]: literature reports a positive impact of programs aimed at promoting healthy habits in the workplace, an increase in physical activity (including walking) has been reported in programs whose main purpose was physical activity [25, 26]. Other interventions focused on dietary intervention reported an increase in the consumption of fruit and vegetables and a reduction in lipids [27]. These interventions reported a parallel improvement of the psychological state, of the quality of life [28], a reduction of absenteeism [29] and absences due to illness from work [30].

In particular a recent review [31] suggest that workplace healthy lifestyle interventions with a group-based element can be implemented for shift workers by ensuring flexible modes and organizational level adaptations, and can be effective in promoting weight loss and physical activity.

The initiatives should be tailored according to the type of worker we need to improve, but interventions based on groups of workers with similar characteristics have the advantage of support among colleagues, are the most advantageous in cost-effectiveness and often are the type of initiatives preferred by employees to improve the lifestyle in the workplace [32].

Interventions to improve the lifestyle require an approach that considers not only the characteristics and habits of the workers, but also the organizational determinants that act as a barrier or facilitator in order to successfully implement [33].

In this context, a preliminary assessment of the lifestyle of workers should be performed in order to obtain the information necessary to plan an adequate intervention to improve physical fitness related to health of employees.

### Conflict of interest statement

None of the Authors declares competing financial interests.

### Funding

The study did not receive any grant or financial support.

### Ethical approval

The local ethics committee approved the study.

### Informed consent

Informed consent was obtained from all the participants included in the study.

### Authors' contribution

GM, CP, EE and AG carried out the evaluation and drafted the manuscript; GM and CP perform the design of the study. VB performed the statistical analysis; GM conceived of the study and coordination to draft the manuscript.

*Received* on 6 September 2019.
*Accepted* on 27 February 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 142-149
DOI: 10.4415/ANN_20_02_03

# *Verba volant, scripta manent*: breastfeeding information and health messages provided to parents in the neonatal discharge summary in the Lazio Region, Italy

**Sofia Colaceci[1,2], Elise M. Chapin[3], Francesca Zambri[1,4], Laura Reali[5], Lisa Cedrone[4], Anita Del Brocco[4], Mariagiovanna Masi[4], Ameni Mohamed[4], Federica Dellafiore[6], Stefania Nichinonni[7] and Angela Giusti[1]**

*[1]Centro Nazionale per la Prevenzione delle Malattie e Promozione della Salute, Istituto Superiore di Sanità, Rome, Italy*
*[2]Facoltà Dipartimentale di Medicina, Saint Camillus International University of Health and Medical Sciences (UniCamillus), Rome, Italy*
*[3]Italian National Committee for UNICEF, Rome, Italy*
*[4]Dipartimento di Biomedicina e Prevenzione, Università degli Studi di Roma "Tor Vergata", Rome, Italy*
*[5]ASL Roma 1, Rome, Italy*
*[6]Area di Ricerca e Sviluppo delle professioni Sanitarie, IRCCS Policlinico San Donato, San Donato Milanese, Milan, Italy*
*[7]Gruppo per la Promozione dell'Allattamento al Seno della Regione Lazio, Rome, Italy*

**Abstract**

***Objective.*** We aimed to evaluate the contents of the neonatal discharge summary (NDS), an important communication tool that should contain evidence-based information.

***Methods.*** A quali-quantitative study of NDSs delivered from 29 hospitals of Lazio (Italy) in 2014 and 2017 was conducted. We used content analysis to assess the written information and logistic regression to estimate the association between outcomes (compliance with the International Code, health messages, and information on neonatal screenings) and some hospital's characteristics.

***Results.*** NDSs conforming to International Code were associated with low rate of C-section ($p < 0.05$). Hospitals belonging to Local Health Authorities ($p < 0.05$) and with a lower prevalence of C-section ($p < 0.05$) had a greater attitude to promote infant health. The year of collection was associated with information on neonatal screenings ($p < 0.05$).

***Conclusions.*** An effort is required by hospitals to reduce their level of medicalization, in clinical practice and prescriptive attitudes, which affects the NDSs delivered to parents.

**Key words**
- international code of marketing of breast-milk substitutes
- breastfeeding
- qualitative methods
- cesarean section

## BACKGROUND

The neonatal discharge summary (NDS) is a clinical and communication tool given to parents during discharge to facilitate the transition of care from the hospital to the family. It's the main tool to orient parents to resources available in the healthcare and community support systems. For this reason, NDSs should contain information that is practical, clear, complete, and correct, as well as based on national and international recommendations and consistent with the care plan that has been discussed with the mother/parents during the hospital stay.

The Academy of Breastfeeding Medicine (ABM) [1] and the Italian Society of Neonatology (ISN) [2] state that specific information should be given to all new parents in written form as part of the NDS or as an additional attachment.

The importance of the written form of the NDS can be well-expressed by this Latin locution: *"Verba volant, scripta manent"*, which means "Spoken words fly away,

*Address for correspondence:* Sofia Colaceci, Saint Camillus International University of Health and Medical Sciences (UniCamillus), Via di Sant'Alessandro 8, 00131 Rome, Italy. E-mail: sofia.colaceci@unicamillus.org.

written words remain". The idea is that while the verbal information given at hospital discharge might easily be forgotten, written documents are available at any time.

According to the ABM [1] and ISN [2], topics that should be covered include infant feeding, indicators of adequate intake, infant health messages (about vitamins D and K, neonatal screening tests, umbilical cord care, prevention of Sudden Infant Death Syndrome (SIDS), vaccines, and car safety), maternal nutrition, and follow-up and contact information. Furthermore, the information provided must comply with the "International Code of Marketing of Breast-milk Substitutes (International Code)", adopted by the World Health Assembly (WHA) in 1981 [3] and by further WHA resolutions on infant feeding. The purpose of the International Code is "to contribute to the provision of safe and adequate nutrition for infants, by the protection and promotion of breastfeeding, and by ensuring the proper use of Breast Milk Substitutes (BMS), when these are necessary, on the basis of adequate information and through appropriate marketing and distribution." In order to avoid undermining lactating women's confidence in their ability to breastfeed, the International Code prohibits all forms of advertising or promotion of BMS, including formula for children up to the age of 3 years [4], as well as foods and beverages marketed as appropriate for children under 6 months of age, bottles/teats and related equipment. The European Commission Directive [5] only requires adoption of parts of the International Code, as does the Italian version carried over into legislation as Decree n. 82 of 9 April 2009 (IT Decree) [6].

Unlike the International Code, the IT Decree applies only to BMS advertising of products promoted as nutritionally adequate for a child during the first six months of life, when exclusive breastfeeding is recommended, and does not apply to formula for the whole 36-month period. Furthermore, the IT Decree affirms that "NDSs should not present a pre-defined space for the prescription of BMS. In cases where these prescriptions are necessary due to maternal or neonatal causes, the NDS must provide the clinical indication for BMS use as well as appropriate information for its correct use." In Italy, each maternity hospital (MH) develops and uses its own NDS, leading to a wide heterogeneity in terms of contents. Two previous surveys were carried out in Rome on the information contained in NDSs [7, 8]. The more recent study from 2006 concluded that 67% of those NDSs reported incorrect information and 63% had a handwritten or pre-printed prescription of a specific infant formula brand.

The purpose of this study was to evaluate the information contained in NDSs in Lazio's MHs in 2014 and 2017 and compare the evolution of these contents. A secondary purpose was to identify if some contents were associated with MH's characteristics.

## METHODS

### *Design*

This was a quali-quantitative study. We used a conventional qualitative content analysis approach to assess informative contents of NDSs, and a quantitative analysis to evaluate whether compliance with International Code and IT Decree, the presence of infant health promotion messages, and the presence of indications for neonatal screenings were associated with MH's characteristics.

### *Setting*

In Italy, the National Health System (NHS) offers free access for all citizens and residents through a system of public hospitals and Community Health Services (CHS), with some accredited private facilities. The public facilities are university hospitals, hospital corporations or hospitals belonging to a Local Health Authority (LHA). These, together with accredited private facilities, offer services covered by the regional health system. Moreover, there are non-accredited private hospitals, but they represent a low percentage of all facilities [9]. Maternal-infant care is offered in CHSs and MHs with different levels of care. Level I MHs can provide care to healthy women with low-risk pregnancies, while Level II MHs are specialized for high-risk conditions.

About CHSs, they include centres which provide care from pregnancy through the first years of life, and a primary care paediatrician who is provided to every newborn.

### *Sample*

A copy of the NDSs and any other documents given at discharge from the MHs in the Lazio region were collected. For privacy protection, personal information (name, surname, date and hour of birth, ID number) was deleted. Forty-four MHs were open in 2014 in Lazio, 39 in 2017. The study included all public and accredited MHs, while the private clinics were excluded due to the low number of births (< 2%). To obtain paired samples of NDSs, we included only the MHs that were still open in 2017 and the MHs for which the NDS could not be collected by our recruitment procedure (*Figure 1*).

### *Data collection*

The research group collected NDSs in 2014 and 2017 from mothers who had given birth respectively in 2014 and 2017 in the MHs of Lazio. Women were recruited on a voluntary basis through mother-to-mother support groups and an informed consent form was obtained for their participation. The Institutional Review Board approval was obtained from the University involved in the study.

### *Data analysis*

Content analysis was used to code and classify the pre-printed information on the NDSs. Some categories were pre-defined (e.g. neonatal screening, vaccination and breastfeeding information, pre-printed space for formula prescription, drugs or supplements prescription), other emerged during the analysis (information on maternal nutrition during breastfeeding, specific product for the hygiene of mother and newborn and umbilical cord care). Handwritten contents were excluded because they depend on multiple factors, such as the health conditions of the newborn and the clinician doing the discharge. The coding process was carried out deductively and inductively, all categories were discussed and agreed by 3 researchers and classified using NVivo v. 10 software.

A multi-year database was developed using binary variables. Considering the official data of the Lazio Region [10, 11], we included some MH's characteristics (level of care provided, prevalence of cesarean section, MH belonging to LHA). Moreover, we considered some qualitative categories, transformed into the following outcomes: 1) "compliance with International Code and IT Decree", i.e. the absence of a pre-defined space for formula prescription on NDS; 2) "infant health promotion messages", i.e. at least one message of the following: importance of vaccinations and/or infant's supine sleeping position; and 3) "information on neonatal screenings", i.e. at least 3 out of 4 neonatal screening tests (hearing, cardiac, ophthalmic, hip) performed during hospital stay or recommended after discharge. Information on metabolic screening has been excluded from the analysis because it's reported in all almost NDSs.

Statistical analysis was conducted using Epi Info statistical software v. 7.2.2.6. Descriptive statistics data are presented as absolute and relative frequencies (*Table 1*). Bivariate analysis was performed between each outcome and MH's characteristics. Variables with p-values less than $p < 0.10$ were included in multivariate logistic regression models and presented as adjusted odds ratios and 95% confidence intervals. P-values were considered significant at $p < 0.05$.

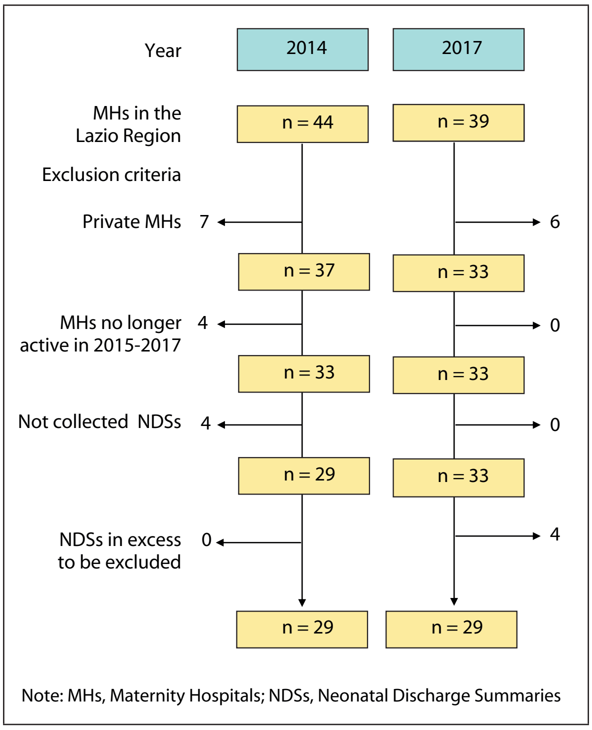

**Figure 1**
Paired samples of neonatal discharge summaries (NDSs) collected in 2014 and 2017.

**Table 1**
Identification, birth, anthropometric and clinical data reported in neonatal discharge summaries (NDSs) collected in 2014 and 2017 ($N = 29$ per year)

| Selected contents | 2014<br>n (%) | 2017<br>n (%) |
|---|---|---|
| **Main identification and birth data** | | |
| Surname and name | 29 (100) | 29 (100) |
| Date of birth | 29 (100) | 29 (100) |
| Time of birth | 18 (62) | 20 (70) |
| Type of delivery | 28 (97) | 28 (97) |
| Gestational age | 28 (97) | 28 (97) |
| Sex | 7 (24) | 7 (24) |
| Apgar score | 27 (93) | 28 (97) |
| **Anthropometric data** | | |
| Birth weight | 29 (100) | 29 (100) |
| Discharge weight | 29 (100) | 29 (100) |
| Length | 29 (100) | 29 (100) |
| Head circumference | 29 (100) | 29 (100) |
| Chest circumference | 6 (20) | 1 (3) |
| **Blood tests** | | |
| Blood group | 27 (93) | 28 (97) |
| Direct Coombs test | 20 (70) | 22 (76) |
| Bilirubin test | 24 (83) | 26 (90) |
| Haematocrit test | 18 (62) | 19 (65) |
| Glucose test | 4 (14) | 7 (24) |
| **Discharge data** | | |
| Discharge diagnosis | 15 (52) | 15 (52) |
| Outpatient follow-up | 27 (93) | 28 (97) |
| Discharge date | 25 (86) | 29 (100) |
| **Maternal data** | | |
| Blood group | 19 (65) | 18 (62) |
| HBsAg status | 4 (14) | 5 (17) |
| Family history | 6 (20) | 4 (14) |
| Obstetrical history | 6 (20) | 6 (20) |

## RESULTS

We collected the NDSs of 29 MHs in 2014 and 2017 with a coverage of births in the region of 89.9% and 93.0% respectively.

In the MHs included, one third provided Level 2 care and the mean overall cesarean section rate was 41.8% in 2014 and 39.6% in 2017. One of the MHs had been certified as a Baby-Friendly Hospital by Unicef in 2014, and in 2017 was undergoing re-certification, while 2 other MHs were in the area served by a certified Baby-Friendly Community Health Service since 2014.

Information in the NDSs was summarized into the following categories: infant feeding practices, indicators of adequate intake, infant health promotion messages, maternal nutrition and follow-up information (*Figure 2*, available on line as Supplementary Material).

Information on infant feeding practices was reported in 27 (93%) in 2014 and 28 (97%) in 2017. The main contents described human milk as "the ideal food" (22 *vs* 25) and discussed breastfeeding on-demand (25 *vs* 24) and not limiting the length of a feed (5 *vs* 9). Some MHs proposed outdated breastfeeding practices such as scheduling feeds (5 *vs* 4), limiting time at the breast (4 *vs* 1) and information on breast care and hygiene (2 *vs* 1).

Other types of appropriate content were found only in a small number of NDSs: information for effective latch-on technique (5 *vs* 5); explaining the mechanism of "the more you breastfeed, the more milk you make" (5 *vs* 4) and hand expression of human milk (2 in both years); avoiding pacifier use before breastfeeding is well established (2 *vs* 1), and following World Health Organization (WHO) recommendations (6 *vs* 7 for exclusive breastfeeding for six months, 0 *vs* 1 for continued breastfeeding with complementary foods after 6 months). Information about the type of infant feeding adopted during the hospital stay was available in 9 (31%) NDSs in 2014 and 5 (17%) in 2017, but all the WHO feeding definitions (exclusive or predominant breastfeeding, complementary feeding or formula feeding) were included in only 3 and 2 NDSs, respectively.

About the BMS, the most frequent indications concerned instructions on how to prepare formula (10 *vs* 7) and how to determine the correct amount to prepare (9 *vs* 7). A pre-defined space for formula prescription was pre-printed in 14 NDSs in 2014 and 7 in 2017. This signifies that 54% of children born in the selected MHs in 2014 and 23% in 2017 received an NDS that violates not only the International Code, but Italian law as well.

The main indicators of adequate intake were the infant's weekly's weight gain (19 *vs* 18) and the number of wet diapers (14 *vs* 17). Test weighing before/after breastfeeding was recommended in just 1 and 3 NDSs, respectively.

All of the NDSs included at least some infant health promotion messages. Pre-defined spaces for prophylaxis and screenings regarded mainly vitamin K (21 *vs* 27) and ocular prophylaxis (11 *vs* 18), as well as metabolic (29 *vs* 28), hearing (9 *vs* 23) and cardiological screening (7 *vs* 17), hip ultrasound (15 *vs* 18) and examination of the eyes and vision (7 *vs* 16). Prescriptions of supplements mainly regarded vitamin D (13 *vs* 12) and in fewer cases fluorine (6 *vs* 5). Information on umbilical cord care was frequently provided (21 *vs* 24) suggesting a specific brand for umbilical cord disinfection (or an empty space to prescribe it) (9 *vs* 11) or dry cord care (9 *vs* 11).

In 2014, 15 NDSs (52%) contained at least one indication for SIDS prevention, while the number increased to 22 NDSs (76%) in 2017. The most frequent recommendations were to place newborns to sleep on their back (13 *vs* 18) and in a cot (7 *vs* 9), to avoid excessively warm environments (9 *vs* 13), to avoid smoking (7 *vs* 11), while breastfeeding (3 *vs* 4) and room-sharing (1 *vs* 5) are less frequently mentioned. Information about the importance of vaccines was rare (4 *vs* 2) and information on car safety was reported only in two NDSs in 2017.

There was a marked increase in information on maternal nutrition: 48% of NDSs in 2014 and 72% in 2017. The main advice concerned the importance of following a well-balanced diet (11 *vs* 19) and foods to avoid during breastfeeding (5 *vs* 4). Hard alcohol was explicitly contraindicated in 3 NDSs in 2014 and 6 in 2017. Two NDSs in 2014 and 4 in 2017 provided information on the use of medications during lactation. Several supplements for the mother [vitamins/multiminerals (3 *vs* 4), galactogogues (2 *vs* 1)] are prescribed, with no clinical indication.

Follow-up information in NDSs often included phone numbers of hospital paediatric services (14 *vs* 13) and main switchboards (8 *vs* 10), while rarely providing information on community breastfeeding support services (4 *vs* 5), mother-child community health centres (2 *vs* 1), and local peer support groups (1 *vs* 1).

Further content regarding information on the main maternal-neonatal blood tests, newborn's identification and other data are summarized in *Table 1*.

The quantitative analysis revealed that NDSs compliant with the International Code and IT Decree were associated with MHs with a lower prevalence of cesarean section ($p < 0.01$). Infant health promotion messages were more frequent in NDSs of MHs belonging to the LHA ($p < 0.001$) and those having a lower prevalence of cesarean section ($p < 0.001$). Information on neonatal screening tests had a higher probability of being reported in the NDSs collected in 2017 than 2014 ($p < 0.003$) and were more frequent in MHs with lower prevalence of cesarean section ($p = 0.10$) (*Table 2*).

**Table 2**
Bivariate associations between each outcome (Compliance with International Code and IT Decree, Infant health promotion messages, Information on Neonatal Screening Tests) and MH's characteristics (Year of collection, Level II MHs, MHs belonging to LHA, cesarean section) (N = 58)

| | Compliance with International Code and IT Decree | | | Infant health promotion messages | | | Information on Neonatal Screening Tests | | |
|---|---|---|---|---|---|---|---|---|---|
| | **OR** | **95% CI** | **p-value** | **OR** | **95% CI** | **p-value** | **OR** | **95% CI** | **p-value** |
| Year of collection (2017/2014) | 2.9 | (0.9-9.3) | 0.06* | 1.5 | (0.5-4.5) | 0.45 | 5.3 | (1.7-18.1) | <0.003* |
| Level II MHs (Yes/No) | 0.6 | (0.2-2.0) | 0.38 | 0.8 | (0.2-2.4) | 0.62 | 2.6 | (0.8-8.3) | 0.17 |
| MHs belonging to LHA (Yes/No) | 1.3 | (0.4-4.0) | 0.60 | 6.4 | (2.0-21.9) | <0.001* | 0.7 | (0.2-2.2) | 0.56 |
| Cesarean section (<40%/≥40%) | 5.1 | (1.6-17.5 | <0.01* | 6.6 | (2.0-24.6) | <0.001* | 1.7 | (0.6-5.1) | 0.10* |

OR: odds ratio; CI: confidence interval; *p ≤ 0.10; MH: maternity hospital; LHA: Local Health Authority.

Variables with p-value less than or equal to 0.10 in the bivariate analyses were selected for logistic regression (*Table 3*). Compliance with International Code and IT Decree was significantly associated with a low prevalence of cesarean section (CI, 1.4-15.9) but not with the year of collection. Infant health promotion messages were significantly associated with MHs belonging to the LHAs (CI, 1.2-14.7) and with a low prevalence of cesarean section (CI, 1.2-16.0). Information on neonatal screenings was significantly associated with the year of data collection (CI, 1.6-16.8) but not with the prevalence of cesarean section.

## DISCUSSION

In Italy, Government Guidelines do not exist relatively NDSs' contents, causing a wide heterogeneity in terms of written information provided by the various hospitals.

Considering that the primal period, from pregnancy to 2 years of life, is critical to lifelong health, good communication aimed at health promotion and parents' empowerment assumes a key role. An NDS is often the only official document given to the parents during discharge to facilitate the transition of care from the hospital to the family. It can be used as a mere information tool or can be part of a communication process, actively engaging the parents and the professionals along the care pathway.

Taking account of the information provided by International Code, IT Decree, the ABM [1] and ISN [2], our study shows a relevant improvement in written informative delivered to parents over the years, albeit with some persistent critical issues.

Written clinical information is necessary for the healthcare providers, such as mother-child CHS and family paediatricians, who will take care of the newborn after discharge, while infant health promotion messages are important for the new parents, especially for those who didn't attend childbirth education classes. In fact, a national survey published in 2012 showed that about 41% of Italian and 62% of foreign primiparous women didn't attend childbirth education classes [12]. For these families, the NDS may represent their only opportunity to receive information about their children and healthcare options.

Almost all the MHs mention infant feeding, including the superiority and importance of human milk. However, some information is contradictory. For example, responsive breastfeeding is often encouraged in the opening sentence but a preset length and/or frequency of feedings is suggested in the following paragraphs. This discrepancy may be attributed to a dual approach to breastfeeding by healthcare professionals deriving from the conflict between formal knowledge and practice-based situations [13].

Moreover, the recommended duration of exclusive breastfeeding is explicitly discussed in a fair number of NDSs, while continued breastfeeding after the introduction of solids is rarely mentioned, although MHs should encourage responsive exclusive breastfeeding for the first 6 months and continued breastfeeding up to 2 years of life and beyond [1].

From 2014 to 2017, the quality of information on breastfeeding seems to be improved. However, it's surprising that there are still NDSs providing a pre-defined space for formula prescription even though the International Code and the 2009 IT Decree prohibits it and economic sanctions have been established since 2011.

In some cases, the prescription of a specific infant formula brand was written on a separate piece of hospital letterhead that was not part of the NDS and no clinical indication for the use of formula was given. In other NDSs, there is no pre-defined space for formula prescription to be used after discharge, but one in which to write the brand of formula used during the hospital stay. In total, 3 NDSs with a pre-defined space for formula prescription provided the printed indication "in case of hypogalactia", supporting what has nowadays become more of a cultural construct than a real clinical condition. While no data are available on the prevalence of clinically-diagnosed hypogalactia, it's very rare, even though it's the first reason given by Italian women for abandoning breastfeeding in the first 3 months [12]. The BMS prescription at hospital discharge is left to the paediatrician's discretion, according to her/his clinical judgment. As is done for medications, the prescription should be written and provide complete and personalized information to parents on the safe and correct use of formula. When prescribing BMS, the AFAAS criteria (Acceptable, Feasible, Affordable, Sustainable and Safe) should be applied [14].

In our study, an improvement in compliance with the International Code and IT Decree was found over the years. In fact, in 2017 the number of MHs that use non-compliant NDSs is half of what it had been three

**Table 3**
Logistic regression models. Adjusted odds ratios are presented (N = 58)

| | Compliance with International Code and IT Decree | | | Infant health promotion messages | | | Information on Neonatal Screening Tests | | |
|---|---|---|---|---|---|---|---|---|---|
| | aOR | 95% CI | p-value | aOR | 95% CI | p-value | aOR | 95% CI | p-value |
| Year of collection (2017/2014) | 2.4 | (0.7-7.9) | 0.15 | - | - | - | 5.2 | (1.6-16.8) | <0.006* |
| MHs belonging to LHA (Yes/No) | - | - | - | 4.2 | (1.2-14.) | <0.03* | - | - | - |
| Cesarean section (<40%/≥40%) | 4.7 | (1.4-15.9) | 0.01* | 4.4 | (1.2-16.0) | <0.03* | 1.3 | (0.4-4.2) | 0.65 |

AOR: adjusted odds ratio; CI: confidence interval; *p < 0.05; MH: maternity hospital; LHA: Local Health Authority.

years earlier. However, the quantitative analysis showed that MHs with lower rates of cesarean sections have a greater proportion of NDSs conforming to the International Code and IT Decree, while the year of collection is not significantly associated. Cesarean section rate is a good indicator for assessing the over-medicalization of childbirth. We assume that this "medicalized attitude" extends to the design of written communication given to new parents, which is more focused on clinical and prescriptive aspects (e.g. drugs, supplements, infant formula) than on practices for health promotion.

According to ABM [1] and ISN [2], NDSs should include some essential infant health messages. The ISN recommends vitamins K and D to all newborns [2]. Most of the NDSs collected contain written information on the vitamin K prophylaxis performed in hospital. In our study there is less emphasis on vitamin D supplementation, as the prescription is often handwritten in the generic space dedicated to post-discharge medications. Some NDSs recommend fluoride supplements, although their effectiveness in preventing tooth decay is not demonstrated in children younger than 6 months [2].

Information on umbilical cord care denotes a prescriptive attitude, e.g. providing a field to be filled in with indications of disinfectant or brand products for cord care. This advice is more conservative than the 1998 WHO recommendations for high-income countries [15] (World Health Organization, 1998) for "dry care", i.e. using soap and sterile water if umbilical stump is dirty, while chlorhexidine is indicated only in case of low sanitary conditions and/or when the risk of infections is high [16].

Information on neonatal screening has increased significantly in 2017, probably as a result of the implementation of the Italian National Plan of Prevention (INPP) [17]. Ultrasound screening for hip dysplasia and hearing screening are often mentioned in pre-printed messages. Although the INPP [17] recommends that all MHs offer both neonatal hearing and ophthalmic screening, information on eye examination is less frequent than the other.

Information on infant's safe sleeping is important for SIDS prevention. Some behaviours and conditions are considered risk factors [18], while supine position of the infant, breastfeeding and a high-quality prenatal care [19] are positive protective factors. In our study, recommendation for using the supine position is the most common message for SIDS prevention while room-/bed-sharing [20-22] and pacifier use [23, 24] are rarely mentioned, possibly because the scientific debate is still underway.

As for other messages, content on vaccines is rare although providing information to parents on importance of immunization is recommended [2, 25]. Since 2015, the ISN has recommended that a standard message be inserted in NDSs, describing the importance of vaccines currently available, the increase in their efficacy, the decreased risk of adverse reactions, and the advice to contact the paediatrician or the ISN website for further information [2]. In spite of this, few NDSs offer this kind of information.

Information about car safety is lacking in almost all NDSs, although motor vehicle accidents are still one of the main causes of death and injuries for children [26].

The MHs belonging to LHAs and with a lower prevalence of cesarean sections provide more written infant health promoting messages about safe sleeping and vaccines compared to the other types of MHs. This could reflect a greater integration between public hospitals and CHSs as they fall under the same management and pay more attention to health promotion and disease prevention at the level of the community they serve.

Although NDSs suggest that the appropriate maternal diet should be well balanced and varied during lactation, some food restrictions are still advised (e.g. spicy foods, shellfish, beans, dairy products). This result confirms that health professionals can convey some "food taboos" [27] to the mothers although no dietetic restrictions should be routinely recommended during breastfeeding [28]. Few NDSs provide information on the use of maternal medications during lactation, limiting their content to the recommendation "do not take drugs without a medical prescription". Mothers, as well as health professionals, should be supported by official and evidence-based information on medications, breastfeeding management, and pharmacovigilance [29, 30]. Therefore, the NDSs could be enriched by providing references to the main institutional websites dealing with the topic and/or phone numbers of the drug information services.

In our NDSs, phone numbers of hospital paediatric wards are often provided, while contacts of CHSs and breastfeeding peer support groups are rare. This confirms the concern about the gaps in communication between hospital and resources in the community.

Space limit is a challenge when health professionals want to design a clinical record or an information document for patients or their caregivers. Our study shows that some important health information is frequently omitted (e.g. car safety, practical advice for breastfeeding technique, regaining birth weight). Other contents that are less relevant or not evidence-based (e.g. products or techniques for breast hygiene and care, fluoride supplements, test weighing before/after feeding) should be omitted.

After hospital discharge, the Italian NHS requires mandatory, free registration for all newborns to a paediatrician. As the system is not proactive, the time between the hospital discharge and the first contact with the paediatrician or mother-child CHSs can vary significantly. During this period, parents will rely on information acquired from health professionals during pregnancy and hospital stay. Thus, the information contained in NDSs can play a key role in orienting the parents during the first days of life and within the health system. As emphasized by the ABM [1] and ISN [2], information should be provided verbally during pregnancy and hospital stay and be reinforced in the form of short and simple written messages on the NDSs. A survey similar to ours was recently published but limited to the city of Rome and the year 2017 [31]. These results, in line with ours in terms of emerged contents and great variability between the different hospitals, led to the publication of an official document from the Region of Lazio recommending that MH directors standardize NDSs.

## LIMITATIONS

Our study has limitations. Some missing information (e.g. recommended neonatal screenings, prescription of vitamin D) may be handwritten in the white spaces by the paediatrician. Some health messages may be missing in the NDSs but, in a few cases, be written in other information booklets given to parents. Moreover, there could be an underestimation of the number of letterhead sheets that are systematically attached to the NDSs and used for formula prescription but are not compliant with the current Italian legislation and the International Code, as compared to those collected during the study. For the purposes of statistical analysis, the number of MHs, as well as NDSs, is small and this could have affected the statistical significance.

## CONCLUSIONS

This study contributes to a better understanding of the information included in NDSs in Lazio (Italy). Compared to previous years, relevant improvements emerge in terms of greater compliance with International Code and IT Decree and attention to health messages. Further progress needs to be made by MHs to reduce their level of medicalization in both clinical practice and prescriptive attitudes, which also affects the written information content delivered to parents. Additional improvements can be achieved in the coming years, such as deleting the pre-defined space for formula prescription from all NDSs and giving priority to information and health promotion messages useful to all children and parents. Clear, complete, correct and evidence-based information to promote infant health contributes to giving every child the best start.

### *Acknowledgments*

Thanks to all the midwives and mothers who have contributed to data collection.

### *Funding source*

This research received no grant from any funding agency in the public and private sectors for the research, authorship, and/or publication of this article.

### *Financial disclosure*

Authors have no financial relationships relevant to this article.

### *Conflicts of interest statement*

Authors have no conflicts of interest.

### *Authors' contribution*

All Authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

*Received* on 16 October 2019.
*Accepted* on 17 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 150-156
DOI: 10.4415/ANN_20_02_04

# Perception of climate change, loss of social capital and mental health in two groups of migrants from African countries

**Enrico Di Giorgi**[1], **Paolo Michielin**[1] **and Davide Michielin**[2]

[1]*Dipartimento di Psicologia dello Sviluppo e della Socializzazione, Università degli Studi di Padova, Padua, Italy*
[2]*A.P.S. Europa Donna Italia, Milan, Italy*

**Abstract**

***Introduction.*** The negative effects of climate change affect community subsistence models, thus determining an increase in social conflicts, a loosening of social capital, an increase in the incidence of traumas and diseases, and a push for migration.

***Aim.*** This exploratory research compares the perception of climate change, as well as the reduction of social capital and mental health, in two groups of migrants arriving in Italy from African countries with high or extreme vulnerability to climate change.

***Methods.*** The perception of climate change and the degree of social capital were assessed with a semi-structured interview. The psychological condition was investigated through a clinical psychological interview and tests.

***Results.*** The group of migrants coming from countries with extreme exposure to climate change perceive greater vulnerability of their country and reports a greater loss of social capital. The level of education does not seem to affect the ability to perceive climate change. In the entire sample, there is a strong correlation between the perception of change and the loss of social capital, and between the loss of social capital and emotional disorders.

***Conclusions.*** The study suggests that actions to preserve the social capital of a community strongly exposed to climate change can mitigate the impact of change on mental health.

**Key words**
- climate change
- social capital
- mental health
- migration

## INTRODUCTION

Climate change is a gradual and long-term process, producing environmental effects of varying duration: acute and catastrophic events, such as floods; subacute events, such as drought or heat waves; and finally longer-term changes, such as desertification, modification and erosion of the physical environment on which food supply and the economic condition of the population depends. The exposure of the communities to the effects of climate change are differentiated in various countries. Within the same country, it is greater for those who live in rural areas, those already suffering from a condition of malnutrition, children, women and the elderly, those suffering from chronic diseases, those with a low level of education and technological knowhow, and those who are poorer and have less access to credit [1]. The negative effects of climate change affect community subsistence models, determine an increase in social conflicts, a loosening of social cohesion, an increase in the incidence of traumas, diseases, epidemics and early deaths, and a push for migration to urban areas and other states, with a gradual abandonment of the most exposed environments [2].

According to the data published by the Internal Displacement Monitoring Center [3], from 2008 to today on average 26.4 million people a year have been forced to migrate due to natural catastrophic events.

The international agencies estimate that by 2050 there will be 200 million migrants for climatic reasons [4]. The number of "environmental refugees" has now surpassed that of war refugees, although the Geneva Convention only recognizes the rights of the latter.

The perception of climate change appears to be greater in rural areas and the most frequently felt aspects are, in developing countries, the increase in temperatures and the decrease in precipitation [5, 6].

*Address for correspondence:* Paolo Michielin, Dipartimento di Psicologia dello Sviluppo e della Socializzazione, Università degli Studi di Padova, Via Venezia 8, 35131 Padua, Italy. E-mail: paolo.michielin@unipd.it.

A study by Ishaya and Abaje [1] shows that the perceived threat of change concerns health, food supply, biodiversity reduction and the availability of firewood; other aspects that are felt are the catastrophic events, the reduction of resources, such as water and electricity, as well as that of basic public services.

A greater perception seems to be directly linked to the level of income, age and life experience, education, exposure to the media and available information [7, 8].

An important negative effect of climate change is the reduction of social capital, a construct that combines community participation and social cohesion. Social capital can be defined as "the characteristics of a social organization, in particular trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions" [9]. It is expressed at both individual and community level. At the individual level it is linked to the number of family members, to relations of confidence and non-family friends, to contacts with the neighborhood, to participation in recreational and associative activities, to the consideration enjoyed in one's own community and to attachment to the place. At the community level, social capital is expressed in the network of public services, such as education, security and health, in the associative and voluntary network, in trust in others, and in the absence of ethnic, religious or political conflicts. Many studies have investigated the impact of climate change on the physical health of a population, while there is little research on the impact of climate change on mental health [10-12]. There is evidence about the relationship between climate change and mental health gathered in specific populations of Australia or Northern Canada, such as the Inuit. However, studies on populations equally exposed to climate change, such as those in Central Africa, are lacking.

Our research examines a sample of migrants arriving in Italy from African countries, divided into two groups, one from countries characterized by extreme vulnerability to climate change, the other coming from countries with high vulnerability.

Objectives of the study are:

- to verify, through the comparison between the two groups, the differences in the perception of change, both global and in its different components, in the loss of social capital and mental health;
- analyze the most perceived aspects of the change in the entire sample;
- investigate the relationships between the perception of change, the loss of social capital and mental health in the entire sample;
- analyze if the perception of climate change is influenced by variables such as school years and the place of life (city-village).

The hypotheses are that migrants from countries with extreme vulnerability present a greater perception of climate change, a greater loss of social capital and a greater presence of emotional disturbances compared to those from countries with high vulnerability. Other hypotheses are that there is a significant relationship between the perception of climate change and the loss of social capital and between the loss of social capital and the extent of emotional disturbances. Finally, we assume that the perception of climate change is conditioned by the level of education.

## MATERIALS AND METHODS

### *The ND-GAIN Vulnerability Index to climate change*

Encouraged by policy makers, numerous research groups in recent years have attempted to quantify the effects of climate change on a national scale. This effort culminated in the development of several indices, based on an extensive number of indicators [13]. As for the countries of origin, one of the most used indexes to measure the severity of climate change is the one developed by the research group of the University of Notre Dame, called Notre Dame Global Adaptation Initiative (ND-GAIN). The ND-GAIN Country Index [14] is a global index that combines a vulnerability index of the country with climate change and an index of readiness as well as the willingness to face the changes.

In this study to distinguish the different countries of origin and compose the groups, we considered only the index of vulnerability. It measures the exposure, sensitivity and adaptability of the country in six vital sectors: food, water, health, ecological services, human habitats and infrastructures. The exposure reflects the degree to which a system is exposed to climate change from a physical and biological point of view. Sensitivity measures the degree to which the most important productive sectors of the country are negatively influenced by climate risk and the proportion of the population particularly susceptible to a risk of climate change. Adaptive capacity assesses the availability of social resources for adaptation to climate change.

Vulnerability is composed of 36 indicators. Each component has 12 indicators, crossed with 6 sectors. To obtain the overall score, the score for each sector was calculated by taking the arithmetic mean of its 6 constituent indicators (all on a 0-1 scale, weighted equally). Then the overall vulnerability score was calculated by taking the arithmetic mean of the 6 sector scores. The ND-GAIN Index therefore has a value ranging from 0 to 1; the higher it is, the more vulnerable the country is to climate change. A score more than 0.45 indicates a high vulnerability, while a score more than 0.55 an extreme vulnerability.

Among the available exposure indexes, in the present study it was decided to adopt the ND-GAIN Index for the high number of countries considered (181), the use of public data processed by international bodies and organizations, and its comparability with other indexes.

### *Participants*

The research was conducted in three extraordinary reception centers for migrants (Centri di Accoglienza Straordinaria – CAS) based in Treviso, Oderzo and Vittorio Veneto, Northern Italy. In these centers, asylum seekers receive food and lodging, medical and psychological assistance, and participate in integration activities, such as learning the Italian language or professional training. 651 migrants are currently welcomed in these centers, the majority of which come from African countries. Some countries, particularly Nigeria, are highly represented, while other countries, such as

Liberia or Afghanistan, are under-represented. Two different groups of migrants were recruited: a group of 50 people from countries with extreme vulnerability to climate change and a group of 50 from countries with a high degree of vulnerability. Many of them were economically and socially disadvantaged people even in their countries of origin and therefore they were most exposed and vulnerable to climate change [15].

*Table 1* shows the ND-GAIN Vulnerability Index of the different countries, considering that at a higher value corresponds a greater vulnerability. As can be seen, they range from extreme values such as those of Niger and Liberia to values that are as high as those of Ghana and Cameroon.

**Table 1**
ND-GAIN (Notre Dame Global Adaptation Initiative) index of countries with extreme, very high, and high vulnerability to climate change

| Country | Score | World ranking |
|---|---|---|
| Niger | 0.680 | 180 |
| Liberia | 0.616 | 174 |
| Mali | 0.614 | 173 |
| Afghanistan | 0.596 | 171 |
| Burkina Faso | 0.582 | 162 |
| Sierra Leone | 0.560 | 156 |
| … | | |
| Gambia | 0.538 | 141 |
| Senegal | 0.538 | 139 |
| … | | |
| Nigeria | 0.485 | 127 |
| Cameroon | 0.484 | 124 |
| Ghana | 0.469 | 114 |

Some countries from which migrants come, such as Gambia and Senegal, present intermediate values and were not considered in the research.

As can be seen in *Table 2*, there are no considerable differences between the two groups regarding the months of stay in Italy and the presence of a diagnosed psychiatric pathology. Screening for mental disorders was done by CAS psychologists, using the clinical interview and PHQ-9 and GAD-7 tests; the diagnosis was carried out by the psychiatrists of Mental Health Center. Gross domestic product was calculated by attributing to each migrant the GDP *per capita* of their country; the data refers to 2017 and was provided by the World Bank.

For some countries, all asylum seekers were recruited, while for other countries, such as Nigeria, which were over-represented, the subjects with characteristics most similar to those of the other sample were selected; despite this, the two groups differ in many variables, such as education, religion, the place of life, gross domestic product per capita, due to the differences that characterize the countries of origin.

### Materials and procedures

In each of the two groups, we evaluated, through a semi-structured interview, the knowledge and perception of climate change and the magnitude of social capital.

In the first part the questions asked in the interview reproduced the factors already illustrated by the ND-GAIN Vulnerability Index regarding the knowledge and perception of climate change; subjects were required to report changes in the country of origin in the last 5 years of their stay. In a second part of the interview the questions concerned the constitutive elements of the social capital: availability of health services, presence of the State and public safety, availability of schools, extension of the family network (cohabitants and neighbors with daily reports), satisfaction with relationships in the fam-

**Table 2**
Demographic, socio-economic, and clinical characteristics of the two groups of migrants

| | High vulnerability (n = 50) | Extreme vulnerability (n = 50) |
|---|---|---|
| Native country | Nigeria 60%<br>Ghana 28%<br>Cameroon 12% | Mali 60%<br>Burkina Faso 14%<br>Sierra Leone 12%<br>Afghanistan 6%<br>Liberia 4%<br>Niger 4% |
| Age (mean) | 27.90 | 23.68 |
| Years of schooling (mean) | 7.56 | 4.36 |
| Religion | Christian (94%) | Muslim (96%) |
| Gross Domestic Product per capita (mean in US dollars) | 2017 | 778 |
| Place of life: | | |
| • Village | 34% | 50% |
| • Shanty town or suburbs | 16% | 26% |
| • City center | 50% | 24% |
| Months from arrival in Italy (mean) | 18.1 | 17.6 |
| Psychiatric diagnosis | 1 (2%)<br>Psychosis, substance abuse | 1 (2%)<br>Psychosis, substance abuse |

ily, extension of the friendly and neighborhood network, problematic relationships with neighbors, existence of at least a relationship of trust outside the family, consideration enjoyed within the community of reference; participation in any form of association, including those of a religious kind; relationships with people of different ethnicity or religion, problems and conflicts, poverty compared to the rest of the community, and deaths not expected and not determined by old age.

Finally, the same people were evaluated from the psychological point of view both through a clinical interview and through two psychological tests, the PHQ-9 and the GAD-7 [16, 17].

The study was worked out according to the International Guidelines and Ethical Codes of the Belmont and Oviedo Chart as well as the first section, paragraph 9, of the Italian ethical code of Psychologists. The research protocol was approved by the Ethics Committee and the Prefect of Treviso.

The PHQ-9 is composed of 9 items and investigates depressive symptoms, has versions in many languages, and a score greater than or equal to 15 indicates the probable presence of major depression.

The GAD-7 is composed of 7 items and investigates the anxious symptoms, has versions in many languages, and a score higher than 10 indicates the possible presence of an anxiety disorder. The Global emotional disorders score was obtained by adding the PHQ-9 and GAD-7 scores and dividing the result by two.

As can be seen in *Appendix 1* (available online as Supplementary Material) the guide for the semi-structured interview included for each factor the definition of the construct, the guiding questions to be used, and the criteria for classifying the answers. Both the interviews and the tests were administered either in the language of origin, with the support of a cultural mediator; or for French-speaking or English-speaking subjects in French or English.

## RESULTS AND DISCUSSION

The results obtained from the interviews are shown in *Table 3* and the significance of the differences between the two groups was analyzed with Student's t Index. Furthermore, the effect size of the difference between the means was calculated using Cohen's d. Statistical analysis was performed with SPSS Version 25.0 statistic software package.

As you can see the total perception of climate change shows a significant difference between people who come from countries with extreme vulnerability, which therefore perceive a higher degree of climate change, and people who come from countries with high vulnerability.

The difference is significant also for two single items, i.e. the lower availability of water and the lower availability of electricity. Cohen's d scores indicate a medium effect size for the items reduced water availability, heatwave periods/ delay in rainy season, no improvement in agriculture, and for global perception; a large effect size is noted for reduced electricity availability.

*Table 4* shows the scores of the interview on the social capital.

The social capital has a global value that shows a difference which, however, is at the limits of significance, precisely 0.05. Two aspects are instead relevant, with a significant difference between people from countries with extreme vulnerability and people from countries with high vulnerability; these are membership participation and social security.

Cohen's d scores indicate a medium positive effect size for the following items: health services availability, school availability, friend network, and global social capital. Instead we observe a medium negative effect size for family satisfaction and relationship outside family. A large positive effect size is noted for social safety and associative participation.

The differences must be interpreted with caution because the two groups differ in many variables. For this purpose, we conducted two multiple regression analyses with perception of climate change and social capital scores as dependent variables, and socio-economic (age, schooling, place of life and gross domestic product per capita) and vulnerability scores as explanatory variables. The two models have weak explanatory power

**Table 3**
Mean 9 item Interview on perception of climate change and global perception scores, by two groups of migrants

| Variables | High vulnerability (mean) | Extreme vulnerability (mean) | Student's test t (98) | Student's test p value | Cohen's d |
|---|---|---|---|---|---|
| Dependency on food supply | 1.30 | 1.34 | -0.281 | 0.779 | -0.05 |
| Reduced food avalability | 0.60 | 0.72 | -0.710 | 0.480 | -0.14 |
| Reduced water avalability* | 1.18 | 1.64 | -2.037 | 0.044 | -0.41 |
| Problem in waste disposal | 0.60 | 0.54 | 0.601 | 0.549 | 0.12 |
| Heatwave periods/delay in rainy season | 0.66 | 0.76 | -1.098 | 0.275 | -0.21 |
| Catastrophic weather events | 1.24 | 1.34 | -0.521 | 0.604 | -0.10 |
| Changes in vegetation | 0.56 | 0.50 | 0.767 | 0.552 | 0.11 |
| Reduced electricity avalaibility* | 1.10 | 1.52 | -3.100 | 0.003 | -0.61 |
| No improvements in agriculture | 0.64 | 0.80 | 1.793 | 0.076 | -0.35 |
| Global Perception* | 0.88 | 1.02 | -2.163 | 0.033 | -0.32 |

* statistical significance ($p < 0.05$)

**Table 4**
Mean 11 item Interview on social capital and global social capital scores, by two groups of migrants

| Variables | Hight vulnerability (mean) | Extreme vulnerability (mean) | Student's test t (98) | Student's test p value | Cohen's d |
|---|---|---|---|---|---|
| Health services availability | 1.56 | 1.36 | 1.375 | 0.172 | 0.27 |
| Social safety * | 0.74 | 0.40 | 3.463 | 0.001 | 0.69 |
| School availability | 1.66 | 1.34 | 1.943 | 0.055 | 0.38 |
| Family network size | 2.10 | 1.96 | 0.685 | 0.495 | 0.13 |
| Family satisfaction | 0.64 | 0.80 | -1.793 | 0.076 | -0.35 |
| Friend network | 0.72 | 0.58 | 1.469 | 0.145 | 0.29 |
| Relationships outside family | 0.60 | 0.70 | -1.043 | 0.299 | -0.21 |
| Respect from community | 0.98 | 1.08 | -0.866 | 0.389 | -0.17 |
| Associative partecipation * | 0.70 | 0.42 | 2.910 | 0.004 | 0.58 |
| No poverty | 0.84 | 0.76 | 0.681 | 0.498 | 0.13 |
| No unexpected bereavements | 0.98 | 1.06 | -0.598 | 0.551 | -0.11 |
| Global social capital | 1.05 | 0.95 | 1.982 | 0.050 | 0.31 |

* statistical significance ($p < 0.05$)

**Table 5**
Mean GAD-7, PHQ-9 and Global emotional disorders scores, by two groups of migrants

| | Hight vulnerability (mean) | Extreme vulnerability (mean) | Student's test t (98) | Student's test p value | Cohen's d |
|---|---|---|---|---|---|
| GAD-7<br>General Anxiety Disorder-7 | 4.88 | 5.94 | -1.254 | 0.213 | 0.37 |
| PHQ-9<br>Patient Health Questionnaire-9 | 5.40 | 5.54 | -0.138 | 0.890 | 0.03 |
| Global emotional disorders | 5.14 | 5.74 | -0.721 | 0.473 | 0.18 |

($r^2 = 0.102$ for perception and $r^2 = 0.098$ for social capital); therefore, it seems that the differences observed between the two group are scarcely affected by these predictors.

As for emotional disorders (*Table 5*) there are differences between the overall scores of PHQ-9 and GAD-7, but they are modest and not significant. D Index shows a medium effect for anxiety symptoms.

Again, based on the results of the interview, but analyzing the data of the entire sample of 100 subjects, the aspects of climate change most perceived by people were analyzed. For each aspect, the subjects who in the last 5 years detected a change in the negative direction and regardless of the intensity of this change (slight, moderate or high), were therefore counted.

*Table 6* shows how the most perceived aspects are the dependence in obtaining food and the lack or reduction in the availability of electricity.

Regarding the data studied from the correlational point of view on the total subjects, then the bivariate correlations using Pearson's r-index, a first element that seemed important to us is that the years of schooling do not correlate with the perception of change climate ($r = -0.022$). This seems to show that even people with lower education or illiteracy and poorer people perceive signs of climate change equally and accurately.

*Figure 1* shows that, as was our hypothesis, the perception of climate change is very strongly correlated with the social capital. It is a moderate relationship ($r = -0.416$) and a negative one, that is, as the perception of climate change increases, the social capital decreases. Equally significant ($r = -0.256$) is the relationship between loss of social capital and emotional disorders. Finally, a direct relationship, equally significant, but weaker ($r = 0.231$), is between perception of climate change and emotional disorders.

## CONCLUSIONS

The group of migrants coming from countries with extreme exposure to climate change perceive the greater vulnerability of their country as being linked to the reduction in the availability of water and electricity. In both groups the aspects of climate change that are most strongly felt are the greater dependence on food supply and the lack or reduction in the availability of electricity.

About 2 migrants out of 3 noticed an increase in heat waves, a delay in the rainy season, an increase in extreme and catastrophic atmospheric events, and a lower availability of drinking water. The perception

**Table 6**
Perception of the variables of climate change by all subjects (n = 100)

| Variable | N of subjects that detect a negative change in the last 5 years |
|---|---|
| Dependency on food supply | 86 |
| Lack or reduction of electricity availability | 86 |
| No improvements in agriculture technologies | 72 |
| Heath wave periods and delay in rainy season | 71 |
| Lack or reduction in access to reliable drinking water | 67 |
| Catastrophic weather events | 65 |
| Problems in waste disposal | 57 |
| Reduced food availability, malnutrition | 42 |

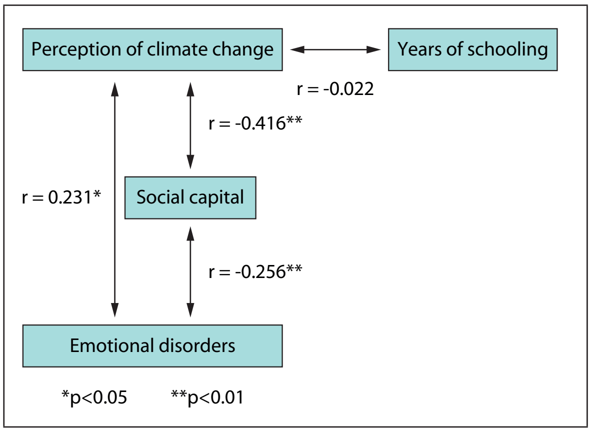

**Figure 1**
Bivariate correlations between the variables (total score) using Pearson's r.

of food shortages, malnutrition, and problems with waste disposal are lower, although still quite high. The extremely vulnerable group reports a greater loss of social capital, relating to public security and membership participation.

The level of education does not seem to affect the ability to perceive climate change. In the entire sample, at a personal level there is a moderate correlation between the perception of change and the loss of social capital and between loss of social capital and emotional disorders. Significant but weaker is the correlation between perception and emotional disorders. There are therefore indications that social capital is a useful intermediate variable between climate change and mental health; actions to preserve social capital can mitigate the impact of climate change on mental health.

The limitations of the study are many. It is, on the other hand, an exploratory study.

The two groups, for the reasons we have seen, differ in age, schooling, place of life, gross domestic product per capita and religion. Finally, the research was conducted from the 15th to the 19th month after arriving in Italy, even though it would have been more appropriate to conduct it in the first months of arrival to investigate more effectively the emotional disorders related to climate change and life in the country of origin.

### *Acknowledgements*

Authors are grateful to Alice Bisso, Madeline Cohn, Anderson Iyamu, Gianlorenzo Marinese, Loretta Ros and Barbara Spangaro for their generous support.

### *Conflict of interest statement*

The Authors declare that there is no conflict of interest regarding the publication of this paper.

*Received* on 9 September 2019.
*Accepted* on 3 April 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 157-167
DOI: 10.4415/ANN_20_02_05

# Study on the health status of the population living in Marghera (Venice, Italy) through the use of a longitudinal surveillance system

**Francesca Gessoni, Silvia Macciò, Claudio Barbiellini Amidei and Lorenzo Simonato**

*Dipartimento di Scienze Cardio-Toraco-Vascolari e Sanità Pubblica, Università degli Studi di Padova, Padua, Italy*

**Abstract**
The aim of this study is to carry out an investigation to evaluate the industrial area of Porto Marghera (the only Site of National Interest – SNI – for clearance operations in the Veneto region) by means of data from the Venetian Epidemiological Surveillance System (SEIVE – Sistema Epidemiologico Integrato di Venezia). In particular, the aim is to assess the extent at which chronic exposure to industrial pollutants contributes to the genesis of non-communicable diseases such as tumors. We have employed healthcare administrative databases to analyze health conditions of the population residing in the area of Marghera, separately from the rest of the mainland. The results obtained highlight a series of critical problems concerning the population residing in Marghera. These issues, such as an excess in the overall cancer mortality rate, have been observed in both genders, as well as in the lung cancer incidence and mortality rate. In addition, we detected an increase in mortality for respiratory diseases only in the male population.

**Key words**
- contaminated site of national interest
- healthcare administrative databases
- longitudinal study
- Marghera, Italy

## INTRODUCTION

### *The development of Marghera*

Marghera, together with the neighborhoods of Catene and Malcontenta, represents one of the mainland municipalities of the city of Venice. Its structure consists of a residential neighborhood and an industrial waterfront area, known as Porto Marghera.

According to the popular tradition, the name "Marghera" came from an expression in the local dialect "Mar ghe jera", which can be translated as "There was sea/The sea was there" to recall the swampy territory that had hosted the port for many years.

The genesis of Marghera as well as its industrial area are relatively recent. At the beginning of 1900, the harbor of Venice was among the most important ones in Italy. However, it needed new spaces to grow as well as newer and modern infrastructures [1].

At that time, most areas of the Venetian mainland were being affected by the development of road and rail infrastructures, with large areas that had yet to be used. It was the engineer Giuseppe Volpi, Earl of Misurata, who identified this area as the most adequate for the establishment of the new port and to develop an industrial pole. In 1917 the project was assigned to Enrico Coen Cagli, and it was submitted to the Ministry of Public Works of that time. The project was approved in only 75 days. In 1918 the industrial center was born, also thanks to financial aids for reconstruction from the Veneto region [2].

At the same time, however, the historic center of Venice was facing overcrowding issues: most of the dwellers, in fact, were living in poor conditions in terms of health and housing.

For this reason, the engineer Pietro Emilio Emmer designed the residential area of Marghera following the criteria for a "Garden City".

The original project for the area included schools, offices, libraries, churches, leisure areas and more.

In the plan there were also supposed to be 80 meters wide tree-lined avenues, private citizens' houses, which could not be higher than three stories, all with a private garden [3-5].

Unfortunately, the project was abandoned due to the cuts on the funds. However, it is still possible to spot some of these traces in the oldest and most central part of the city of Marghera.

The geography of the area that now hosts Porto Marghera (Port of Marghera) can be divided into three

*Address for correspondence:* Francesca Gessoni, Dipartimento di Scienze Cardio-Toraco-Vascolari e Sanità Pubblica, Università degli Studi di Padova, Via Giustiniani 2, 35128 Padua, Italy. E-mail: francesca.gessoni@studenti.unipd.it

macro-areas that were developed at different times and hosted various types of industries:

- first industrial area: located in the Northern part of the city, where the industrial plants were initially established. It is the most critical area as it is the closest to Marghera's residential center. Hence, it was the first among the macro-areas that underwent clearance operations;
- commercial port and shipbuilding industries area;
- second industrial area: characterized by the presence of industrial plants associated to the chemical and petrochemical businesses.

The subdivision in macro-areas is particularly important because the lands in each area share a similar genesis. Some of the areas consisted of pre-existing land, whilst some others were reclaimed through the use of backfilling material. For instance, the second industrial area was built over lands built with the materials excavated from canals as well as wastes of the first industrial area.

A further project was proposed, to realize a third industrial area, which was abandoned as a result of the crisis in the 70's that involved all Porto Marghera.

Porto Marghera, therefore, was planned as an industrial area, located on the coast and faced an unprecedented development. By 1925 there were 33 operating companies with 3440 employees in the area.

In the 30's, metallurgical industries as well industries of non-ferrous materials were installed and developed in Porto Marghera. In addition to the former, other industries dedicated to the production of nitrogen fertilizers, food, contact lenses, and perfume. In this situation, also transport companies began operating and expanded across the area. Industries for energy production services also started developing. In 1935 Porto Marghera had the largest thermal power station in Italy.

During the Second World War, bombing of the area caused a sudden stop of the productive activities in Porto Marghera. With the end of the conflict, the facilities were re-built, and the industrial area started expanding again.

At the beginning of the 1950s, Porto Marghera was growing and employed about 2200-2500 people. In these years, the second industrial area underwent an enormous expansion, with the installation of petrochemical industries. In 1965, during the period of maximum productive activity, 3300 people were employed in Porto Marghera [6].

In the 70's the area suffered from an important crisis. Multiple causes contributed to this crisis: the rise in oil prices, the increased sensitivity to environmental issues and the global crisis of chemical industries. As a result, many plants and industries stopped.

Despite having been scaled down in its productivity, Porto Marghera still remains an important area for the economy of the whole Veneto region [7].

### *Porto Marghera – Site of National Interest*

The industrial area of Porto Marghera is the only area in the region of Veneto that was inscribed in the sites of national interest (SNI) registry, for clearance operations. SNIs are vast contaminated areas that have been listed as dangerous for human and environmental health, according to specific Italian laws. These areas require clearance operations.

The extension of the area was defined by the 23/02/2000 Decree of the Ministry for the Environment (*Decreto del Ministro dell'Ambiente* – DMA) within the Venice-Porto Marghera SNI, which extends for about 5730 hectares. In addition to exclusively industrial areas, the SNI also includes areas that border with the lagoon. The administrative order underlines the presence in such area of chemical, petrochemical, metallurgical, electrometallurgical plants, refineries, as well as areas designated for energy production, docks and areas used as waste disposal [8-10].

The pollutants found in the SNI area of Porto Marghera have different origins and are not solely due to the industrial activity, but also to the bordering agricultural and farming activities. The Resites study, published in 2016, among the many observations, reports the analysis on the environmental contamination in the area of Marghera. In particular, the data collection following the soil survey has highlighted the presence of several groups of pollutants such as aliphatic carcinogens, chlorinated substances, hydrocarbons and dioxins. The highest concentration of these substances is found within the soil of the macro-areas that once were hosting refineries and petrochemical plants [11-17].

When focusing on the main air pollutants produced by the industries of Porto Marghera, we can list nitrogen oxides, sulphur dioxides, volatile organic compounds, chlorine and inorganic compounds of chlorine, vinyl chloride monomer, acrylonitrile and ammonia.

In the last decades, emissions of these substances have decreased. This is due to both a greater attention to environmental protection and a progressive decommissioning of many production plants.

The SENTIERI Project (National Epidemiological Study of Territories and Settlements Exposed to Pollution Risk) of the Italian National Institute of Health (*Istituto Superiore di Sanità, ISS*) carried out in collaboration with the Ministry of Health, aims at analyzing and monitoring the health conditions of populations that live close to major active and disused industrial areas, or close to contaminated areas that have been defined as SNIs.

Results of the findings of the SENTIERI Project were published in two reports in 2011 and 2014. Both publications contain a section on the SNI Porto Marghera [17, 18].

The study published in 2011 highlights an excess in the cancer incidence rate, both in men and women. Moreover, among the causes of death that are already known to be associated to an environmental exposure, from numerous studies, this work has underlined an excess in lung and pleura cancer mortality rate, in both genders. The same report also underlines a higher incidence of pleural mesothelioma in the male population residing in the city of Venice, which is most likely due to professional exposure to asbestos, as confirmed by the 2014 report. The limit of these two reports is the analysis of health effects on all residents of the city of Venice. Due to a high socioeconomic heterogeneity in the population that lives in the city of Venice, in a city-wide population-based study it is not possible to observe the impact on specific subjects at greater risk, such as industrial workers and residents in the area of Marghera. For this reason, previous works have analyzed the city of Venice, dividing it into smaller areas. These were historical divisions, especially in the insular part (the six *sestieri* or neighborhoods and the smaller islands of the lagoon) and in the mainland, the various neighborhoods, characterized by a more recent history and with a more homogeneous socioeconomic background, but with different environmental exposures.

## MATERIALS AND METHODS

In order to carry out these analyses, data from the Venetian Epidemiological Surveillance System (*Sistema Epidemiologico Integrato di Venezia* – SEIVE) was employed. This system has been active in the area of Venice since the late 90s with the aim to monitor the state of health of the Venetian population and to assess its trends [19-30].

The building of this surveillance system can be divided in 4 different phases:

1. assessment phase: assessing the availability of both current and past population healthcare registers, which was the founding element of our system, as well as the availability of current sources such as death certificates, hospital discharge records comprising passive mobility, healthcare co-payment exemption and drug prescription records database;
2. testing phase: evaluating the completeness and the quality of the registers through standard logic controls;
3. record linkage phase: linking healthcare administrative databases by cross-referencing the data from the healthcare population register, by using a standard semi-deterministic approach. This allows to link all healthcare services provided or reimbursed by the National Health Service to the study population, in order to obtain a historical reconstruction of each patient's health profile;
4. analysis phase: analyzing the data collected, by applying disease-specific algorithms. This allowed us to identify and quantify the main diseases that affect the population and to calculate their incidence and prevalence.

The SEIVE (currently updated to 31/12/2014) examines the population that was assisted in the former Venetian Local Healthcare Unit (*Unità Locale Socio Sanitaria* – ULSS 12) and that was residing in one of the four municipalities that composed said unit from 2000 to 2014 (Venice, Marcon, Quarto d'Altino and Cavallino Treporti) [21] Furthermore, the former territories of the ULSS 12 were divided into two areas (insular and mainland) and then into 20 smaller territorial units (composed of the 3 smaller municipalities of Marcon, Quarto d'Altino and Cavallino Treporti, and 17 areas of the metropolitan city of Venice). The territories were divided in the following manner:

- the municipality of Cavallino Treporti is located in the insular area;
- the municipality of Marcon is located in the mainland area;
- the municipality of Quarto d'Altino is located in the mainland area;
- the municipality of Venice is separated into an insular part, which includes 11 units among which the *sestieri* (neighborhoods) and other islands of the lagoon and a mainland area, made of 6 neighborhoods.

This study is based on the data collected from the Municipality of Venice (mainland) and analyzes separately the areas of: Favaro-Campalto, Carpenedo-Bissuola, Mestre (city center), Cipressina-Zelarino-Trivignano, Chirignago-Gazzera, Marghera-Catene-Malcontenta. Based on their residence every subject of the cohort was assigned to one of the 20 possible territorial units in order to compare differences in the health conditions of the residents between these areas.

For these analyses, in addition to the aforementioned population registers, we have used the following healthcare administrative databases:

- death certificates;
- hospital discharge records database, drug prescription database;
- healthcare co-payment exemptions;
- cancer registry of the Veneto region.

Death certificates hold diagnoses on the cause of death, coded according to the International Classification of Diseases, ninth revision, Clinical Modification (ICD-9-CM). Hospital discharge records contain up to 6 diagnostic codes for each hospitalization, coded according to the ICD-9-CM and comprise of passive mobility. Drug prescription record databases hold data on all drugs reimbursed by the National Health Service, coded according to the anatomical therapeutic chemical (ATC) classification system that provides a univocal code to identify specific active ingredients. Healthcare co-payment exemptions contain disease-specific healthcare co-payment support, registered according to a national coding system. The cancer registry holds data on the date of incidence and the type of cancer (coded according to the ICD-9-CM) for all subjects affected by cancer in the region. Information held in these databases are commonly used by algorithms to identify subjects affected by specific diseases, in population-based studies [22]. All these archives have been updated to the year 2014, apart from the cancer registry of Veneto region which is updated only to 2010. All these databases were cross-referenced with the data from the population assisted and residing in the area of the former ULSS 12 from 2000 to 2014, by means of a procedure of record linkage. The latter is employed in order to determine whether two records belonging to different data sets refer to the same person. For this paper, we have employed a semi-deterministic record linkage procedure (stepwise). In each step, the exact correspondence between the records is assessed based on a sub-group of identifier fields. This procedure has been described in detail, in a previous paper [23].

Hence, in the SEIVE each subject of the cohort under examination is linked to the records of all health-related services funded by the National Health Service.

**Mortality trends**

Based on death certificates we have analyzed mortality rates in all areas of interest for all-cause mortality (all ICD-9-CM codes excluding all external causes of death = E*). Specific rates for the main causes of death were also estimated for malignant tumors (ICD-9-CM = 140-208) and diseases of the circulatory (ICD-9-CM = 390-459) and respiratory system (ICD-9-CM = 460-519), as well as for more specific causes: lung cancer (ICD-9-CM = 162), pleural mesothelioma (ICD-9-CM = 163) and ischemic heart disease (ICD-9-CM = 410-414). Incidence rate for colorectal cancer (ICD-9-CM = 153-154) and breast cancer (ICD-9-CM = 174-175) have also been estimated. General and disease-specific mortality analyses were based on death certificates. Incidence rates of malignant tumors were estimated by means of the data held in the cancer registry of the Veneto region.

**Prevalence estimates**

Prevalence estimates were calculated for some of the main health conditions, identified by applying disease-specific algorithms, as defined in the supplement of the journal *Epidemiologia & Prevenzione* [24]. By employing the algorithms offered by the National workgroup AIE/SISMEC (Italian Epidemiological Association/Italian Society for Medical Statistics and Clinical Epidemiology), we have estimated the prevalence of:

- asthma [25];
- diabetes [26];
- chronic obstructive pulmonary disease (COPD) [27].

The prevalence of each of these diseases was calculated on a yearly basis, from 2000 to 2014. The analyses of COPD only covered the period from 2006 to 2014, since information on the number of drug prescriptions was not present for the years 2000 to 2005.

*Asthma case-identification algorithm*

The prevalence of asthma was calculated on a population aged 0-34 years. Prevalent cases were identified by employing the following sources: hospital discharge records, death certificates, drug prescription database and healthcare co-payment exemptions. In particular, for each of the years under examination, we have selected patients deceased by asthma as first cause of death in death certificates (ICD-9-CM = 493*), and we have selected all hospital discharge records that displayed asthma as main or secondary diagnosis (ICD-9-CM = 493*). Healthcare co-payment exemptions for asthma (code = 007.493) were also selected, as well as prescriptions for anti-asthmatic medications according to specific conditions, such as the presence of "at least one prescription per year of interest" of any of the following drugs:

- adrenergic drugs – inhalers (ATC = R03A*);
- adrenergic drugs for systemic use (ATC = R03CC02, R03CC04, R03CK*);
- leukotriene receptor antagonists (ATC = R03DC01, R03DC03).

In order to be considered a prevalent case, the subject had to be recorded in at least one of the four health registers in the year of interest and for drug prescription record database, satisfy the algorithm's requirements.

*Chronic obstructive pulmonary disease (COPD) case-identification algorithm*

COPD prevalence was calculated exclusively on subjects aged over 35. The sources employed are the following: hospital discharge records, death certificates and drug prescription database. For each year under review, we have selected all hospitalized subjects (ICD-9-CM = 490*-492*, 494*, 496*) as well as those hospitalized at least once in the previous four years, who were still alive on January 1st of the year of interest. We have also selected cases with COPD as main cause of death. Drug prescriptions were also considered, taking account the following criteria:

- prescriptions of at least 5 packages of drugs for obstructive airway diseases (ATC = R03*) during the year of interest and with no more than 120 days distance between the prescriptions;
- prescriptions of 3 to 10 packages of drugs for obstructive airway diseases (ATC = R03*) during the year of interest with a distance between prescription dates of 2 to 3 months;
- prescriptions of a total of 3 to 4 packages of drugs for obstructive airway diseases (ATC = R03*) during the year of interest, with a distance between the prescription dates of 4 to 6 months.

Prevalent cases of COPD were defined as subjects that satisfied the algorithm's requirements in any registry used by the algorithm.

*Diabetes case-identification algorithm*

In order to identify diabetes cases, hospital discharge records, drug prescription database and healthcare co-payment exemptions were used. From the archives, we have selected all hospitalizations in the year under review as well as those dating back to the previous four years, with a main or secondary diagnosis of diabetes (ICD-9-CM = 250*). Among the prescriptions for antidiabetic drugs during the year under review, we have selected those patients that had at least two prescriptions of drugs used in diabetes. This choice aimed at reducing false positive results and transcription errors. Lastly, from healthcare co-payment exemptions, we have selected subjects that had an exemption code for diabetes (code = 013.250) that was released during the year under review or during the previous three years. Prevalent cases were identified as subjects that had appeared in at least one of the archives used and that resulted to be alive and still residing in the area by January 1st of the analyzed year.

**Data analyses**

Data concerning residents of all areas belonging to Venice's mainland from the population health registry were linked to death certificates to estimate mortality rates and were linked to all other available healthcare administrative databases to estimate prevalence and incidence of specific diseases through case-identification algorithms.

Exposure was defined by the area of residence during the study period. Subjects that changed residence during this period, from one area to the other, were excluded from the analyses. Residence changes within the same area did not lead to exclude the subject from the analyses. All results were standardized by age (reference population: Veneto region as of the census of 2011) and the respective 95% confidence intervals (95% CI) were calculated. Point estimates of specific areas, stratified by gender and for the entire population, were then compared to a reference value calculated as the average estimate of all areas, for that stratum. Separately we compared trend differences relative to each area included in the analyses and its 95% CI. Linear regression was performed on estimates concerning prevalence algorithms. All statistical analyses were conducted with SAS software (version 9.2, SAS Institute, Cary, NC, USA).

## RESULTS

### *All-cause and cancer mortality rates*

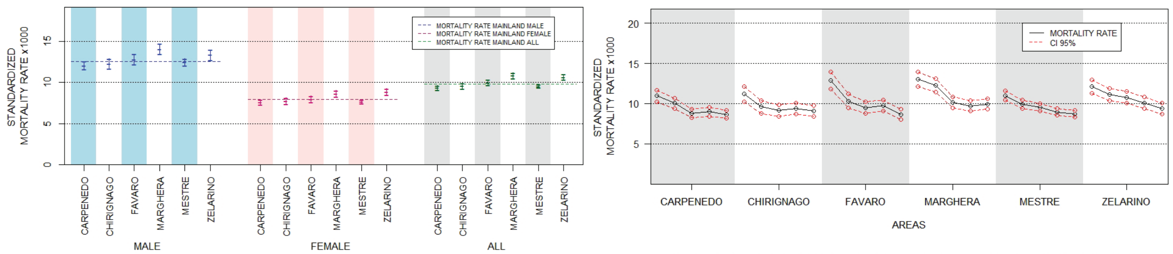
Standardized mortality rates for all causes of the population that resides in Marghera and that of the population residing in the other areas of the mainland of the city of Venice, compared to the average mortality in the mainland, stratified by gender and for men and women combined is shown in *Figure 1.1*. As shown in *Figure 1.1*, only the areas of Zelarino and Marghera present an excess in the mortality rate compared to the average mortality rate of the mainland, both in men and women. The mortality rate trend in the 15 years of follow-up is shown in *Figure 1.2*. The trend shows a decrease in the all-cause mortality rate for men and women, in all areas, throughout the entire period. The decrease is more marked in the areas where the mortality was higher at the beginning of the study period. Overall, there is a homogenization of mortality rates across all areas, that reach comparable values at the end of the study period.

*Figure 1.3* shows the mortality rate for malignant tumors and a marked excess can be observed in the male population residing in Marghera, while among the female population, the excess is less pronounced. Moreover, Marghera is the only area that shows a mortality rate that differs significantly from the rest of the mainland. While analyzing the mortality trend for malignant tumors, once again, there is an overall downward trend, despite in each area the rate decreases at a different pace *(Figure 1.4)*.

### *Mortality and incidence rates of specific types of cancer*

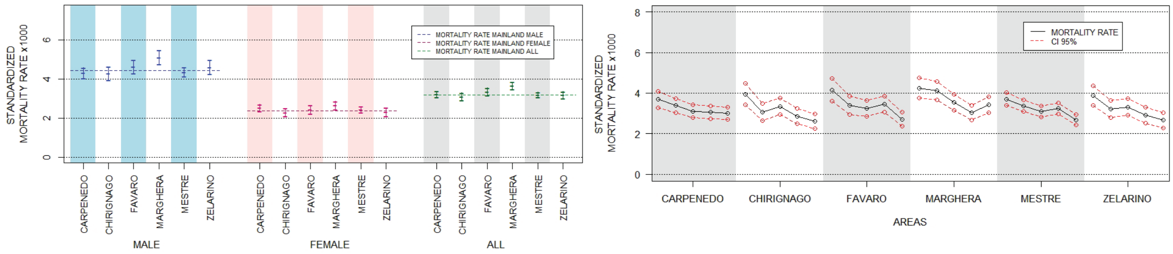
*Figure 2.1* shows the mortality rate for lung cancer. We note a significant excess of lung cancer mortality in the male population of Marghera, compared to the other areas and compared to mainland area of the Venetian ULSS. The female population as well has an excess mortality compared to the average rate of the mainland, although it remains lower than the one observed in the male population. The trend in the mortality rate for lung cancer, in the male population is shown in *Figure 2.2*. Despite very heterogeneous rates at the beginning of the study period, there is an overall downward trend, also in the area of Marghera. Nevertheless, the rate at the end of the study period remains the highest compared to the other areas.

*Figure 2.3* shows the mortality rates for pleural mesothelioma. We have only calculated the mortality rate for the entire study period because of a scarce number of



*1.1 Standardized all-cause mortality rate, Ulss 12 mainland area, years 2000-2014 - male, female, both genders divided by area*

*1.2 Trend of standardized all-cause mortality rate, Ulss 12 mainland area, years 2000-2014 - both genders divided by area*

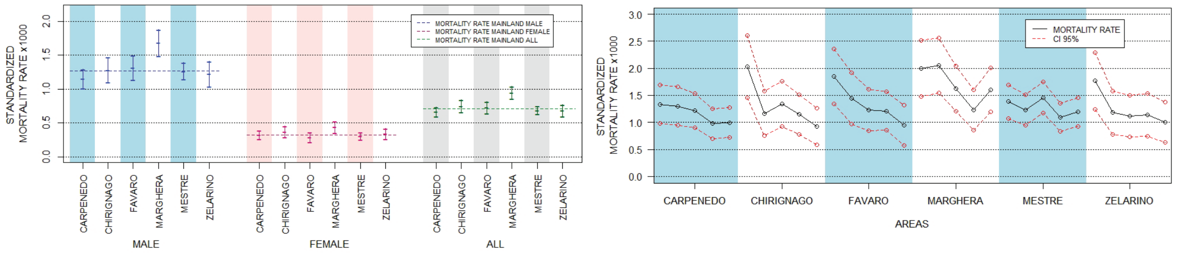


*1.3 Standardized mortality rate for malignant tumours, Ulss 12 mainland area, years 2000-2014 - male, female,* both genders divided by area

*1.4 Trend of standardized mortality rate for malignant tumours, Ulss 12 mainland area, years 2000-2014 -* both genders divided by area

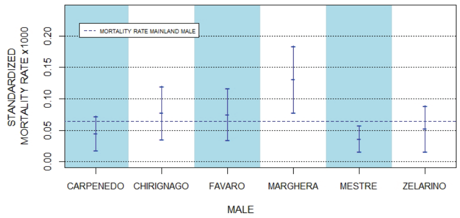
**Figure 1**

SEIVE analysis - Porto Marghera. 1.1 Standardized all-cause mortality rate, Ulss12 mainland area, years 2000-2014 - male, female, both genders divided by area. 1.2 Trend of standardized all-cause mortality rate, Ulss12 mainland area, years 2000-2014 -both genders divided by area. 1.3 Standardized malignant tumours mortality rate, Ulss12 mainland area, years 2000-2014, - male, female, both genders divided by area. 1.4 Trend of standardized malignant tumours mortality rate, Ulss12 mainland area, years 2000-2014 - both genders divided by area.



2.1 Standardized morality rate for lung cancer, Ulss 12 mainland area, years 2000-2014 - male, female, both genders divided by area

2.2 Trend of standardized mortality rate for lung cancer, Ulss 12 mainland area, years 2000-2014 - male divided by area



2.3 Standardized mortality rate for pleural mesothelioma, Ulss 12 mainland area, years 2000-2014 - male divided by area

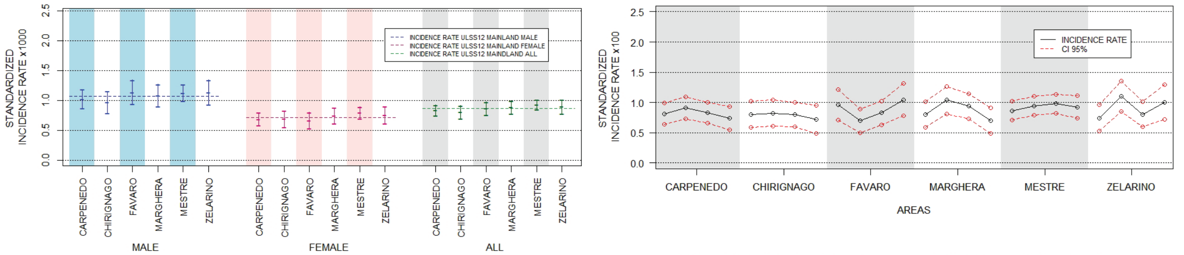
**Figure 2**

SEIVE analysis - Porto Marghera. 2.1 Standardized lung cancer mortality rate, Ulss12 mainland area, years 2000-2014 - male, female, both genders divided by area. 2.2 Trend of standardized lung cancer mortality rate, Ulss12 mainland area, years 2000-2014 - male divided by area. 2.3 Standardized pleural mesothelioma mortality rate, Ulss12 mainland area, years 2000-2014 - male divided by area.

cases affected by this disease. The figure highlights an excess in the mortality rate among the male population residing in Marghera, compared to the rest of the population living in mainland areas, despite the confidence intervals are quite large.

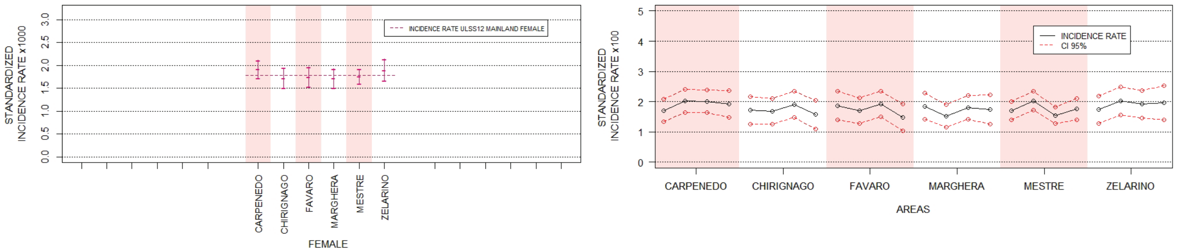
*Figures 3.1 and 3.2* show the incidence for colorectal and anal cancer for the entire study period and the 2000-2010 trend. No differences in the incidence have been observed, among the various areas in the mainland.

*Figure 3.3 and 3.4* represent the incidence of breast cancer (female population) for the entire study period and the 2000-2010 trend. Incidence rates are similar in the entire period and the trend is stable and homogenous across the areas.



3.1 Standardized mortality rate for colorectal and anal cancer, Ulss 12 mainland area, years 2000-2010 - male, female, both genders divided by area

3.2 Trend of standardized mortality rate for colorectal and anal cancer, Ulss 12 mainland area, years 2000-2010 - both genders divided by area

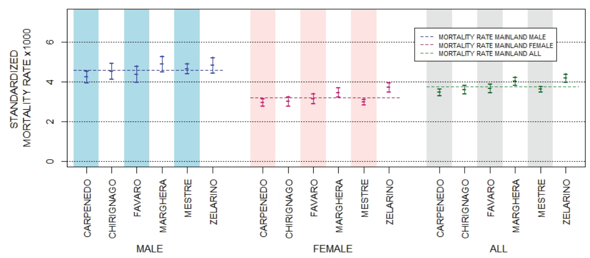


3.3 Standardized mortality rate for breast cancer, Ulss 12 mainland area, years 2000-2010 - female

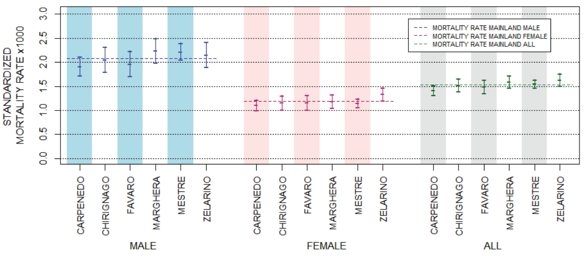
3.4 Trend of standardized mortality rate for breast cancer, Ulss 12 mainland area, years 2000-2010 -

**Figure 3**

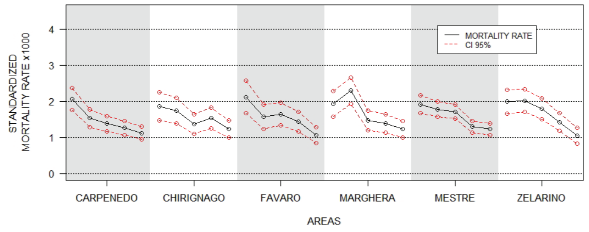
SEIVE analysis - Porto Marghera. 3.1 Standardized colorectal and anal cancer mortality rate, Ulss12 mainland area, years 2000-2010 - male, female, both genders divided by area. 3.2 Trend of standardized colorectal and anal cancer mortality rate, Ulss12 mainland area, years 2000-2010 - both genders divided by area. 3.3 Standardized breast cancer mortality rate, Ulss12 mainland area, years 2000-2010 - female divided by area. 3.4 Trend of standardized breast cancer mortality rate, Ulss12 mainland area, years 2000-2010 - female divided by area.



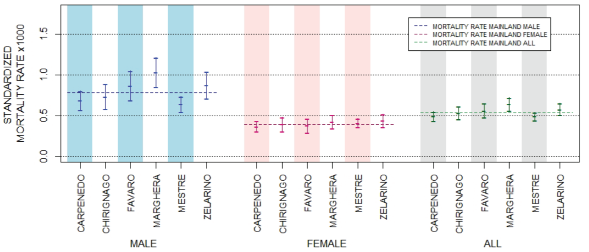
*4.1 Standardized mortality rate for cardiovascular diseases, Ulss 12 mainland area, years 2000-2014 - male, female, both genders divided by area*



*4.2 Standardized mortality rate for ischemic heart disease, Ulss 12 mainland area, years 2000-2014 - male, female, both genders divided by area*



*4.3 Trend of standardized mortality rate for ischemic heart disease, Ulss 12 mainland area, years 2000-2014 - both genders divided by area*



*4.4 Standardized mortality rate for diseases of the respiratory system, Ulss 12 mainland area, years 2000-2014 - male, female, both genders divided by area*

**Figure 4**

SEIVE analysis - Porto Marghera. 4.1 Standardized cardiovascular diseases mortality rate, Ulss12 mainland area, years 2000-2014 - male, female, both genders divided by area. 4.2 Standardized ischemic heart disease mortality rate, Ulss12 mainland area, years 2000-2014 - male, female, both genders divided by area. 4.3 Trend of standardized ischemic heart disease mortality rate, Ulss12 mainland area, years 2000-2014 - both genders divided by area. 4.4 Standardized diseases of the respiratory system mortality rate, Ulss12 mainland area, years 2000-2014 - male, female, both genders divided by area.

### *Mortality rate of the circulatory diseases and respiratory diseases*

*Figure 4.1* shows the mortality rate for diseases of the circulatory system [24]. The mortality rate among males in Marghera is not significantly different from the mortality rates observed in the rest of the mainland. On the other hand, the mortality among the female population in Marghera is slightly higher than that observed in the rest of the mainland, while the highest rate is present in Zelarino.

To further examine the diseases of the circulatory system, we have calculated mortality rates for ischemic heart disease *(Figures 4.2 and 4.3)*. No substantial differences can be observed between Marghera and the other areas in analysis, neither in the overall population, nor in the analyses stratified by gender.

*Figure 4.4* shows the mortality rate for the diseases of the respiratory system [24]. There is a significant excess in the mortality rate for the male population living in Marghera. This excess is not present in the female population.

### *Prevalence of asthma, COPD and diabetes*

We have also calculated the annual prevalence of the some common and highly impacting diseases, through the use of specific pathology algorithms.

Prevalence of asthma has slightly increased between 2000 and 2014 *(Figure 5.1)*. Residents in Marghera have similar prevalence trends compared to the other mainland areas.

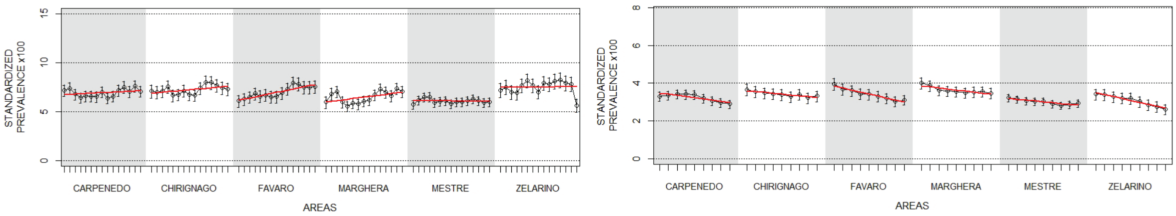
*Figure 5.2* shows the prevalence of COPD from 2006 to 2014. All areas have a similar downward trend and rates in the population of Marghera were comparable to those observed in the other areas.

Lastly, *Figure 5.3* shows the annual prevalence of diabetes between the years 2000 to 2014. There is a slight increasing trend in all the mainland of Venice. However, the prevalence of diabetes in Marghera is higher than that found in other areas.

## DISCUSSION

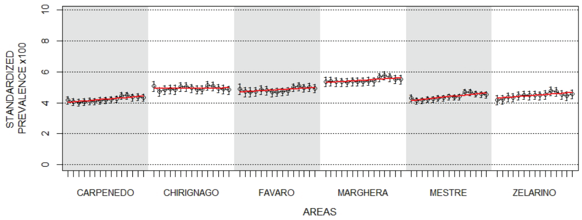
An epidemiological surveillance system allows to identify individuals affected by specific diseases in a population to rapidly observe changes in health trends. This information is essential to evaluate issues concerning overall health conditions of citizens, as well as increases in specific conditions or in specific areas, which is especially important in neighborhoods at an increased environmental risk, such as Marghera. This possibility allows to plan interventions to promote improvements in the population's health conditions and to invest in prevention campaigns.

The SEIVE's structure allows to observe trends concerning the population living in the area of Marghera alone, separately from the rest of mainland. This is an important innovation, compared to previous studies published by the SENTIERI project, which were based on aggregated data on the entire population living in the municipality of Venice, with no possibility of greater spatial resolution. Areas belonging to the municipality of Venice exhibit a profound heterogeneity [29]. It is enough to think that the *sestieri*, in which the historic city center of Venice is divided, the islands and mainland all have different backgrounds, different urban developments and types of dwellers. If these differences are not taken into account, they might act as confounding variables in the analyses of the population and might not allow to identify relevant health conditions



*5.1 Standardized prevalence of asthma, Ulss 12 mainland area, years 2000-2014 - both genders divided by area*

*5.2 Standardized prevalence of COPD, Ulss 12 mainland area, years 2000-2014 - both genders divided by area*



*5.3 Standardized prevalence of diabetes, Ulss 12 mainland area, years 2000-2014 - both genders divided by area*

**Figure 5**
SEIVE analysis - Porto Marghera. 5.1 Standardized prevalence of asthma, Ulss12 mainland area, years 2000-2014 - both genders divided by area. 5.2 Standardized prevalence of COPD, Ulss12 mainland area, years 2000-2014 - both genders divided by area. 5.3 Standardized prevalence of diabetes, Ulss12 mainland area, years 2000-2014 - both genders divided by area.

that are present in specific subgroups of the population.

The trend that emerges from the study is a general improvement of overall health conditions of the population living in the Venetian mainland. Despite greater disparities in health conditions were present in the past, we have witnessed a gradual process of homogenization. Furthermore, the areas that presented worse health conditions at the beginning of the study period, underwent a more rapid improvement and have reached health parameters similar to the areas with a higher socioeconomic status [29].

The rate of all-cause mortality is decreasing in the entire mainland, but an excess was observed for men and women residing in Marghera, compared to the rest of the mainland.

A marked increase in cancer mortality rate is evident when comparing residents in Marghera to the other mainland areas. This excess mortality is especially high in the male population.

It is noticeable, that there seems to be a slightly higher cancer mortality rate, only among the residents of Marghera. We can also detect an excess in the mortality rate for lung cancer among all residents in Marghera. In this case, the higher mortality rate of lung cancer is mainly attributable to the male population. Nevertheless, in all mainland areas, the trend of lung cancer mortality rate is homogeneously decreasing. This trend can be observed also in Marghera, where, however, we an increase in lung cancer mortality rate is present in the final phase of the observation period. This increase is most likely responsible of the increase observed in the overall cancer mortality rate, for the area of Marghera. Although lung cancer has a multifactorial genesis, in which tobacco plays an important role, many epidemiological studies have identified elevated risks associated to occupational exposures, among employees that work in refineries and in the chemical industry [30, 31].

Pleural mesothelioma is a tumor that has a well-known association with asbestos exposure. The analysis that we have carried out has shown an increased mortality rate for pleural mesothelioma in the male population living in Marghera, compared to the population living in the other mainland areas. This observed increase is understandable as Marghera was a very important harbor of the region of Veneto and the exposure to asbestos among workers that commonly lived in that area, was very relevant, especially in relation to naval constructions [32]. The reduced number of cases did not allow us to carry out analyses on the female population or to establish trends in the male population [33, 34].

We have also assessed incidence rates of other common types of cancers: colorectal and anal cancer in both genders and breast cancer in women. These types of cancers do not have an etiology that is closely related to the exposure to industrial pollutants [35, 36]. Colorectal and anal cancer incidence rate in the total population resident in Marghera is in fact consistent with the incidence rate observed in all other areas of the mainland with a stable trend over time. A similar argument can be exemplified by the breast cancer incidence in the female population, where no substantial differences can be detected in the different areas, with stable trends.

In addition to the abovementioned health conditions, the study has also calculated cardiovascular mortality rates, which are one of the main causes of death in Italy and in other high-income countries. Punctual estimates of mortality rates from cardiovascular diseases among male residents in Marghera are slightly higher, but not significantly different from the mortality rates observed among the male population in the rest of the mainland, while female mortality rates for cardiovascular diseases in Marghera are significantly higher. Mortality rates for cardiovascular diseases in the female population living in Zelarino are also elevated. These higher rates are potentially responsible for the increase in the general mortality rate of Zelarino, seen in *Figure 1.1*. The mortality rate for ischemic heart disease is similar across all mainland areas and has undergone a constant decrease and in the last study period with rates that reach comparable levels in all areas. Considering the relevance of ischemic heart disease in overall mortality, its decrease has strongly contributed to the overall decreasing trends that has been observed for all-cause mortality.

Mortality rates from respiratory diseases show an excess in the male population residing in Marghera, if compared to the rest of mainland. On the other hand, this excess risk is not present in the female population. This is likely due to occupational exposure of men living in Marghera who worked in the industrial area. Given this marked gender difference, environmental exposure seems to have played a marginal role in the genesis of this excess of respiratory mortality.

The study has employed algorithms that have been presented in the supplement of *Epidemiologia & Prevenzione* [23] to assess the prevalence of some of the most relevant chronic diseases: asthma, COPD and Diabetes. To estimate the prevalence of asthma (years 2000-2014), we have exclusively considered the population aged 0-34 years, as overlapping pharmaceutical treatments with COPD, would have led to a vast misclassification, especially for cases identified by means of drug prescriptions only [37]. A slightly increasing trend in the prevalence of asthma has been observed in all mainland areas. The prevalence of asthma in the population residing in Marghera has a similar trend to the one observed in the rest of the population of the mainland.

COPD prevalence (2006-2014) was calculated through the use of a COPD case-identification algorithm, that focused exclusively on the population aged 35 or more, always to avoid possible case misclassification with asthma. For the population of Marghera, we have not detected a higher prevalence of COPD compared to that of the other mainland areas.

Among chronic diseases, the prevalence of diabetes was also calculated through a disease-specific case-identification algorithm. It was possible to estimate the annual prevalence of diabetes from the year 2000 to 2014. As described by IDF Diabetes Atlas [38] for global trends of diabetes, our data also shows a slightly increasing prevalence of diabetes, which is common to all mainland areas of Venice. However, diabetes appears to be more prevalent in Marghera, than in the other areas, for the entire study period.

This epidemiological report shows the relevance of having an epidemiological surveillance system and the potential this tool has of analyzing in depth the heterogeneous realities that would otherwise risk to pass unnoticed. Furthermore, this study adds evidence to what has already been observed in literature, that there is a close connection between the exposure to pollutants, especially through occupational exposure as well as environmental exposure, and the development of chronic diseases and consequently worse health conditions, along with higher mortality rates.

## CONCLUSION

These analyses stem from the SEIVE, which allows to monitor a population's health state. In particular, the novelty of this study is to focus on the resident population in a subdivision of the municipality of Venice, precisely the area of Marghera, that is the closest to the SNI of Porto Marghera. By doing so, it is possible to reduce the confounding effect that derives from different socioeconomic statuses and environmental exposures, that is inevitable when considering heterogeneous populations as a whole.

Despite the presence of an overall downward trend of mortality rates in all mainland areas, with decreasing differences among the areas, the present study has highlighted a number of critical issues concerning the population residing in Marghera. Nevertheless, it is important to notice the presence of higher cancer mortality rates and especially lung cancer mortality, in Marghera, compared to the other mainland areas. Higher mortality for diseases of the respiratory system as well as mortality for pleural mesothelioma, exclusively for the male population living in the area of Marghera. Both these diseases are closely linked to exposures to carcinogenic substances among which industrial pollutants that might likely affect the former employees of Porto Marghera's industrial area.

In particular, the latest observation period of mortality from malignant tumors and that of lung cancer among residents in the area of Marghera has increased. However, to have a more complete overview of the trends, future studies with a more extensive observation period are required.

This paper also confirms the need of a regular longitudinal monitoring system, to control a population's most relevant health parameters, especially for citizens that reside in proximity to an SNI. In fact, one of the most efficient ways to record epidemiological changes over time is through longitudinal observational studies.

This paper has also raised new concerns on the health state of residents in Marghera that can only be answered by a constant update of the Venetian epidemiological surveillance system.

### *Conflict of interest statement*

Neither financial nor other relationships might lead to a conflict of interests.

*Received* on 31 May 2019.
*Accepted* on 20 April 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 168-170
DOI: 10.4415/ANN_20_02_06

# Life planning for people with neurodevelopmental and intellectual disability: effective support, quality of life, and community engagement

*Edited by Aldina Venerosi and Francesca Cirulli*

# Preface

**Ivan Brown**

*Department of Applied Disability Studies, Brock University, St. Catharines, Ontario, Canada*

It is an honour and a pleasure to be asked to introduce this monograph. The contents of the articles it contains represent recent thinking and research in the field of neurodevelopmental and intellectual disabilities (NDID) that are important to share and apply. It also affords me an opportunity to review the major trends in the field of NDID today, and to stress the importance of its principal applications.

Over the past three decades, two philosophical concepts have dominated our thinking and guided our research and practice: social inclusion and quality of life. Social inclusion represents a major shift in our thinking – away from seeing disability as "difference" and something that is devalued and unwanted in our societies, and toward seeing human diversity of all kinds (including disability) as contributing to a richer and healthier society. The central view here is that all citizens have a right to fully access the life that is common to us all but, more than that, we are all better individuals, better communities, and better societies when we adopt practices that include and involve everyone. Quality of life represents the end goal we are striving for when we put social inclusion into practice. Its core sub-concepts – life satisfaction, availability of opportunities, and freedom of choice in important areas of life across the lifespan – act as ways for us to enhance quality of life within the broader context of social inclusion.

Both social inclusion and quality of life are socially-constructed concepts. That is, they do not have concrete meaning, but rather have a meaning that we ascribe to them. But all socially-constructed concepts evolve over time in response to changing thinking, values, and conditions, and it is for this reason that they need to be re-examined and tweaked from time to time so that they are relevant to the present times and conditions. This is precisely what several of the authors in this monograph have endeavoured to do, with the article by Bertelli, Francescutti, and Brown an explicit example.

Philosophical concepts such as social inclusion and quality of life guide our thinking and sometimes our actions, but two things that are highlighted in this monograph are essential to put them into practice effectively. First, international, country-specific, and disability organization policies that set out rights, entitlements, and systems of support for people with disabilities create the environment for a better life. The United Nations' 2006 *Convention on the Rights of Persons with Disabilities* (CRPD) [1] is one of the most important international documents that has ever emerged in this regard. Its 50 Articles combine to act as the standard against which all other national and organizational policy is judged. But rights are ideals and are not always acted on. Our challenge is to ensure that they are acted on to best effect for all, and, perhaps even more important, that they are acted on in person-centred ways that respond to the characteristics and needs of individuals.

Second, for rights to be acted on effectively there needs to be commitment from governments, social service organizations, the education sector, and even the business sector. Applied rights need new models of organizing services, providing care, and allocating funds that respond to individual conditions and to changing social and economic conditions, and these need to be constantly generated and assessed. Genuine attempts to explore new models are represented by the contributions of Cappa *et al.*, Varrucciu *et al.* and of Camoni and Venerosi, and are accentuated by the interesting alternative in social agriculture described by Borgi *et al.* Two areas of social functioning that are particularly important to applying rights, and the philosophical concepts that underlie them, are those that almost every citizen participates in to some degree: school and work. The article by Laghi stresses the importance of both, and it sets out some practical ways to apply rights and principles in a useful and inclusive way.

It is individuals with NDID who experience both social inclusion and quality of life in a personal way, and the focus of our field needs to be kept on ensuring that they are able to do so. As such, the ultimate measures of success for all our efforts and endeavours are the an-

*Address for correspondence:* Ivan Brown, Department of Applied Disability Studies, Brock University, 1812 Sir Isaac Brock Way, St. Catharines, ON L2S 3A1 Canada. E-mail: ivan.brown@live.ca.

swers to the questions: "Do they feel truly included?" and "Are they leading lives that they consider to be of high quality?". But people's lives do not unfold in isolation, and the degree to which these questions are answered in a positive way often relies on the immediate context of their lives – the family for children and the family or other close others for adults. As exemplified by the Ferraro *et al*., and the Leoni *et al*. articles, the field of NDID has recognized the importance of family and caregiver quality of life since 2000 as the immediate environment within which inclusion and quality of life can flourish (or languish) for people with NDID. The personal and professional lives of family members and close others are highly affected by the very presence of disability and the support they provide, and, in turn, they are in the best position to understand the unique aspects of individual and family life that contribute to both inclusion and quality (see Bertelli *et al*.). The Alzani and Cavagnola article highlights the importance of understanding that the process of providing care and a nurturing environment needs to evolve over the lifespan of individuals with NDID and those who share their closest personal relationships, because life-stage needs and the circumstances within which they unfold change over time.

The field of NDID is not without future challenges. Three of these, in particular, come to light implicitly or explicitly in the articles of this monograph. First, family life is critically important, but it is not always ideal. What Robert Cummins [2] calls the "golden triangle of happiness" eludes some families: they struggle financially or receive financial support that is not individualized enough to meet their needs, they experience severed personal relationships, or they struggle to identify a positive meaning to disability and to their family life. In addition, not all family members are willing or able to provide positive care and a quality living environment that promotes social inclusion. How to support families and caregivers in the best way requires ongoing focus, experimentation, and assessment. Second, although inclusive education is becoming the usual practice, at least in the more developed countries, the quality of the educational experience has only begun to be examined in both theoretical and practical ways [3]. For children, particularly, the school environment is without doubt the most important environment outside the family for fostering social inclusion and quality of life. We need to learn the multiple ways that we can foster both in creative and productive ways, thereby applying aspects of the CRPD that address the right to education. Third, how to find meaningful roles for people with NDID as they live their adult and senior years has often eluded us to date. Large numbers of people with disability are not employed in our market-driven economies, despite sustained efforts by disability organizations to find jobs and willing employers. Other ways that adults with NDID can contribute to the betterment of their immediate environments to their larger societies is often not a strong focus of our research or our applied work. The ultimate question here is how people with NDID attribute positive purpose and meaning to their lives, how they experience a feeling of being worthwhile and valued, and how they understand that their life makes a contribution to the human condition.

The explosion of knowledge and practice in recent years in the areas of human anatomy, disease prevention, and especially genetics are having a strong influence on the ways we think about disability. The human genome – the approximately 25 000 genes contained in the nucleus of most cells of our bodies – has been mapped, and we now understand the causes and contributing factors of more than 300 neurodevelopmental disorders [4]. We can already identify a great many of these prenatally, and some genetic interventions can be carried out at this early stage of development. Gene therapies and stem-cell therapies are gaining in both acceptance and effectiveness. Genetic manipulation is a common practice in vegetable, fruit, and animal production, and thus in the foods that we eat. It seems highly likely, although illegal in most countries at this point in time, that it will be scientifically possible before long to carry out at least some genetic manipulation of our species itself. In other words, the means to prevent or amend some disabilities by identifying their causes and intervening in their development appears to be a future reality [5]. Thus, as we focus on the social inclusion and quality of life of people with disabilities and that of their family members and closest associates, we need also to be mindful of the fact that there is a strong wave of "progress" that appears to be working against valuing disability and even against the presence of disability within our cultures.

Speaking out for the positive experience of disability to out broader culture and the positive contribution it makes to the lives of individuals, as occurs throughout this monograph, is an important way to ensure that disability is not devalued. Disability is a reality in our current cultures, and it will continue to be as far as we can see into the future. Our focus must remain on finding valued ways for disability to contribute to the way we currently live, and on finding ways for people with disabilities themselves to experience the full enjoyment of human life.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 171-179
DOI: 10.4415/ANN_20_02_07

# Life-long individual planning in children with developmental disability: the active role of parents in the Italian experience

**Maurizio Ferraro[1], Barbara Trimarco[1], Maria Carla Morganti[2], Giovanni Marino[3], Pasqualina Pace[3] and Letizia Marino[3]**

[1]*Cooperativa Sociale Giuseppe Garibaldi, Rome, Italy*
[2]*Autismo Firenze, Florence, Italy*
[3]*Fondazione Marino ONLUS, Reggio Calabria, Italy*

**Abstract**
Many young adults with neurodevelopmental disorders experience poor transition outcomes in key areas, including employment, health care, and independent living. Innovative welfare models highlight the importance of involving the local community, and in particular the parents, as important stakeholders capable to generate services and affect local economy. As indicated by the World Health Organization, the availability of person-centered responses, also providing a health budget, appears to be the basis for taking into account person's rights to self-determination. Health services and local stakeholders could play an important role to facilitate the implementation of support networks that are functional for an effective social inclusion. In order to improve current practices in transitioning to adulthood, it is of paramount importance to collect and learn from the living experience of people with neurodevelopmental disabilities and their families.

**Key words**
- employment
- social value
- services
- neurodevelopmental disability
- entrepreneurship

## INTRODUCTION

The growing prevalence of young adults with autism spectrum disorders (ASD) calls for increased efforts to improve transition programs and appropriate support strategies. Researchers in quantitative studies have established an evidence base documenting poor outcomes and identified a range of contributing factors, including a lack of financial resources, low parent expectations and involvement and poor interagency collaboration between high schools and adult service providers (for a review on the transition of individuals with ASD see [1]). In many countries, budgetary spending cuts of the National Health Systems are the most urgent concern, while continuity of care remains another big issue for parents. Difficulties in the recruitment and retention of tutors, mainly due to reduced social care funding and low wages, threaten the relationship with ASD individuals. Constant changes in personnel make it difficult to create stable relationships with the person they support and their family, and to understand what works best for them. In particular, some studies reveal the need for services to help families and young adults preparing for and understanding the transition process [2]. Inappropriate assessments of children's needs have a profound impact on provision of care and life-long individual planning. Living arrangements are a further important issue that emerges from parents' perspective. Considering that young persons with ASD might need ongoing support in their daily lives, some families accept community home solutions, although a semi-independent flat or studio within the family unit, or even independent living in their own home, represent further aspirations [3].

In Italy, about 5 million (38%) of disabled people aged 15 to 64 years do not work and do not attend training courses [4]. Parents call for policies and services focused on maximising the participation in higher education, employment and independent living, giving opportunities to thrive in the areas of work and study. Environmental intervention and person-centered and individualised approaches could be the right approach to accomplish the best results for their children [3]. Flexible work practices tailored to the needs of the individual with neurodevelopmental disability can facilitate workplace success as well as being advantageous for the individual because employment is a major determinant of well-being and health and has a social and inclusive impact [5]. Although it is agreed that young adults with ASD thrive in flexible and tolerant environments, current options do not always fit the individuals' requirements and personal abilities. Incorporating principles of person-centered planning in adult services and

*Address for correspondence*: Giovanni Marino, Fondazione Marino ONLUS, Prunella di Melito Porto Salvo (RC), Reggio Calabria, Italy. E-mail: fondazionemarino@gmail.com.

programs may help practitioners tailor supports to the needs of individuals. Person-centered planning is an approach to supporting people with disabilities that emphasizes individual choice and community engagement (see [6] for school-life transitioning in ASD).

Some authors [7] have noted that microenterprises can be a suitable mean for people to find their own workplace environment, best suiting the needs of the person. Introduction of a personal health budget [8] endorses this microenterprise model where a person with special needs could be involved individually or as a group in a meaningful workplace characterised by a relative control over risks, cost estimates, and outcomes forecast, but providing individually tailored support and social inclusion. In order to achieve this goal, external resources are required and a personal health budget could help meeting support costs. Overall, we need to promote a business model that considers achieving quality of life and inclusion as a mission and a value of the enterprise. This needs enterprises to evolve from an exclusively profit-driven business to a model which includes consideration of social value, alongside economic outcomes. In Italy, these experiences have been consolidated by Third sector, particularly in the agricultural sector (social farms) [9]. Notably compared to other countries, Italy has many examples of work inclusion in the private sector [10].

The closest implementation of a private microenterprise model in Italy has being achieved thanks to the initiative of the parents. These represent sporadic experiences, most of them mediated by groups of parents (associations, cooperatives, foundations), and represent examples of good practices characterised by a high awareness and implementation of the current scientific recommendations and strong flexibility to best fit individual strengths and job skills. These experiences suffer the lack of an adequate network of services and funding, all conditions that put at risk their sustainability, in spite of their ability to produce "social goods".

Compared to other European countries, the Italian experience is rather peculiar. As an example, in countries such as UK, not-for profit advocacy organizations play a very important role in collecting family voices and needs, as well as coordinating services and opportunities for life planning. In Italy, by contrast, the activity of charities and advocacy groups are scattered, due to geographical and historical as well as political reasons. In the US multi-family group psychoeducation models have been produced which involve education on a variety of topics relevant to transition planning and ASD as well as guided practice in helping families to problem-solve around current difficulties and stress [11].

Notwithstanding the reported models, many experiences have a hard time becoming good practices that can be taken up at the regional or national levels. It is thus of paramount importance to report some of the experiences characterizing ASD transitioning to adult life in Italy. In the present paper three examples of good practices implemented by parents' associations are presented as narrative reports. They describe the attempt to tackle the critical time of transition from the young to the adult stage, when individuals need to move from school and parents supervision to independent life. These examples, although providing qualitative data, testify, in a narrative way, the importance of fostering participatory networking between the parents, health and social professionals, private microenterprises and not for profit organizations to favour transition of individuals with autism to adulthood.

## CASADASÈ. A FLEXIBLE FRAMEWORK TO MANAGE THE TRANSITION TOWARDS AUTONOMY

"Autismo Firenze" was born in 2003 as an association of families with grown up children, already out of school, or about to finish. Our experience of school integration was generally a negative one: none of the children integrated themselves within the class and only a few obtained some results on a personal level; the approach was generic, the work was often improvised, impossible to verify through results and disconnected from everyday life and its great difficulties.

However, school structured their time, it was a place other than home to go to every day, it offered an environment with numerous and diverse people. In the absence of school attendance, many hours of the day remain empty and parents' main occupation became the search for possible activities to put in place: from various "therapies" (hippotherapy/music therapy/art therapy), through outings with specialised educators (who were difficult to find and instruct, and couldn't be relied on for regular availability), to planning family activities around inevitable gaps. We managed to fill up the time somehow or other, but the day was fragmented into many activities, which were not oriented towards a purposeful goal: it lacked a project, which was all the more necessary given the extremely difficult period of transition our children were facing.

A deterioration of their condition over time seemed inevitable to us, while their families would become less and less able to support them due to ageing.

The idea of a Centre, which is today Casadasé, was born from the difficult situation many parents were facing, especially in relation to problematic behaviours that occurred for the first time or were becoming more frequent. At the same time, however, we believed that in all of them there were still many capabilities to develop: at that time, at least among us, discussions on rehabilitation also during adulthood started.

Our Centre would work to achieve the greatest possible autonomy for each young person, in anticipation of adult life, directing educational intervention to tangible and useful objectives, valuable for that individual person, for their needs and preferences; the educational process would be clear in all its steps. A scientifically validated approach, a careful assessment of the person, an individual program explaining objectives and strategies, continuous monitoring through collection and elaboration of data and, at the end of the process, a life plan preferably focused on work either in a natural or protected environment.

We wanted a real focus on families, who partake in the whole educational process starting from the skills evaluation which is videotaped and shared during the final review meeting. Relatives are asked to work on the generalisation of the skills learnt at Casadasé through specific programs and tools developed for them; potential changes to the ongoing plan would be discussed with them, as well as an annual evaluation in June and a new plan proposal in September. At all times, families have access to meetings with the supervisor (who also carries out regular sessions of parent training), as well as the management and the workers.

A different role for the educators was sought, more active: by focusing on their expertise it has been possible to create a framework with no intermediaries in which educators develop and are responsible for all the stages of the intervention.

Casadasé is a flexible framework: it takes on young people who are at least 18 years old (often one year in advance so that they can adjust to the service while alternating attendance with school). There is not a maximum age limit (given that there are still many young adults who, having finished school, remained at home without any kind of support); it receives individuals with different skill levels, from non-verbal with behavioural problems to high-functioning individuals with peaks of excellence; it envisages varying the frequency of attendance according to the individual plan requirement. Today 40 young adults, 13 of them high-functioning, attend Casadasé. The educational intervention affects all areas of life; self-care and care of their living environment, physical well-being, the cognitive and affective spheres, skills and inclinations towards future work.

We apply an integrated system of intervention based on behavioural standards with reference to applied behavioural analysis and the TEACCH behavioural strategies.

Data collection is a characteristic that runs through all the activities of Casadasé. It seems like a technical matter, but actually it is the result of a call for clarity from the families. Collecting data related to the educational activities means being able to objectively present achievements and provide the families with factual information which is reliable and therefore useful. In relation to work planning, it means being able to evaluate the effectiveness of the intervention in real-time and make any variation promptly, while also ensuring the effectiveness and interchangeability of the educators, by informing them from which point to resume work that may have been carried out by a colleague in the previous session.

The work of Casadasé is integrated within the project "School of Life": the National Rail agreed to loan for use (project "Volunteers in the Station") an apartment in Figline Valdarno, a town about 25 kilometres from Florence. Our young people, in groups from 4 to 6 individuals, spend 24 hours in a natural environment, a house without the visual aids and structure present in Casadasé, with the educators in the role of observers. "School of Life" has proved to be a valuable tool for assessing the process of generalisation of the skills learnt at Casadasé, and more generally, to get to know the young people better and update the ongoing educational projects. Both high-functioning individuals and those at a medium-low level take part in the project. Attendance is on a monthly basis and at present there are 4 groups; members are included as soon as they achieve the minimum necessary skills.

We have been working for about 7 years: the project "Autonomy", which envisaged the creation of a Centre devoted to autism in adult age, was presented to the Region in 2008 and Casadasé started its activities in May 2011 as a pilot project. The Association manages the structure through the Board of Governors (*Consiglio Direttivo*) deriving its authority from the members' Assembly, which approves the annual budget and moral report. The operational management is entrusted to the Board of Directors (*Direzione*), formed of the Director of Health, the Coordinator and President of the Board of Governors, who acts as a bridge between the two institutions.

From a technical point of view, since 2001 the framework has evolved and the characteristics we prefigured have gradually been specified and achieved in practice. Activities, strategies and tools are tested and retained or abandoned on a case-by-case basis through a continuous updating process. We produce, for example, specific work tools for each activity area, often studied for individual cases; we have created a "library" of over 500 folders and work kits to date, which are real tools for a structured approach to learning. It is a continuous production and 6 young people, 3 of them medium-low functioning, work on it. Precisely these 3 individuals – who work half a day 5 days a week to photocopy, crop, laminate and assemble the folders – indicate that even with limited skills it is possible to carry on a real job. Our environment is protected, designed to guarantee the best conditions for these special workers, but they work in complete autonomy, asking the educators for help only if needed, just like any worker would do with their team leader. In total, we have achieved 13 socio-therapeutic placements, 3 internships and 5 regular contracts.

For placements outside of Casadasé, our educators are responsible for tutoring for as long as necessary and stay at the disposal of employers to resolve any possible issues. This is a form of "protection", but it is occasional and does not weaken the worker's autonomy and it is a great result for a small price to pay, considering how often even high-functioning individuals lose their jobs, for instance because of unexpected changes in the work environment or social misunderstandings.

Regarding the results, we can say that all of our young people have achieved significant improvement in all areas affected by the educational intervention and that learning has been generalised and in the majority of cases achieved within a small period. The young people have either declared their satisfaction, or their appreciation is otherwise clear, and we have received very encouraging feedback from questionnaires submitted to the families.

The progressive establishment of Casadasé is also due to the increasing recognition from public institutions: we collaborate with the School, Social Services and the Department of Mental Health, which forwards the majority of the requests to join the program. Together with the Town and County Councils, we are carrying out projects to improve accessibility by training courses for Museums and Public Entities (the project to improve accessibility to Florence airport is already completed). In particular, we studied itineraries for people with autism, both low and high-functioning, for the Uffizi Gallery, the Museum of the Opera Del Duomo and (on a case by case basis) certain exhibitions at Palazzo Strozzi. These itineraries are open to Associations, Centres, Schools and Families.

In the past year, through the process of authorisation and accreditation we stipulated a convention with the Local Health Authority (USL), overcoming the previous economic insecurity stemming from the experimental nature of the initial project. The Convention provides a grant based on the number of standard users (with daily attendance for the whole week) equivalent to the highest number of effective users (with variable attendance during the day and the week). Today there are 16 equivalent users corresponding to 40 effective users.

We are well aware that the issue of effectively taking care of a person with autism is far from being resolved. When we talk about life plans we are aware that they should be developed by many entities with different competencies and that adequate resources are needed to implement them. However, even without talking about such a challenging plan, today there simply are not any places with structured environments, such as day centres or residential centres, for people with severe autism that are not merely assisted living facilities. Casadasé takes charge of only a part of the process, but we believe that when a more appropriate way to take care of people with autism will be achieved, Casadasé could find a functional role within a broader process. After all, we can present the experience of Casadasé precisely because it is confined, concrete, clear and thus easy to replicate if desired.

## SOCIAL AND WORKING INCLUSION FOR YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER (ADS) REQUIRING VERY SUBSTANTIAL SUPPORT. THE SOCIAL FARM COOPERATIVE GIUSEPPE GARIBALDI

The Social Cooperative Giuseppe Garibaldi has the objective to promote social and working inclusion of young adults with Autism Spectrum Disorder (ASD) requiring very substantial support. The path that led to the foundation of the Cooperative began during high school. A group of parents of adolescents with ASD requiring very substantial support met each other while their children were attending an agricultural high school (ITAS Giuseppe Garibaldi, Rome).

According to the Italian law 104/1992 [12], every student with a certified disability should be provided with Individualized Educational Program (*Piano Educativo Individualizzato* – PEI). The PEI identifies individualized tools, tactics and methods to accomplish an optimal learning environment in the following dimensions: relationships, socialization, communication, interaction, orientation and autonomy. The same law also establishes a working group for school integration (GLH) for each student with disability enrolled in the school. The working group is composed of the Headmaster or a delegate, the Class Council or, in its representation, one or more curricular teachers or the support teacher, the healthcare operators following the case and the pupil's parents. In addition, eventual educational-assistance operators and/or technicians provided by the Municipality, school collaborators and desirably all other institutional and professional figures of interest for the inclusion of the pupil participate in the working group.

During the high school years, with the help and supervision of The Department of Social and Developmental Psychology of Sapienza University, a group of parents and their children were able to experience, by their PEI, habilitative and support interventions, such as Parent training, Parent counseling and Peer mediated intervention (PMI). All of these interventions are object of research studies that indicate positive evidences, though a restricted number of controlled studies are available.

For the parents who, later, founded the Cooperative, PEI and GLH were the preparatory resources for planning the social and working inclusion after school. The efforts of these parents showed that a good use of these tools, guaranteed by the Italian legislation, are able to prepare the continuity of social inclusion during the transition from school to work. The Individual Project (*Piano Assistenziale Individuale* - PAI, as defined by the Italian law 328/2000 [13], represents the keystone for this continuity. According to the law, the local authority (Municipality), together with the local sanitary district, individualizes the social and health services to the specific needs of the individual with disability to develop the Individual project. The objective of the Individual Project is the successful inclusion of the person with disability in family, social, educational and working contexts.

When high school came to an end for this group of adolescents, their parents had no support to continue their children's habilitation process from a legislative and institutional viewpoint. The only opportunity given by the national health system was the adult day care service, where one health worker or one educator takes care of various individuals with disabilities. Nevertheless, the activities offered by this kind of services do not consider social and working inclusion as a central goal, on the contrary this was the main objective for this group of parents for their daughters and sons, so they needed a different option.

Therefore, the critical moment for the foundation of the Cooperative was the end of high school. The parents obtained the management of a part of the field belonging to the agricultural high school previously attended by their children and established the Social Cooperative Giuseppe Garibaldi in which half of the members of the Cooperative are young adults with ASD requiring very substantial support. The main Cooperative business is agritourist service and agricultural production. Every family has its own resources and has an active role in their management. Young adults with ASD receive disability pensions. Additionally, these families requested and obtained the activation of a specific type of assistance (indirect assistance through a small voucher), active in the city of Rome, namely the Autonomy and Social Inclusion Service of the Person with Disability (SAISH), for their children. This service can be provided either directly through an operator, chosen by the social assistance system, or as indirect assistance, through the definition of a financial support which allows the family to choose their own operator. The SAISH service is usually considered a home care assistance service for non-self-sufficient individuals. The families of the Cooperative requested and obtained that this service could be given to the individual not only at home, for personal autonomy needs, but also in other contexts, where these operators can be of support for social and working inclusion, opening the way for new welfare solutions. However, it should be emphasized that in the case of the families of the Cooperative the individual project is completely projected and self-managed by the families and does not require any services, except for the indirect assistance above mentioned. This indirect financial assistance is weighted on the degree of disability and covers the cost of individual care attendant, who has the role of individual tutor in the Cooperative activities. The Cooperative has not formal agreement with Local Health Authority or Municipality to provide services to people with disabilities. The Cooperative is made up of the individual projects brought in by the children.

The Cooperative supports the individualization of the habilitative process following the principle that the objectives and the strategies to accomplish them must be tailored on the specific individual's needs and abilities. In line with this principle of individualization, in the last few years the Cooperative has been using the Collaborative Model for Promoting Competence and Success (COMPASS) in an adapted version for young adults and working contexts [14]. This model has been successful in improving accomplishment of individual educational planning goals in pre-school and elementary school settings [15]. The adaptation was provided by The Department of Developmental and Social Psychology of Sapienza University, that has subsequently been monitoring the Cooperative activities through the years and after the transition to post-school experience. This model allows for the individualization of the goals and the selection of specific educational strategies. The accomplishment of the goals of each individual is continuously monitored and the goals are regularly updated.

The Cooperative has collaborated with research institutions, such as Sapienza University and Istituto Superiore di Sanità (ISS), for the implementation of a project financed by the European Community (i.e. European Social Fund) aimed at implementing innovative strategies for individual planning of disabled people in rural context. Through the years, the support of these institutions has been central for the adoption of a scientific monitoring of the of the Cooperative actions, in addition to providing training opportunities for families and tutors.

The good practices of the Cooperative include: i) every young adult with ASD has his/her own tutor, who has the role to facilitate the habilitative process and the accomplishment of the individualized goals, ii) the family actively participates in the habilitative process, iii) team work (parent-educator-consultant psychologist-young adult) is promoted.

The Cooperative activities are aimed at integrating practices used in individual rehabilitation. Thus, the foundation and growth of the Cooperative gradually developed a real inclusive reality, which has been more and more open towards the citizens and the local community, such as the schools, in addition to attracting volunteers from foreign countries.

Recently, the results of a survey performed by the economy, management and social innovation Master of the University Tor Vergata, clearly indicate that the Cooperative is better described as a "Community Cooperative" rather than a "social enterprise". As such, it relies on the production of the "social goods" rather than "economic goods". Its sustainability relies on the individual contribution of the partners and donations which limit its economic sustainability and its further development with social disabilities into agriculture. The central goals are social and working inclusion of individuals with ASD, but these activities also have the objective of promoting educational and cultural services to support families and educational institutions. The Cooperative maintains a new and different idea of enterprise, more responsible and linked to the needs of local communities. This path is made possible through the particular nature of social agriculture, which consists in the production of public goods connected to the life of the community and the territory. The fact that the Cooperative is a real agricultural company promotes an open attitude: the members of the Cooperative, with and without ASD, interact with the people living and working in the local area by selling agricultural food products in the city farmers markets, by serving the tables in the Cooperative restaurant and by working in the field side by side with the people growing vegetables in an urban vegetable.

The opportunity for social and working integration for a group of young adults with ASD is made possible through the active action of the cooperative members to keep the Cooperative active, despite administrative and economic management difficulties. Hopefully, in a near future, the public administration, as it has already happened in other Italian regions, will play a more active role in favoring the network of services which may facilitate active involvement of the individual and her/his parents, in promoting the sustainability of these spontaneous initiatives.

## THE FONDAZIONE MARINO PROJECT: FORGING THE PATH TOWARDS AN INDEPENDENT LIFESTYLE FOR PEOPLE WITH INTELLECTUAL AND NEURODEVELOPMENTAL DISABILITIES

Autism is a disorder leading to a permanent disability and manifests itself in different ways and with different levels of severity. We often think of autism as a developmental disorder, forgetting that the child will eventually become an adult affected by autism: the sooner we intervene on it, the better the outcomes will be. Thinking about a child's future means building adequate and competent paths, which could lead him/her to the adult life with cognitive, relational and professional tools useful to express him/herself and fully live his/her life.

In recent years, research advances in the conceptualization of the disorder, has contributed to prevent families from feeling directly responsible for their children's disorder, framing it as a complex and definite diagnostic entity, with an organic base in which genetic and environmental risk factors concur manner. However, families still carry the burden of organising a comprehensive support which although explicitly stated in one of the most complete regulatory framework in the international scene, is still slow to become a reality. Therefore, families are left alone in trying to think about and build the future of their children.

### *The Marino Foundation for Autism ONLUS*

The Marino Foundation for Autism ONLUS is a high-integration, residential health facility with rehabilitation and enabling purposes, which has been operational since the 4th August 2008. It is currently accredited by and agreed upon the Provincial Health Authority (ASP 5) of Reggio Calabria as a residential centre, which provides people affected by autism with continuous care. It also delivers cognitive-behavioural interventions, in line with the international scientific recommendations and evidences.

The Marino Foundation for Autism ONLUS was started by a couple of parents having two children affected by autism to create an environment to foster their children, creating an environment that could help them also in the transition to adulthood. This family wanted to interpret the needs and difficulties of other families who find themselves foreseeing what would happen in the future, when their children will be alone in the desert of a social care system, which does not respond to the life-time perspective of autism. The model of the Foundation follows a main philosophy: the search for well-being and the highest level of self-determination for each of the young people living there.

The realization of the Marino Foundation's residential service did not start from a pre-established model; it is rather based on the idea of a parent, who developed the design and suggested precise choices, which move from the reality of a family that has been living in contact with autism. The Marino Foundation shares and adheres to the principles established by the Convention on the Rights of Persons with Disabilities adopted by the UN in December 2006. It has a Code of Ethics to which all users are bound.

The aspects that acted as a framework in the fulfilment and sustainability of the project concern:

- the presence of the family in the management of the service;
- location and size;
- specificity and adequacy of the intervention in the various stages of adulthood;
- acquisition and enhancement of capabilities;
- job placement;
- social inclusion.

The philosophy and practice of intervention is defined first and foremost by the direct involvement of parents in the management of the service, putting in place the professional and personal experience deriving from their direct contact with and knowledge of the autistic disorder from within. No professionalism can ever equal the attention in care, assistance and rehabilitation of a parent, who always looks for a higher and higher level of professional skills and humanity. This element differentiates Marino Foundation from a prevalent bureaucratic-administrative and rehabilitative management, including an interest centered on the fulfilment and well-being of the person affected by autism, which represents the regulating principle for all those people who contributed to build such an enterprise. In order to promote this kind of management the Marino Foundation, by statute, takes the form of a Social Enterprise participated by the community to guarantee continuity and cautious management. In addition to the founding partner registers the participation of the Province of Reggio Calabria, the Municipality of Melito Porto Salvo, and the Parish in the figure of the Archpriest as supporting members. Each of them owns the right to appoint a representative in the Board of Directors and to take charge of the management in case the founding partner is absent, through the appointment of the Board of Directors and its Chairman.

The choice of an adequate residential area represents a complex and delicate topic: this choice is often accompanied by a certain mental rigidity due to – and justified by – the vision and experience of a residence that does not resemble a typical home, excluding participation to the social environment and to life itself. In this regard, the Marino Foundation follows the perspective of building a real home, a personal place including affections, history, choices and acquisition of skills. In this home, the family has a relevant role in the path towards the acquisition of independence outside the household, showing its continuous presence to the child during this phase. Parents can access the facility at any time and without a pre-announcement when they desire to share small daily moments with their child; they can participate in the drafting of their child's life project by suggesting precise choices and indications and are regularly informed about the child's progresses.

The Marino Foundation facility has a particular location and particular dimensions. The structure is located on the slopes of a hill, adjacent to an urban settlement. It is 1800 metres from the sea and includes a park of 6000 square metres around. The small size of the town in which it is located facilitates the processes of inclusion, keeping away the frenetic pace of the city; however, it is possible to reach the city centre in a few minutes. Its architecture is similar to that of a common house with welcoming and safe environments, fitting the needs and difficulties of children and meeting the safety standards. The structure is built on three floors: the ground floor is entirely dedicated to work activities. It includes structured environments within which the activities foreseen by individualized projects drawn up on the basis of the needs and emerging skills of the child are carried out daily. In order to achieve the goals foreseen by these projects, cognitive - behavioural procedures are performed. On this floor, there is also a gym for physical activities.

The first floor includes a medical office, rooms for social and psycho-educational assessments, a dining room, a kitchen, a music and relaxation room, a television room. Here, there is also a wide courtyard; part of the courtyard is covered by an insulated roof and another part is cultivated with grass lawn. On the second floor there are bedrooms and a laundry service. Each bedroom has two beds with independent sanitary facilities. On this floor there is also a room equipped with a monitoring system linked to all bedrooms, which is occupied by an operator at nights and through which it is possible to control the children constantly and discreetly. The monitoring system represents a valid working tool, and allows the families to view the child's room from home, by connecting to the system through the internet.

The structure is equipped with a swimming pool that is used both by the children who carry out various activities followed by a specialized operator, and by external people for their motor and hydrotherapy rehabilitation. The idea of providing a service that is open to the community stems from the desire to open the doors to a new culture of illness and disability. Only by knowing the disability and, above all, by knowing people with disabilities, we can learn to love them, accept diversity and avoid labels. The workspace extends to an outdoor area, surrounded by greenery, where are held the laboratories of horticulture and production of ceramics, paper and pasta.

The maximum number of people that can be admitted to our facility is ten; this low number responds to one of the starting hypothesis, supported by international research, to give the residence the aspect of a condominium in order to prevent the "pulverization" of the medical and enabling intervention. This makes it possible to guarantee an increased attention and quality of services to each of our guests.

The current dedicated organizational model clearly reflects our de-medicalized perspective of the intervention, promoting a strongly educational approach; as a matter of fact, our staff includes seven professional educators, three health and social care workers and an auxiliary. More specifically, the general operating staff is composed of a coordinator of the psycho-educational team, a psychologist, a general practitioner, a social worker, a psychiatric rehabilitation therapist, six educators, three health and social care workers, an auxiliary and a gardener. The Marino Foundation has preferred not to include the figure of a professional nurse in its staff, favouring the presence of one more educator and a full time-employed psychologist. The psycho-educational team is responsible for carrying out the functional assessment and for drafting the individualized project that must be read and shared by the family. The choice to include a qualified doctor in the staff stems from the awareness that the person affected by autism, can also contract other various diseases as any non-disabled person during the course of his/her life; the only drawback is represented by the serious communication difficulties of an autistic person, who often cannot reveal the symptomatology, which is expressed through problem-behaviours. By direct observation of the children, a consistent number of pathologies have been detected which could have led to dysfunctional behaviours. The consequent observation and treatment of these pathologies has eliminated the discomfort and drastically reduced the issue of problem-behaviours, improving children's quality of life. The enabling and rehabilitative activities are structured according to the psychoeducative model based on efficiency/effectiveness parameters [16].

An individualized project is realized considering each child's strengths, weaknesses and attitudes. These are specified by a functional diagnosis that indicates the emerging or absent abilities, which represent the enabling goals for the child to be pursued, in the medium or long term, in different contexts of life (rehabilitation, free time, etc.). The project foresees individualized or small group interventions; while the skills already present in the child represent the main points on which the entire treatment will be based. "Intelligent", non-accidental learning is favoured by the fact that the individualized training activities for the acquisition of specific skills are accompanied, on a daily basis, by "generalization" activities that are carried out in different laboratories: the flora- nursery laboratory, the laboratory for the processing of ceramics, or the greenhouse that is used for the winter cultivation of vegetables and flowers. The laboratories complete the employment and work space of the Marino Foundation. The so structured rehabilitation intervention, promotes the autonomy and independence of the children, increasing their level of freedom and awareness of the environment they live in.

The choice of the occupational activities not only depends on the various specific skills and competences we want the child to improve, but also on other equally important variables. Considering that the child is approaching adulthood, it is fundamental to promote activities, which are respectful of this aspect; this will make them feel an active part of their community.

## "SPITI TI STOLI" – HOLIDAY HOME

The values of solidarity, participation and attention to others and to the complex problems that families have to face, led the Marino Foundation to take on another project with the purpose to give families relief and help them detach from the difficulties of everyday life. In 2016, the Holiday Home "Spiti Ti Stoli" was inaugurated: it is an apartment on the sea confiscated from the mafia, which offers a temporary residential service. It was especially readjusted and structured to accommodate people affected by autism from all over Italy, with the intention to give relief to their families and, at the same time, allow each child to continue to carry out enabling activities in a protected environment, followed by specialized personnel. For what concerns laboratories, activities linked to everyday life have been privileged, so much so that they can be considered real work within an existential perspective.

## "LOCANDA TRE CHIAVI" – SOCIAL CANTEEN

The Marino Foundation, has not only carried out and implemented rehabilitation programs, but has also launched a methodological-operative model for the purpose of a protected job placement for the young people it hosts, creating a fundamental collaborative network in the reference territory. Therefore, as well as making use of efficient educational and enabling methods that lead to an improvement in the quality of life as a final goal, the job placement for children, now adults, has been set as a goal and as a good practice. This is how Locanda Tre Chiavi was born in 2014, after three years of intensive training, adaptation, acquisition of social, cognitive and professional skills by the children. Here, three of the Marino Foundation's young people are employed, supported by a supervisor who acts as coordinator. The work activity carried out by each child working in the Locanda was chosen based on personal inclinations, from manual and sensorial skills, to cognitive ability and attitudes. A child completed his studies, attending a hotel school, where he learnt to work as a waiter and obtained a diploma. The Locanda Tre Chiavi is a social canteen and offers up to 40 hot meals a day to poor people for free. Our children take care of the reception of guests, the arrangement of the room where meals are served (setting and clearing the table, local cleaning ...), the supply of the food that will be cooked (going to the supermarket to buy bread, fruit, vegetables ...), table service. The Locanda is the place where the acquired skills are expendable for oneself and for others and have a clear purpose: achieving personal autonomy, emancipation, solidarity and self-determination. The Locanda is a place where the concept of disability is turned upside down: the person affected by autism is no longer a burden for the society, someone who needs assistance; he becomes an active element for the territory he lives in, he can express himself and become a source of help. Moreover, the possibility for the child of being able to buy what he wants with the money he gained by himself makes him feel motivated and happy. Work is the springboard for adult life that has made it possible to strengthen many unexpressed skills, to acquire adherence to the task, to interact with others, to stimulate the ability to manage time. The Locanda is a workplace where you can smell pasta and dignity.

Since the very beginning, the Marino Foundation has adopted an innovative approach in the realisation of its main goal, which has become a real mission: searching for children's well-being as a result of the combination of different factors contributing to the fulfilment of a life project in which the residences represent only a starting point, rather than places where all dreams and expectations could end. Focusing just on the perspective of "what will happen to our children when we will not be present anymore", the choice of a residence could be seen as a forced act, as a sad handover of an adult person from his/her family environment to a facility supplying the services and assistance this person needs. However, this perspective does not take into account the existential paradigm, which is at the basis of such a choice. The Marino Foundation was created to become a place able to satisfy, at the same time:

- he search for autonomy and independence of families, no longer able to cope with the needs of their children becoming adults affected by autism;
- the need of these children to acquire autonomy despite their disability and far from their family environment, in order to achieve self-determination through personalized paths, according to their age and skills.

The model of life and work offered by Marino Foundation represents a laboratory for organizing independent services for people affected by autism. It inspires a model of emancipation for the achievement of an autonomous life, supported by a protected job placement; this leads to easier housing solutions, maintaining a continuity of care with the residential structure of origin. A new Decree of Accreditation by the Regional Administration of Calabria (DCA 81/2016) originated from this experience; this Decree establishes the construction of a Multifunctional Centre for each Provincial Health Authority, consisting of 4 modules. The housing module as well as the day care centre module are connected to two housing communities with the purpose of creating a living environment for those who have achieved a good level of autonomy through the acquisition of skills within the residence or day care centre; these people can live in a protected environment, which will have a lower burden of care, giving them a higher possibility of self-determination in approaching the lifestyle of a non-disabled person. Work, free time, personal autonomy and quality of life are central and essential elements for the sustainability of the multi-purpose centre. A person-oriented approach gives value to various aspects of life and to the individual perception of satisfaction. The skills acquired or their enhancement through specific projects are key element for accessing services or activities with a lower need for assistance, having the possibility to live in a protected environment.

In order to face the continuous changes concerning the needs and achievements of the adult affected by autism, it is necessary to imagine multi-faceted housing solutions, organized in standardized way, but open to changes, with a certain flexibility in budget management, allowing differentiation of care costs and foreseeing the possibility to allocate in itinere resources for specific objectives.

The outcome would be positive for many aspects:

- economic: cost rationalization;
- effectiveness: adequate service response to the demand;
- quality of life and opportunities: anyone, regardless of the severity of his/her initial impairment, can have an opportunity for redemption.

The residence becomes the fulcrum of habilitation and civilization and the Marino Foundation has given proof of this.

## CONCLUSIONS

The examples of good practices reported in this contribution place particular emphasis on some of the key points addressing the need of young and adults with autism spectrum disorders. The experiences described here are necessarily focused on specific issues, since we are aware that when we talk about life plans, these should be developed in connection with social and health services and implemented with adequate resources. However, today there are no places with structured environments, such as day care or residential centres for people with severe autism that are not merely assisted living facilities. Casadasé, Cooperativa Garibaldi and Fondazione Marino are the answer to the lack of a network of services capable to sustain and stimulate a life project for people with autism. They create settings and provide competent support and opportunity for the development of those individual outcomes that promote quality of life of persons with autism. These experiences aim to manage the transition towards autonomy, and, remarkably, they produce solutions strongly dependent upon the resources available in their territory. Meanwhile, they all share the same guidelines that allow accounting for the needs and achievements of young and adults affected by autism. The three experiences are best described as: a self-managed special school that becomes a "school of life", a social farm offering sheltered employment to young people with severe autism and promoting urban regeneration caring for a public green space converting it into a small farm, a multifaceted residential housing for a small group of young and adult people with autism that looks ahead, aiming for quality of life and opportunities for anyone, regardless of the severity of the impairment. Hopefully, in the near future, the public administration will play a more active role in favouring the birth of a network of services which may promote sustainability of parents' spontaneous initiatives [9, 10].

### *Conflict of interest statement*

The Authors declare that they have no conflict of interest.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 180-192
DOI: 10.4415/ANN_20_02_08

# Reframing QoL assessment in persons with neurodevelopmental disorders

**Marco Bertelli[1,2], Carlo Francescutti[3] and Ivan Brown[4]**

[1]*CREA (Centro Ricerca E Ambulatori), Fondazione San Sebastiano, Misericordia di Firenze, Florence, Italy*
[2]*SIDiN (Società Italiana per i Disturbi del Neurosviluppo), Genova, Italy*
[3]*Servizio di Integrazione Lavorativa, Azienda Sanitaria Friuli Occidentale, Pordenone, Italy*
[4]*Department of Applied Disability Studies, Brock University, St. Catharines, Ontario, Canada*

**Abstract**

The paper reviews the international literature on quality of life (QoL) for persons with neurodevelopmental disorders (NDD) in order to define the theoretical frame for optimal assessment. The application of the QoL approach to assessment procedures should be based on three main aspects: shared QoL, personal QoL and family QoL. The first aspect refers to characteristics of individual life that are shared with other people. The second aspect proceeds from the fact that each individual has a changing set of personal attributes that determine the subjective experience of life. In the third aspect the previous two are applied to the family that includes a person with NDD. Disability impacts the whole family and the determination of appropriate conceptualization of family outcomes requires an understanding of the impact of members with a disability on family QoL. At any level, it seems best to take a comprehensive approach to assessing QoL, integrating subjective and objective aspects, self-reports and hetero-evaluations. The QoL approach is above all a way to explore the rich intricacies of personal quality of life. Such assessment may be used effectively with people with NDD, independently from the severity of their functioning impairment. Individuals with profound ID may express their inner states through consistent behavioural repertoires, which can be discerned by persons closest to them and validated by more independent others. Attention must be paid in using non-generic instruments, such as those that measure health-related QoL. Although they do focus on the individual person, they still support a theoretical perspective of QoL that has not departed significantly from the traditional medical approach. Currently available generic tools, although they have some common conceptual and evaluation characteristics, still show considerable differences in the areas to be included in "shared QoL", the dimensions used to evaluate "Individual QoL", and the role attributed to indicators of QoL. QoL assessment should not represent a classification of individuals, services or systems, but it should help provide, within service systems and organizations, a value system that is consistent with those values held by people with NDD.

**Key words**
- quality of life
- intellectual disability
- autism-spectrum
- assessment
- measurement

## INTRODUCTION

Person-centred care originated in the area of disability and is now widely used within the areas of mental health, aged care services, education, general healthcare, and the criminal justice system. Its focus within disability support organisations is to ensure that services provided concentrate on what matters most to the people receiving them and their families. Person-centred approaches ensure that service users are seen as unique individuals with valued strengths and contributions [1].

Among person-centred approaches, Quality of Life (QoL) has raised particular interest in the scientific community across the last 30 years. Hundreds of research and conceptual articles have been published, and numerous books have focused directly on QoL. At present, the QoL concept seems to be at the crossroads of all intervention strategies in the various branches of social care and medicine, especially in psychiatry.

The meaning of the term QoL may appear easy to understand and, in its general sense, it is. But because it is so frequently used to refer to the "goodness" of life only in general, it runs the risk of becoming a banality. When we dig deeper and apply the term QoL to real life, it can take on multiple meanings, so much so that it is almost impossible to talk about it without a clarification of contextualized its meaning. When QoL is used in the public media, especially for promoting new ideas or products, it typically refers quite clearly to high level

*Address for correspondence:* Marco Bertelli, CREA (Centro Ricerca E Ambulatori), Fondazione San Sebastiano, Misericordia di Firenze, Via Del Sansovino 176, 50142 Florence, Italy. E-mail: mbertelli@crea-sansebastiano.org.

of life quality or the "best" of life. This popularization of the term QoL has resulted in it being understood and used in ways that are considerably less substantial than the conceptualizations that have been described and applied by academics and researchers. For this reason, it is sometimes considered that QoL is a concept that lacks sufficient precision to have specific usefulness in the field of intellectual disability (ID), and that it is more advantageous to focus on clearer concepts or simply on providing practical supports.

Yet, a considerable amount of substantive work has been done in the area of QoL and ID. Numerous thoughtful books, book chapters, and academic articles have been published that not only advanced our understanding of QoL, but have made ID the leading field for substantive work in QoL. In the last ten years, the research activity in the area of QoL and ID has been extended to autism spectrum disorder (ASD), especially to persons with low functioning. ID and Low-Functioning ASD (LF-ASD) often co-occur and are difficult to distinguish, especially when cognitive impairment is more severe [2].

It is clear from this work that achieving high quality of living is not the main purpose. Rather, it provides an approach for how professionals view the patient-person, and for how they view the relationship between the patient-person and the system of care. The QoL approach has to be interpreted in qualitative rather than quantitative terms, as it consists more in choosing a course than in achieving a goal. It provides both a viable and an alternative approach to the traditional medical approach. In fact, it tries, overall, to help people feel satisfied with their own lives in ways that are customary to them and valued by them, while the latter focuses primarily on restoring morphological and functional integrity to aspects of the person that have been affected by the morbid condition. The QoL approach begins by professionals understanding what is important to and valued by each individual, and what aspects of life or the environment contribute positively to life quality or detract from it. This approach makes every effort to respect the right of the individual to help choose the course of action that best suits him or her, and endeavours to provide whatever positive supports are required to assist the individual to live an effective life that is uniquely shaped by individual characteristics and circumstances [3]. One of the fundamental principles of the QoL approach is that QoL is important for all people, and that all people are thus entitled to a life of quality [4]. This principle applies equally to people with ID and to people who do not have ID.

The question of how we can ensure entitlement to a life of quality for people with ID who have mental health problems is an interesting and challenging one. Yet, the emphasis within the conceptualization of QoL on finding uniquely individual solutions to presenting problems suggests that it may be a particularly apt approach to take with this population.

People with ID are characterized by lower levels of overall intelligence, and lower potential for learning and developing logical-deductive skills. For this reason, it is not a realistic goal for therapeutical interventions to attempt to provide "normal" intellectual functioning, but rather such interventions need to work within the confines of each individual's adaptive functioning, which, by definition, shows deficits that significantly hamper for the individual's independence and ability to meet their social responsibility [5]. Similarly, it is not a reasonable therapeutic goal to have people with ID live their lives as close as possible to people without ID, because ultimately they have to find satisfaction in those aspects of life that are important to them and that they can understand and experience. The more traditional medical approach to therapeutic interventions with people who have ID and mental health problems have tended not to consider the uniqueness of people with ID fully and have been more likely to use the general population norm as their point of reference. This has resulted in interventions that have dealt primarily with containing troublesome behaviours and helping to alleviate symptoms, rather than to address the root causes of the problems. Thus, assuming an overall QoL approach to intervention goes a long way to ensuring entitlement to a life of quality.

A second step to begin to ensure a life of quality is to promote changes in the way mental health professionals perceive people with ID through professional training. Too often, such professionals still perceive people with ID as having intellectual and skill incompetence that is so different from "normal" functioning that the intelligence and skills they do possess are not valued or seen as possible to enhance. As a result, intervention very often focuses on simply changing behaviour so that it is more manageable and less troublesome to the individuals and to those around them. However, it has been recognized for a number of years that people with ID are considerably over-represented among those who present with mental health problems, and this may be increasing in recent years due to people with ID living much longer than was the case in the past. At the same time, it is increasingly recognized that a number of therapeutic interventions are effective with this population, and that they have positive impact on the lives of individuals. These changes are bringing new challenges to mental health services, and they are suggesting the use of positive interventions that view the health – and indeed the whole life – of people with ID in more holistic and integrated ways. The QoL approach is ideally suited to respond to the demands of such changes.

In recent years, scientific interest has already moved from theoretical considerations to measurement methods. The reasons are manifold, but the main ones seem to relate primarily to the growing use of QoL measurement as a crucial aspect of the individualized evaluation and programming, as a comprehensive outcome measure, and as a key to access the application and dissemination of the concept [6-8]. There is also growing support for evidence-based practice, that is, the view that there should be clear and reliable evidence from research that our service practices are effective [9, 10]. In the QoL context, evidence-based practice infers that there should be clear evidence that our practices contribute positively to a person's QoL. The focus on evidence-based practice is placing additional importance on the QoL measures that have been developed since about 1990, and it is encouraging their refinement. Some authors suggested that abandoning highly complex models in favour of simpler and empirically testable propositions could represent the most effective way to support this progression [11]. Already by 2002 the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) argued that QoL should represent the reference frame of all therapeutic and rehabilitative interventions and assume a prominent place in education and training targeted at professionals [12].

Despite its widespread implementation, QoL measurement is still associated with numerous problems, related to the definition of the QoL concept, the way it can be effectively measured, for whom, by whom, and to what purpose. Evaluation tools produced to date are numerous and the fields of application vary, from social support to health, employment, statistics or economics.

### *Study Objective*

The aim of this study was to investigate the state of knowledge and current issues in QoL assessment for people with ID and/or LF-ASD, through a systematic mapping of the scientific literature.

## METHODS

A systematic mapping (SM) of the literature differs from a systematic review (SR) by the breadth of the research topic, the type of questions posed, and the precision of the extracted data [13]. In SM research, topic and data extraction activity are broader than in SR, and the analysis does not include depth techniques, but rather summaries.

The reference questions for the present mapping were: 1) "What is the purpose of the QoL measures available so far?"; 2) "What is actually measured by QoL measures for persons with ID/LF-ASD?"; 3) "For which persons with ID/ASD is measurement possible?" and 4) "By whom should a QoL measurement be made?".

The authors examined the international literature of the past 23 years, from January 1996 to March 2019. The article search was carried out using the engines of Medline, Medmatrix, NHS Evidence, and Cochrane Library. The keywords used were: "quality of life", "subjective well-being" or "person-centered outcome (measures)", combined with "assessment" or "measure (ment)", further combined with "intellectual disability" (or "learning disability", or "mental retardation"), and/or ["autism" (or autism spectrum disorder" and "low functioning"].

Articles identified by this procedure were integrated with those previously collected by the authors of the present paper through direct contacts with members of the international scientific community.

Articles published only in languages other than English and Italian have been excluded. Further additional papers were identified by screening the bibliographic references included in the articles already selected, and by searching the world wide web through using the above mentioned keywords in two of the main generalist search engines, namely Google and Yahoo, and in two of the main directories, namely Dmoz and Digital Librarian.

Articles and chapters that matched the above listed keywords were screened by titles and abstracts, before being read in full.

## RESULTS

The search through Medline, Medmatrix, NHS Evidence and Cochrane Library identified 1536 articles. After title and abstract reading, 221 were selected as relevant. Of these, only 52 were judged to be useful for answering the mapping reference questions.

The search through the generalist engines of the world wide web identified 184 links of potential interest. After reading the full web pages, 24 were found to be relevant. After reading all the documents contained therein, including books and book chapters, and after excluding overlaps with the texts already identified through the engines for scientific literature, only 13 were considered useful to answer the questions of the mapping.

### *Purpose of QoL measures*

QoL measures can be grouped as referring to three main aspects: shared QoL, personal QoL, and family QoL.

#### *Shared QoL*

Much of the QoL work that has emerged in the field of ID/LF-ASD and elsewhere is based on characteristics of human life and humans' environments that are common to, or shared with, other people. For example, humans are social beings by nature and thus the support of other people, especially family, friends, and co-workers, is typically a relevant aspect of life to all people. In some QoL theoretical models and associated measures [14, 15], aspects of QoL based on shared human characteristics are confounded or overlapped with human rights, which are represented by a set of rights and freedoms that belong to every person in the world, from birth until death. However, shared QoL and human rights represent two different concepts, although they are interconnected. Rights are based on shared values like dignity, fairness, equality, respect and independence, while shared QoL refers to areas of life that have qualitative implications for everybody's life. Rights as well as life itself can be considered as presuppositions or antecedents of QoL and not as aspects of shared QoL.

Shared QoL is relatively easy to assess, even in persons with severe ID/LF-ASD, although no consensus has been reached yet within the scientific community on exactly what aspects should be assessed. This assessment is appropriate for groups of people, for services and supports that address the needs of large numbers of individuals, and for making policies that affect populations.

#### *Personal QoL*

In QoL assessment, it is also widely recognized that there are individual differences, and that sometimes these are quite substantial. First, for individuals, shared characteristics take on increased or decreased personal value in response to personal genetic makeup, individual personality, or personal environmental conditions. Second, all individuals have unique characteristics and interests that are sometimes very meaningful in their lives, and thus add to their life quality, but mean little or nothing to another person [16]. For example, a musician may spend hours every day practising her instrument, performing, and seeking out new music and new music-related opportunities. Most of her friends and close acquaintances may be musicians. Music is a dominant and driving force in her life, and one that is highly valued and gives strong meaning and direction to her life. Yet to her neighbour, who knows almost nothing about music and does not care to learn or even listen to it, music is not valued and it means almost nothing to him. Unique talents and interests need to be central to quality of life evaluation, as they can sometimes be central to a person's sense of self and enjoyment of life. Third, QoL is a personal concept in that it is, to a high degree, based on a set of personal perceptions, attitudes, values, and skills, and on the physical and social environment. These factors determine not only how a person's life is experienced, but also how it is interpreted. Finally, the changing nature of QoL has been described for many years (e.g., Raphael, Brown, Renwisk, and Rootman [17]), but Reinders [18] made an important elaboration: "...the concept of QoL is necessarily open- ended. There is on any account of the matter a dimension of incompleteness in assessments of QoL in the sense that we may discover things about ourselves that in due time will change our judgments. Precisely as a comprehensive concept QoL must entail an element of the unknown future of our existence".

Good QoL assessment, then, allows for the concept to be explored at a personal level as well as at the shared level [3]. When QoL assessment is used to improve life quality at the individual level, it is essential to place a strong emphasis on personal QoL.

### *Family QoL*

Due to policy changes in most developed countries, families that include a person with ID/LF-ASD are increasingly being required to accept a larger burden or responsibility than was the case in the past, not always with entitlement to services [4]. As a result, families are often overburdened and marginalized in society, and they often need help, or support, to achieve lives of quality [19]. Disability impacts the whole family [20] and the determination of appropriate conceptualization of family outcomes requires an understanding of the impact of members with a disability on family QoL. According to Summers and collaborators [21], this involves three main issues that research has explored in recent years: stress and caregiving burden, impact on family functioning, and eco-cultural adaptation.

QoL assessment should guide personal, service, or policy enhancement rather than representing a classification of individuals, services or systems [8].

It should help provide, within service systems and organizations, a value system that is consistent with those values held by people with ID. The *Ask Me! Project* in Maryland, USA, is an example of one of many organizations that now use QoL values and information can usefully direct services to develop goals and to monitor achievements. The project puts particular emphasis on predictors of personal development, relationships between QoL domains, and consistency with mission statement [22].

At the front-line staff level, QoL can represent an integral and multidimensional view of the health of the person with ID that allows the multidisciplinary team to identify needs and wishes, and to plan interventions in the most useful way. In Baum's opinion, this is a particularly useful approach in managing challenging behaviours [23].

Generally, a QoL approach should identify the degree to which individuals attribute importance to various areas of their lives, and the degree to which they perceive satisfaction. In doing so, global QoL measures will be increased because we give more strength to those aspects of life that are more important and less strength to those aspects that are of lesser importance.

The goal here is to assess QoL with a view to more accurately reflect overall life satisfaction in the life areas that are deemed to be most important. The QoL approach should also be seen as an effort to mobilize and revalue resources that can help individuals (and the holistic systems that they represent) to embark on or to continue developing personal skills over their lifespans.

### ***What current QoL measures actually measure***

Measuring QoL has been somewhat challenging, especially because it is a social construct (a concept based on ideas that do not have a physical presence), and thus evidence for or against it must be inferred from indicators that of our own construction. Achieving consensus on what the best indicators of QoL are for people with ID/ASD has been a goal of the QoL and ID work (see especially Schalock and colleagues[12]), but a healthy debate continues. There seems to be little doubt that conceptual and measurement knowledge will be enhanced as more of our professional work with individuals takes a QoL approach. While attempting to help solve their real-life problems, we will become better able to understand the essence of their QoL, and how it can be most realistically and effectively measured.

Since QoL is a somewhat complex concept involving the whole life of the person, most theorists and researchers agree that QoL can be best measured by obtaining and combining scores from several life domains. The point to be made here is that precise units of measurement based on a clear, concise definition are not currently available, and, as is the case with other complex social constructs (e.g., health, learning), such measurement may not be available in the future. But there some well-developed measures for QoL for people with ID/LF-ASD that share some agreed-upon structural elements [24].

### ***Elements of QoL measurement***

There is high agreement that QoL measurement should be based on both qualitative and quantitative information from both subjective and objective perspectives [11, 6], with some flexibility depending on the purpose of the measurement. Perry and Felce [25] explored the relationship between objective and subjective measures of three of the most frequently assessed QoL outcomes in British deinstutionalisation research: choice, participation in activities, and community and social integration. This research was conducted within a randomly-selected sample of small community housing services. The results showed that residents' satisfaction with choice, as measured by ComQoL [26] did not correlate with any objective measures. Satisfaction with friends, free time, recreation, and leisure scores of the *Lifestyle Satisfaction Survey* [27] were significantly correlated with engagement in non-social activity but not with participation in domestic life. Again, within the area of social and community affiliation, none of the nine correlations between objective and subjective measures was significant. The study was not designed to give participants an opportunity to rate the degree to which they considered each indicator important, and thus the critical relationship between *importance* to the person and *satisfaction*, often considered a key element of accurate QoL measurement, could not be explored. Nevertheless, the results support previous findings that assessment of objective life conditions and perceptions of personal satisfaction appear to be distinct. It may well be that they simply measure different things. One plausible explanation for this emerges from the extensive work by Cummins and colleagues on the homeostatic effects on subjective well-being [28, 29]. In this view, individuals have genetically-programmed "set-points" to which their moods have a strong tendency to return, despite external (objective) circumstances. Times of joy and times of stress are temporary emotional states for most healthy individuals, but the set-point is the stable mood regulator. In short, we have an innate mechanism for finding contentment in our various circumstances, as long they are not unduly stressful or unduly prolonged. It would be useful in the future to continue these lines of thinking and to undertake new work that would help us understand if objective and subjective measures should be considered as distinct measures, or if each contributes to a broader measure of QoL.

It would also be useful to determine if either objective or subjective measurement should dominate the other in QoL measurement. Measurement based primarily on objective indicators has the advantage of being easier to validate and perhaps to gather information, but measurement based primarily on subjective information honours the person-centred nature of the QoL approach.

The question of whether respondents' perceptions should be considered objective or subjective is an interesting one. An example of this is a study on the difference between the universal (etic) and cross-cultural (emic) properties of QoL reported by Schalock and collaborators [30] and Jenaro [31]. These researchers surveyed three respondent groups (consumers, professionals, and parents) from six geographical areas (South and Central Europe, Latin America, Canada, China, and USA) on the importance and use of the 24 core QoL indicators most commonly reported in the international literature. Results seemed to confirm etic and emic characteristics of the QoL construct by indicating that: (1) there are similar profiles across respondent and geographical groups; and (2) there are significant differences in mean QoL, importance, and use scores. But it is the measurement method that is of interest here. Respondents gave their perceptions of importance and use on the 24 indicators that were themselves QoL domain-specific perceptions, behaviours or conditions that give an indication of the individual's actual well-being. This measurement method, then, uses respondents' perceptions of both others' subjective experiences and objective indicators of life experience as data for QoL measurement [8].

There is general agreement in the QoL measurement literature that the concept quality of life is multi-dimensional (e.g., Schalock and colleagues) [12]. Most instruments set out QoL indicators under a number of logical domains. Schalock and his colleagues identified eight core domains that are most common in the QoL literature: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights [32, 15, 33]. Two things are not clear at this point: first, whether the domains identified to date accurately capture QoL, and second, the extent to which the domains make unique contributions to overall QoL.

There is emerging evidence from analyses of the study referred to above [30, 31], that these two points merit some future exploration. The factor scores on importance and use generally did not fit into the eight core domains proposed by Schalock to describe the set of cross-cultural factors that can impact personal well-being. Furthermore, QoL domains as defined by Schalock et al. have been empirically investigated across the world with different results. In Poland, Otrebski [34] found that professionals' age, education, and place of work can strongly affect the evaluation of the importance and the use of certain domains. In the component analysis of the importance ratings conducted by Xu and colleagues [35] in China, two (personal development and physical well-being) of the original eight domains were highly correlated and loaded onto one component. Aznar and Castanon [36] gathered 111 statements from the pool of answers given by 50 Latin-American families to the question: "What does living a life of quality means for the disabled member of your family?". They found a very high variability of the relevance of these statements to the eight QoL domains. The percentage of statements by domains ranged from 27 in interpersonal relations to 4 in physical well-being.

According to Reinders, an authentic comprehensive evaluation of QoL must necessarily explore the anticipation of a different future and this exploration has to be extended to each domain of QoL investigated. In a critical review of the Schalock and Verdugo's conceptualization, Reinders observed that, without further qualification, objective (shared QoL) measures do not actually measure QoL, but only separate domains of life. People do not typically experience their QoL as divided among separate domains, but rather evaluate how their experiences within these various domains interact with one another. Furthermore, some QoL domains of the

Schalock and Verdugo's model, such as "self-determination" or "personal development" should be attributed to "individual QoL" and assessed as qualifiers of all QoL domains.

A good combination of "shared" and "individual" QoL assessment is provided by the tool produced by the Quality of Life Research Unit, Centre for Health Promotion, University of Toronto, called Quality of Life Instrument Package (QoL-IP) [37]. This tool and the model upon which it is based foresee that there are areas of life with emic transcultural value, which have qualitative implications for anybody's life, independently from the presence of disability and its specific features. The tool also assumes that the best way to assess the individual gradation of quality in these areas is represented by the following four dimensions: 1) importance, attributed by the person to every area of life; 2) satisfaction perceived by the person in the same areas; 3) opportunities that the person had/has to develop importance and to perceive satisfaction in the different areas of life; and 4) choices that the person could/can make in the same areas.

According to our literature mapping, the QoL-IP is the only tool that explicitly applies the relationship between importance and satisfaction to QoL measurement, an idea that was put forward by a number of scholars in the 1990s, including Becker, Diamond, and Sainfort (1993) [38]. According to this idea, a thing that is highly important and gives high satisfaction has a considerable positive impact on a person's QoL, but a thing that does not interest a person or is not valued will never add satisfaction or quality to the person's life [6, 3].

The QoL-IP includes nine areas of emic transcultural value, which are gathered in the three macro-areas of being, belonging, and becoming [39] *(see Table 1)*.

The dynamic QoL model that underlies the QoL-IP is linked in a straightforward way with the well-known capability theory proposed by Amartya Sen [40]. According to Reinders [18], a dynamic approach to QoL "is oriented toward the goal of human flourishing. Human beings flourish to the extent that they are enabled to develop their own capabilities … when they receive sufficient opportunities to develop their own gifts and talents". This claim can be rephrased by saying that QoL in a capabilities approach is agent relative, and that they are typically owned by agents. In Sen's perspective, agency goals are those objectives that people set themselves, even if they do not benefit directly from them, or indeed even if they undermine other capabilities. Sen saw that people often have goals that are not in their interests, such as sacrificing their health or even their life itself for religious, political, or aesthetic achievement. Adding agency goals to the account serves Sen's theoretical objective of criticizing welfarist conceptions of the good human life, such as utilitarianism. "The general idea of the freedom to achieve well-being can be called well-being freedom… The existence of genuine choice may actually affect the nature and significance of the functioning achieved" [41].

Reinders suggests that a QoL measure is effective only if conceived as addressed to a human being and his life story, since the latter "provides the hermeneutical context within which agent-relative capabilities are discovered and realized" [18]. A version of the QoL-IP adapted to the Italian language and culture has been recently validated by Bertelli and collaborators [42].

Another commonly used QoL measure is the one developed by the World Health Organisation (WHO), called WHOQOL-DIS (disabilities module), which is an adaptation (supplementary module) of the WHOQOL-BREF for the general population. The WHO developed two main generic QoL tools for the general population, the WHOQOL-100 and the WHOQOL-BREF which is a shorter 26-item version. The WHOQOL-100 has a hierarchical structure that includes overall quality of life, a next level of domains, then facets within each domain, and then four specific items for each facet. The shorter WHOQOL-BREF has a similar hierarchical organisation, except that each facet is represented by a single item.

This tool includes a smaller number of domains and item in comparison to the previously examined measures. It takes into account some aspects of Individual QoL, but in a very simple and partial way. Nevertheless, the WHOQOL methodology provides for cross-cultural validity for QoL assessment across the adult lifespan and across a range of physical and intellectual disabilities [43].

In healthcare services, a large number of measurement instruments have been developed that purport to measure health-related QoL (HR-QoL). These mea-

**Table 1**

QoL areas/domains in the main QoL assessment tools for person with ID/LF-ASD

| Tool | WHOQOL-BREF and disabilities module [44] | Quality of Life questionnaire [15] | Quality of Life instrument package [37] |
|---|---|---|---|
| Number of QoL areas/ domains | 5 | 8 | 9 |
| List of QoL areas/ domains | - Physical<br>- Psychological<br>- Social<br>- Personal environment<br>- Disability | - Personal development<br>- Self-determination<br>- Interpersonal relationships<br>- Social inclusion<br>- Rights<br>- Emotional well-being<br>- Physical well-being<br>- Material well-being | - Physical being<br>- Psychological being<br>- Spiritual being<br>- Physical belonging<br>- Social belonging<br>- Community belonging<br>- Practical becoming<br>- Leisure becoming<br>- Growth becoming |

sures focus on the effects of overall personal health and medical treatment, the presence of physical or mental health conditions and disorders, and also on the effects on the person of specific diseases and treatments (e.g., cancer, HIV, diabetes, arthritis); (See the Quality of Life Instrument Database of the Mapi Research Institute for a list of available instruments). In fact, for people with NDD, there is international agreement that we must be cautious in interpreting scores from all non-generic (specifically-focused) instruments, such as those that measure health-related QoL [11]. HR-QoL instruments typically try to measure both the degree to which symptoms are present and their effects on daily functioning. Thus, although they do focus on the individual person in a way that is of some benefit, they still support a theoretical perspective of QoL that has not departed significantly from the traditional medical approach of only identifying and effectively treating diseases and conditions [44]. From the time QoL began to emerge as an important focus in the field of NDD in the late 1980s, it has focused more broadly on the whole person's life as well as on key processes that enable people to achieve lives of quality (e.g., identifying what is valued by the person, honouring each person's unique interpretation of satisfaction and happiness, providing environmental opportunities, permitting and enabling personal choice, and promoting the concepts of empowerment and self-determination) [3].

How to measure a whole person's life, and how to weigh in the effects of these key processes, is an ongoing challenge. Brown and colleagues [45] asserted that satisfaction scores weighted by importance scores, by way of a mathematical formula, constituted what they called basic quality of life scores. When an item is important to a respondent, the satisfaction score is weighted more heavily than if the item is not important. These authors also noted, however, that basic quality of life scores do not tell the whole story. To illustrate, they also collected scores for both decision-making, and the availability of opportunities from which decisions can be made, which, they claimed, act as moderators to basic quality of life scores. Thus, we come to the important measurement question of whether specific measures are true outcome indicators of QoL, or if they help to explain current QoL scores. For example, and to expand on the concepts of decision-making and opportunities, a woman who lived in a restricted environment for 40 years valued the recreational activities provided for her and felt very satisfied with them (indicating that she was enjoying recreation of high quality), but she had never been exposed to the many opportunities for recreation offered by her broader community and had never had a voice in making decisions about whether or not to pursue other options. Although her current QoL scores in this area of life were high, it is difficult to assert that her recreational activities were the best ones she could have had. Another example is a man who lived in a group home and was very dissatisfied with his social activities, although they were numerous. His dissatisfaction emerged from the fact that everyone in the home had to attend the same events because there was only one staff on duty at any one time. He had many opportunities, but his decision-making power was low. Variables such as decision-making and opportunities can be useful in explaining QoL scores, but they are not themselves QoL outcome measures [11]. The relationship between making decisions, choices, or other ways to exercise self-determination is a QoL issue that is the subject of ongoing work [46-48], but there are strong indications that these are universal concepts that hold up in cross-cultural contexts (e.g., Zhang and collaborators) [49].

In recent years, the impact on QoL of the participation of the person with ID/LF-ASD in decision-making processes, and the level of self-determination have represented a particularly lively area of research. According to Lachapelle and collaborators [46], self-determination and the possibility of choice co-vary in an almost linear way with QoL scores. Other authors consider these aspects so important as to include their implementation in the guidelines for good practices [50].

In Cummins' opinion [11], QoL measures might be characterized by either indicator or causal variables, or both, and further research should be conducted to make clearer distinctions. In addition, Cummins suggested that work should be carried out to organize QoL indicator variables for life as a whole in a hierarchical way, a process that would help us better define a minimum set of domains with equal variance.

QoL measurement often relies – sometimes quite heavily – on people's own perceptions and expressions of their well-being or general satisfaction with life, referred to in the measurement literature as subjective well-being (SWB). Since life is experienced by individuals through their unique sets of perceptions, SWB may be an essential pathway to recording "true" personal QoL. However, when recording SWB, it is often noted that QoL scores of people with severe disorders or disabilities do not significantly differ from those of the general population. This so-called "disability paradox" originally introduced by the widely-known article by Albrecht and Devlieger [51], has been explained in various ways, such as methodological bias, or the psychological mechanism of adaptation, coping, or resilience.

For many scholars the "disability paradox" is just the result of a poor conceptualization. For example, Koch [52] highlighted the circularity involved in the notion of "disability paradox": "(a) physical normalcy equals acceptable life quality; (b) physical differences result in diminished life quality; ergo, an acceptable life quality cannot exist in the face of physical differences. Paradox demands only that a person (a) exhibits conditions that negatively diverge from the norm and (b) reports a positive life quality".

Considering a population with intellectual disabilities whose cultural marginality, limited opportunities for personal development and social inclusion are widely documented, Reinders does not want to ignore the fact that "...people with disabilities may be content with their lives because they are unfamiliar with other possibilities" [18].

Cummins theory, referred to above, has presented a compelling case for SWB as the result of an affective/cognitive homeostatic system that is characteristic of humans. Simply put, we have a built-in tendency to assess the world around us, and our place within that world, in normative ways by perceiving that "life is okay". Only in extreme cases, where there is a strong overload, does the homeostatic system fail. Thus, SWB may not be a particularly sensitive measure, but, when it is low, it may be cause for serious concern [11].

### *QoL measurement summary and future directions*

QoL conceptualization and measurement have advanced very considerably over the past 20 years, but work in this area is ongoing and requires further development. The tools used for the evaluation of QoL in people with DNS – and the theoretical models from which they derive – present many commonalities but also important differences. The latter represent a considerable obstacle for the implementation of research on practical consequences of using this type of outcome measures.

It will be important to clarify the relationship between QoL based on shared human characteristics and QoL as experienced in unique ways by individuals. It will be essential to address emerging measurement issues, such as those referred to above and others. One expressed goal is to have, in the near future, a generic instrument that can be validly applied to anybody, irrespective of health condition, disability, culture or socio-economical status [11]. Finally, it will be critical to focus carefully on how QoL as a concept and measurement tool are applied in clinical settings, in order to promote practices that enhance QoL of individuals with ID and to avoid practices that (purposely or inadvertently) detract from QoL. For the field of psychiatry and mental health, in particular, understanding that the QoL concept can be applied to everyday practice in a way that is systematic, reliable, and helpful, is the challenge for the near future. To address this challenge, we will need methodologically rigorous research, carried out by professionals with expertise in research and application, that evaluates over time the effectiveness of taking a QoL approach in mental health care practice.

Family QoL is an area of study that has just begun, but it promises to be an important focus in the future. An international group of researchers leaded by Brown and colleagues from Canada [53] developed a theoretical framework and validated a survey instrument for family QoL. The first version of this instrument was published in 2000 [54], and the second version, available in a number of languages, in 2006 [53]. This instrument includes ratings for six core concepts (importance, opportunities, initiative, stability, attainment and satisfaction) across nine domains: family health, financial well-being, family relationships, support from other people, support from services, influence of values, careers and preparing for careers, leisure and recreation, and community integration [55]. Like individual QoL, a life of quality for a family refers to aspects of family life that are valued by families everywhere, tempered by unique values of an individual family [56].

An instrument for assessing the impact of services on family QoL has been developed by The Beach Center on Disability at the University of Kansas. This instrument, which has strong psychometric properties, includes 5 domains (interactions, parenting, emotional well-being, physical/material well-being, and disability-related support) and 25 items [57, 21]. Another tool was developed by Aznar and Castanon [36] in their investigation on 180 Latin American families. The 42 items of this instrument are grouped in the following 6 areas: emotional well-being, personal strength and development, rules of cohabitation, physical/material well-being, family life, and interpersonal and community relations.

Though on a very small sample, Jokinen and Brown [58] specifically investigated the family QoL of older parents of adults with ID. They used an adaptation of the Brown, Neikrug and Brown [59] *Family Quality of Life Survey* referred to above. Findings indicate, among other things, that older parents have many concerns in common and ongoing concerns about issues related to family caregiving. All respondents reported satisfaction with leisure and life enjoyment, while contribution to community and civic affairs received the lowest satisfaction ratings. Recent work in family quality of life also underscores the importance of exploring the relationship between concepts that are QoL outcome indicators and those that help explain it. The Brown et al., [60] family quality of life survey referred to above provides a way to score six key outcome measures: importance, opportunities, initiative, stability, attainment and satisfaction. Of these, attainment and satisfaction are considered QoL outcome indicators, and importance, opportunities, initiative, and stability are measures that help to describe, explain, and modify the extent to which attainment and satisfaction are relevant.

The relationship between individual and family QoL appear to be quite complex and needs to be clarified in future research [61]. To date, few correlations have been found between the perceptions of people with ID themselves and the perceptions of their family members [62], most of which refers to financial well-being, family relationships, support from services, and support from others [62]. This difference in QoL perception could negatively impact on QoL of people with ID, if their views are not taken into account when planning for family support.

### *For which persons with ID/ASD is measurement possible?*

It is sometimes thought in the field of mental health and in related fields, that people with ID do not possess a sufficient level of cognitive ability to process information and perceive emotions to the degree that they can make accurate judgements about their own life satisfaction. This belief has been strongly discredited in the field of ID as having no demonstrated validity. It is now widely held that people with ID, even those who do not have formal communication systems, are able to express their own likes and dislikes, satisfaction and dissatisfaction, and that such expression is valid because it is represents the perception of the person at the time.

Still, other people close to the person with ID have their own perceptions of the person's life. Although there is considerable evidence that proxy data (information given by others close to the person) does not correlate well with data from people with ID themselves [63, 64, 8], it may still be important to assess QoL from others' points of view. As Brown, Raphael and Renwick [37] explained, such other people frequently make decisions on behalf of a person with ID, or are influential in helping the person with ID to make decisions, and thus the perspective of those other people are important to note. They are all the more important to note if they differ from the perspective of the person with ID whose life is being influenced. On the other hand, information from proxies can be very helpful to an assessment of QoL, by adding historical information, clarity and depth that might otherwise be missing due to skill limitations. It might even be argued that proxy information is a necessary addition to self-perception.

It seems best to take a comprehensive approach to assessing QoL for use with individuals with ID. Self-report by people with ID should be central, and any means should be mobilized to enable people with ID to express their own views. Information on the background of the person with ID, descriptions of the person's current context and living/working environments, and the perceptions of proxies constitute addition sources of information that are potentially valuable to add to self-perceptions. There is no formula for assessing QoL, nor should there be. Rather, the QoL approach is above all a way to explore the rich intricacies of personal quality of life.

Such assessment may even be used effectively with people with severe ID, as they express their inner states through consistent behavioural repertoires [65].

### *Additional research findings*

QoL of persons with ID has repeatedly been found to be lower than that of persons without ID. Keith and Bonham [22] identified some main differences in the domains of rights and empowerment/independence, while Bramston and collaborators [66] found that those with ID attribute significantly less importance to all areas of life except material well-being, and report significantly lower satisfaction with intimacy and community involvement, but higher satisfaction with their health. For people with ID, satisfaction with safety, emotional well-being, material well-being, and health are significantly predicted by social support. Health is predicted also by stress in interpersonal relationships [66, 67]. People with ID desire friendship and need support in this area [68, 69], which is often undervalued or presumed to be implicit in the community inclusion [70].

Considerable QoL differences between persons with and without ID have been reported also in respect to employment, with non-disabled workers reporting higher QoL and autonomy. However, Beyer and collaborators [71] found that supported employment can significantly increase satisfaction towards material well-being, productivity, safety, place in the community and emotional well-being despite objective disadvantages. Kober and Eggleton [72] investigated the impact on QoL of open vs sheltered employment, finding no differences for participants with a low Functional Work Ability (FWA), while participants with high FWA in open employment reported statistically significant higher scores of empowerment/independence, social belonging/community integration, and total QoL, than participants in sheltered employment. Verdugo and collaborators [73] indicate that in supported employment, high levels of job typicalness (the degree to which the characteristics of a job are the same as those of workers without ID) and certain characteristics of support (i.e. hours of direct external support) are associated with a higher QoL.

Also for persons with ASD, being employed has been identified as a predictive factor of a better QoL, together with being in a relationship and receiving support, while lower QoL was associated with being female, having a current mental health diagnosis and higher severity of autism symptoms [74].

In general, persons with ASD have been found to have a lower QoL than the general population [74, 75].

### *By whom should QoL be measured?*

Many researchers believe that assessment tools can detect a person's QoL in a valid way only when used directly with people with good cognitive and introspective abilities. For this reason, their use with people with ID might be discouraged, especially in those with greater impairment. This position is not supported by evidence, which indicates instead that people with ID are not only able to process information, perceive sensations or express emotions in a way suitable to the attribution of importance and the perception of satisfaction in the various areas of the life, but also to manifest these importance and satisfaction to others, at least behaviourally. This applies also to persons with more severe cognitive impairment [76]. In general, it has never been shown that lower IQ, however severe, should be sufficient reason to rule out capacity for self-awareness and self-determination [77, 78, 50].

On the other hand, it has never been shown that individual QoL should be assessed only from the person him-self/herself. In fact, assessment in other fields typically emphasizes a comprehensive approach. Practical assessment experiences suggest that evaluations and scores provided by proxies, or other persons less close to the person under assessment, can provide valuable information, adding stability and clarity, and extending the range of assessment information gathered. Such additional information is also an opportunity to understand that assessment information from people themselves is often shaped by various factors, such as specific life events, psychological, or psychopathological states. Some authors have stressed this point of view by claiming that only using individual perception to measure QoL represents a disadvantage to its measurement [11, 8].

Data on the consistency between self-assessments and proxy reports are not homogeneous, even if those indicating a lack of consistency seem to prevail [63]. One argument in support of the low validity of proxy assessment is the presumed existence of a gap in the attribution of quality between people with ID/LF-ASD and those with typical development. Some research findings seem to refute this hypothesis, as they observed a substantial agreement of the assessments performed by proxies with and without ID [79, 80]. Proxy attribution of QoL in the

**Table 2**
State of knowledge and current issues in QoL assessment for people with ID and/or LF-ASD

| Mapping question | Key points |
|---|---|
| Purpose of QoL measures | - shared QoL<br>- personal QoL<br>- family QoL |
| What QoL measures actually measure | - domains/areas (objective assessment)<br>- dimensions (personal appraisal)<br>- indicators (individual objective assessment) |
| Persons for which measurement is possible | - every person with ID/LF-ASD (any degree of impairment) |
| By whom QoL measurement should be made | - individual with ID/LF-ASD<br>- proxies (persons who know the individual well)<br>- external assessors |

instrumental assessment does not seem to be influenced even by the degree of disability. Findings suggest that prejudicial attitudes towards the QoL of people with severe ID may be either absent or contained [42].

In general, the literature indicates that the best way to evaluate QoL is to integrate self- and hetero-assessments, which implies in practical terms the merging of data from questionnaires addressed directly to the person whose QoL is under assessment with data from questionnaires filled in by proxies and external assessors. Within this system, the self-assessment must be considered central and it is necessary to provide persons with ID/LF-ASD with every means that can support them in expressing their point of view.

A good example of how this can be implemented even in people with more severe ID is the Lyons *Life Satisfaction Matrix* [65]. This approach assumes that people with severe ID express importance and satisfaction through recurrent behavioural repertoires, identified by those closest to them and validated by other people less involved in the relationship. Lyons' approach also assumes that individual's routine daily activity preferences can be determined from their affective behavioural repertoires [65]. The QoL-IP referred to earlier [37] also keeps self-assessment central, but supplements that with QoL measures both from "other persons" (two people who know the assessed person well) and the external assessor.

To determine subjective components of QoL in persons with severe ID/LF-ASD, other authors used observable expressions and responses, such as facial reaction (smiling, pouting, etc.), sounds or body movements. Various observers have been used, including unfamiliar observers, and confirmation was often provided by supervisory staff [81-83]. Verdugo and his collaborators, during a long validation process of a new questionnaire for proxy assessment of QoL in people with severe ID, confirmed that the QoL areas upon which the assessment has to be based do not differ from the ones for mild ID and for the general population [84]. This supported earlier assumptions in the use of proxy assessment areas. The World Health Organization has recently completed the validation of an adaptation for people with ID, the WHOQOL-Dis [85, 43] of its QoL assessment tool (WHOQoL) [86] and promoted the evaluation of its applicability to various socio-cultural contexts [87].

## CONCLUSIONS

Key points of the state of knowledge and current issues in QoL assessment for people with ID and / or LF-ASD, identified through our systematic mapping of the scientific literature, are summarised in *Table 2*.

The literature substantially agrees that QoL represents a multidimensional concept, best measured through an integration of qualitative and quantitative methods as well as a through a combination of subjective and objective perspectives. Most authors agree that the assessment should be based on a system of values consistent with that of the person with ID/ASD, and that it should be used to identify the most useful supports and interventions across the life span.

Currently available tools, although they have some common conceptual and evaluation characteristics, still show considerable differences. The most important concerns are: the areas, or domains, that should be included in the "shared QoL"; the dimensions used to evaluate "Individual QoL"; and the role attributed to indicators of QoL.

A highly effective tool should be based on a standardization of all these aspects. The rapid evolution of QoL research in the last decades gives hope that this will occur.

### *Conflict of interest statement*

The Authors declare no conflict of interest.

*Submitted* on invitation
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 193-205
DOI: 10.4415/ANN_20_02_09

# New mode of care. Value and limit of the person-centered care planning for people with mental disability

**Laura Camoni, Angelo Picardi and Aldina Venerosi**

*Centro di Riferimento per le Scienze Comportamentali e la Salute Mentale, Istituto Superiore di Sanità, Rome, Italy*

**Abstract**
The huge increase of people with mental and intellectual disability worldwide, and the advocacy capacity achieved by these patients, which culminated in the Convention on the Rights of Persons with Disabilities (CRPD), came along the shifts in the way governments deliver public services. In particular, in the last decades, many countries examined how to provide a person with disabilities an acceptable social functioning, improve well-being, according to the principles of equity, solidarity and participation. A new political and social-health model was born, called "welfare community", users are protagonists of their health project and the resources put in place assume an investment character on the community and its economic development. Personalisation of social and health services is also considered in many countries as a "new mode of care", although in different forms depending on financial aspect and recipients. The present article is a narrative review that examines and summarize international research and non-research material to survey the different implementation strategies of personalisation in different countries, with a special focus on Italy, in attempting to provide conceptual clarity about this topic in terms of opportunities and pitfalls.

**Key words**
- personalisation
- community
- welfare
- health
- social
- care
- mental disability

## INTRODUCTION

The World Health Organisation estimates that over 1 billion people globally experience disability (15% of the world's population) and that this number will continue to grow into the future, with the consequent challenge of giving appropriate answers to the increase in people's needs [1].

In 2013, in Italy, in line with the last data reported by the National Institute of Statistics (ISTAT), about 13 million people aged 15 and over have serious functional limitations, disability, or chronicity. Among these, 23.4% (about 3 million people) report having severe limitations, i.e. the maximum degree of difficulty in at least one of the motor, sensory, or essential activities of daily life [2].

The impact of this health problem in terms of financial cost, morbidity, and need of care is so high that over the past 30 years there have been major shifts in the way governments deliver public services. Increasing complexity and cost of care have stimulated the planning of integrated healthcare services with the aim of coordinating the delivery of care and reducing waste and burden on the system [3]. At the same time, many countries have deliberated welfare solutions in accordance with the principles of the Convention on the Rights of Persons with Disabilities [4], and they shared the concept that "disability is the result of a complex relationship between health conditions, environmental and personal factors in a dynamic interaction between these elements that can mutually change".

As a result, at the beginning of the last century, models such as welfare community and personalisation call attention to the effectiveness of the system rather than on its efficiency, to grant social answers to the needs of people well off or with severe social problems or disability.

The welfare community model emphasizes the role of the local community and introduces innovative strategies for health systems. The main elements of this innovation are decentralized services, person-centred care, a stronger link between governments and people, and the promotion of a partnership between the community and people with needs in order to increase the spectrum of supports available and to empower and advocate people with needs for more advanced health and social reforms in respect of their rights [5]. Finally, the welfare community could be the best "place" to play democracy and participation and thus to give substance to the Am-

*Address for correspondence:* Aldina Venerosi, Centro di Riferimento per le Scienze Comportamentali e la Salute Mentale, Istituto Superiore di Sanità, Viale Regina Elena 299, 00161 Rome, Italy. E-mail: aldina.venerosi@iss.it.

arytha Sen' capabilities approach [6]. This new mode of giving health and social care is able to improve the freedom of choice of persons and families towards institutions and transform the costs of care and assistance in productive investments that increase social innovation and satisfaction for people and families. Users become protagonists of their health project, and the resources that are put in place assume an investment character for the community and its economic development. This model of welfare differs from welfare based on efficiency, which meets the needs of users and provides answers in the form of pre-ordinate assistance services. In turn, by the "personalization of services", community welfare allows the citizens to be involved in the production process of the service itself, guaranteeing their active participation and stimulating the community to base itself on the values of solidarity, social cohesion, and the good common [7-10]. Personalisation assumes in this framework a pivotal role in the future of the welfare state, as this model appears to increase the value of individual's choice and autonomy in care systems, and proposes itself as a social determinant of health [11]. The concept of personalisation, embedded in the welfare community model, claims for services tailored to the needs and preferences of citizens, and promotes recovery and inclusion. The overall vision is that the state should empower citizens to shape their own lives and the services they receive [12]. In this context, people are granted the power to design the most useful services to meet their specific needs and are an active part in the decision-making process, responsible for their plan, and likely self-directing monetary benefit, with powers of speech and criticism of the service itself.

The aim of this paper is to explore the concepts characterizing the personalised care model through the literature, and the spread of policies that at international and Italian level apply "personalisation" and self-direct support in their welfare strategies.

## METHOD

Research and non-research material was examined and summarised by a narrative review to provide conceptual clarity about the topic of the paper.

The following literature search strategy was devised in order to collect the relevant material and ensure adequate methodological rigour:

- electronic database search (PubMed, Google Scholar);
- relevant content of the websites of the Italian Regions;
- grey literature (institutional, charity, or specific welfare programs reports).

The search included the following terms: person-centred care, personalization, personalized plans, individual budgets, personal budget, direct payments, personal health budget, social budget, health budget, person-centred budget, and self-direct support.

We have intentionally excluded specific terms describing the target population of these programs (older people, children and adolescents, elderly, end-of-life care, people with disability, drug users, people with chronic and chronic degenerative, HIV patients, etc.) to collect the wider bibliographic references on specific and comprehensive welfare programs that implies a personalisation approach.

We also examined the reference lists of selected articles to identify other useful articles and to scan topics in order to overview the countries' policies on "personalisation" and the benefits and drawbacks of personal budgets, especially for people with mental and intellectual disability, in order to highlight specific pitfalls or opportunities of personalisation for these particular groups in need.

In this narrative review, we tried to summarize the available knowledge on the topic. Given that our interpretation of the literature is affected by our personal convictions, this review might be biased to some degree.

## FINDINGS

The main topics that emerged from the narrative review of the literature are summarized here.

### *Personalisation*

In person-centred models, personalisation is the way to have choice and control on welfare solutions. This includes giving funds for the assistance directly to users (direct payment), so they can purchase services and supports or in some case make new ones that best meet their needs, rather than standard "one size fits all" programs [13, 14, 11]. Depending on country or administration, these welfare strategies are called with different names, such as "health budget", "personal budget", "direct payments", "individual budget", "personal health budget", "social budget", "person-centred budget", "self-management model", "independent living fund", and "integrated care" [15]. They may include the following main administrative funding channels: local authority adult social care; integrated community service; people for housing-related support; access to work; independent living fund. Therefore, in this context, the term "personalization" has nothing to do with the concept of "personalised treatment" as it is used in the clinical literature, which refers to the identification of predictors of treatment success in order to apply specific psychopharmacological or psychosocial interventions only to the patients known to benefit especially well from these interventions [16]. The most frequently used strategies to support person-centred care budget are the following ones:

- the local authority places an individual's personal budget with a third party, so that day-to-day business arrangements are between the service user who has a personal budget and the third party provider (purchasing or commissioning);
- the local authority itself holds the personal budget and manages/arranges the services on behalf of the service user (providing in-house owned or managed services);
- a mixed solution including elements of the previous ones;
- direct payment, i.e., people are given the cash to buy the services that they and their doctor or – care manager decide they need. People have to show how they have spent the money, but they buy and manage services themselves.

The introduction of 'personalisation' identifies the (personal) health budget as the ideal tool for the activation of integrated social and health interventions defined by personalized life projects. It is an allocation of funds to users to support directly their individual health and wellness needs, which is planned and concerted between the individual and the health and social services, often through a professional, such as the care planner or manager [15]. Then, the health budget states the centrality of the person and its role in the co-construction of the individual projects that result in the definition of a contract. Some authors have underscored the need of a reflection on the different meanings that personalisation can assume when operational processes are applied. Personalisation is proposed as a distinctly different concept from that of individualisation [17, 18]. On the one hand, the services that operate according to individualisation provide services tailored to the user, specifically and individually for him or her. In this model, the administration has the role of enabling citizens to "purchase" services that best meet their needs from a "service market" [10]. Thus, the provision of eligible services is often within a pre-fixed range, with the risk that the choice concerns how services can be used rather than the purpose of their use and the outcome they want achieve [19]. In individualisation models, the users are passive because they are not recognized as being able to co-plan and/or co-product the service. On the other hand, in greater agreement with a community welfare model, personalisation is conceived in a participative framework, where people who use the services not only choose and control the services necessary for their needs, but also contribute to producing them [20, 21, 3]. In this perspective, the model of governance changes, as the public authority no longer only provides fees for services but it actively programs and calls all the protagonists (person, family, associations, communities, volunteering) to be co-producers and co-responsible for the well-being of the people who express a health need [18]. Thus, personalisation offers a new way and a potential improvement of the supports for the individuals with care needs. Furthermore, such a model of person-centred care might result in significant changes for several different agencies and individuals involved in the design and delivery of welfare services [8, 17].

### *International experiences*

The approach to personalization and its different application strategies has found several implementations at the international and national level as part of the ongoing evolution of welfare systems worldwide, with significant variation in the degree of patient choice and control [22]. In addition, the contexts in which the different programmes are developed differ in many ways, i.e., structurally, organisationally, and culturally. Thus, personalisation is differently shaped in different countries by how they set different categories of services (continuing healthcare, long-term health package, caregivers supports) between e.g., health care and social care. Comparing key aspects of different programmes, such as eligibility criteria, scope, and the ways in which budgets are planned, deployed and monitored, is of paramount importance. However, for the sake of brevity, we present here only a summary of the main international experiences about social and health policy. For a more complete review of international experiences, we refer the interested reader to Alakeson [23] and Wirrmann Gadsby [15]. A more detailed description will be devoted to the Italian experience.

### *USA*

A "consumer-directed care programme" funded by the Medicaid Personal Care Services was firstly experimented in the USA during the 1970s. Rather than being implemented nationally, this benefit option was implemented under the purview of individual states and was addressed to low-income elderly and disabled people. The model comes out of the independent living and disability rights movements, and it initially included mainly services such as home and community-based long-term care [24]. The more flexible Cash and Counselling Program started in the 1990s, and was defined as "an approach to long-term care personal assistance services in which the government gives people cash allowances to pay for the services and goods they feel would best meet their personal care needs" [25]. The main objective of this programme was to enable people with disabilities to decide for themselves the type of social and health service, which completely overturned the traditional model where the decision on the type of intervention to be provided was delegated to the professional [26]. Initially implemented only in fifteen states under Medicaid provider, the number of states in which it is available has now been expanded considerably and relies on non-Medicaid insurance or non-profit assistance agency. In the Cash and Counselling Program, recipients were given the flexibility to choose their own home care agencies, and family members could act as a "home care agency". This meant that relatives, such as the adult children of aging parents, could be hired and paid for the personal assistance they provided. In other words, family members could become paid caregivers [27]. Designed specifically for in-home care, some programs currently include individuals who lived in small group homes and even assisted living residences.

### *Canada*

Programs called Self-Managed Attendant Services – Direct Funding have been run for two decades in Canada [28, 29]. In contrast to conventional programs in which care is managed and delivered by professionals or agencies on behalf of the client, in self-managed care governments directly fund clients, who then purchase services from providers of their choice. The clients have an active and central role both in defining needs and in determining how those needs should be met. However, this programme is not equally widespread in Canada, and the available programs differ widely in terms of patient eligibility and structure. Ontario, for example, offers the largest self-directed care program in Canada, managed by Self-Directed Personal Support Services Ontario [30]. It concerns people with high-need conditions requiring at least 14 hours of support per week (mostly families with autistic children as well as for some seniors and persons with disabilities), who select and schedule their own personal support workers. The Ontario Ministry of Health and Long-Term Care and Local Health Integration Networks (LHINs) has also implemented a new self-directed care program, named Family-Managed Home Care, under which clients or their decision-makers will receive funding to purchase home care or employ care providers. Other provinces that have some form of self-directed care include British Columbia, Alberta, Manitoba, and Saskatchewan. Finally, Canada launched in 2010 a specific program devoted to people with mental illness. The Mental Health Commission of Canada launched this program to address the multifaceted problems affecting mental health system in the country. The driver assumed by the Commission as transforming mental health system was the development of a 'recovery' system (resuming life in the community with dignity and purpose, lived at the individual's full potential) based on a mental health self-directed care model [31].

### *United Kingdom*

In the UK, personalization was introduced in the 1980s by the pressure of disabled people's organisations. In the 1990s some local authorities applied the concept of personalization by introducing "direct payments" (a cash sum to replace the services provided directly) intending to provide physically disabled adults with more choice and control over their lives. In 2003, the Department of Health in England promoted a pilot program called "In Control". People with disabilities are given a budget and establish what level of control they wish to take over that budget; then, they decide how to use it and seek approval from local authorities. People can use their budget flexibly, as they can use statutory services (the cost of which is taken out of the budget) or other forms of support; if they change their minds, they can redirect their budget toward other forms of support viewed as more appropriate. This pilot experience showed that people had an improvement in outcome when given the opportunity to get involved in their own evaluation and intervention plan. The pilot experience initially involved a few local authorities, but after preliminary results suggesting its effectiveness and its potential for saving money, in 2008 it was extended to all the local authorities concerned [19]. The individual budget can either be administered by the users or their family as a direct payment, or it can be managed by the local authority or a third party to which the service is commissioned. The money may be used to support the person's well-being, social inclusion, self-management, and participation in meaningful activities. The assumption of personal budgets stands at 88 per cent of people with disabilities aged under 65, with 42 per cent of these taking the money as a direct payment [32]. The Care Act in 2014 [33] reaffirmed the concept of direct payments, individual budgets, and self-directed support (SDS) as useful tools to empower all disabled persons to obtain a support that is tailored to their needs [34, 12]. In 2014, the Scottish Government introduced an innovative self-directed support (SDS) that helps people and families to have an informed choice on how to use the budget according to their needs by a co-production approach, i.e., support that is designed and delivered in equal partnership between people and professionals [35]. As for Ireland, a National Disability Strategy was launched in 2004 by the National Disability Authority [36]; its main aim is to support the inclusion of people with disability in the society by the elaboration of standards and guidelines that drive person-centred planning. Recently, the Ireland's Health Service Executive launched a reform called Transforming Lives Program with the following three main points in agenda: 1) congregated settings (a time to move on), which is about enabling people to "live ordinary lives in ordinary places" and aims to enable disabled people to move from large institutions (congregated settings) to their own homes in the community with the support they need; 2) the provision of day services (new directions), which aims to set the standards for a new approach to adult day services to be based on person-centred planning [37-38]; 3) progressing children's services (0-18 therapy services).

### *The Netherlands*

In the Netherlands, personal budget (Persoonsgebonden Budget, i.e., PGB) was institutionalised in 1995, after a trial period that started in 1991. Initially it was reserved for specific groups of people, such as those who needed home help or nursing, and people with mental retardation. It was later extended to disabled children. In 1997, it became possible to employ one's own husband or wife.

The personal budget aims to give autonomy and empowerment to the patients. It should also promote competition between providers, increase efficiency, improve the quality of care, and strengthen the role of patients as consumers, rather than only as citizens. As consumers, patients get a stronger voice in both care politics and the organisation of care. Nevertheless, as the market is very bureaucratic, it was necessary to enter a new professional figure, the care consultant, who is paid by the state to help the budget holder. This, in contrast to the goal of stimulating people's independence, carries the risk of making the patient dependant on the care consultant [39, 40].

### *Germany*

Cash payment for care was introduced in 1995 and expanded in 2008. The primary motivation was to increase independence and freedom of choice of individuals by expanding the options available for home and community-based long-term care, increase competition, reduce pressure for care homes, and thus lead to lower costs. Eligible people are "persons with physical, psychological or mental disease or handicap that are expected to need a substantial amount of help to carry out the routine activities of everyday life for approximately six month or more" [41]. It is used to nursing, assistance at workplace, transport, and other services provided by health/care insurance.

### *Norway*

Since the 2000s, Norway has adopted a new model of organization of the social services that strengthens the role of the consumer among users, by offering people an allocation of funding to meet their needs. Furthermore, the personalisation policies encourage greater choice and control regarding care services and allow for the use of "cash-for-care", which gives people an allocation of funding to meet their needs. This cash-for-care system is called user-controlled personal assistance (Brukerstyrt Personlig Assistance, i.e., BPA) [42]. Within this model, the Municipality evaluates the eligible persons, and the user assumes the role of employer/manager with or without the support of the municipality or of cooperatives. Central to this model are the employment and choice of the user's care workers, and the decisions about their working tasks and their time of working [43]. Similar programs are developed in the other Scandinavian countries [44].

### *Australia*

The Australian National Disability Insurance Scheme (NDIS) was introduced in 2013 and rolled out in 2016. The reform arose as a response of the government to reports that Australia was the worst performer of 27 nations in terms of poverty levels for people with disability [45]. The NDIS is a population-wide insurance-based scheme that includes services for several categories of people with disability, including psychiatric disabilities. There have been established personalized funding whereby eligible people choose the services that they need to help them to live well, and funds are then allocated according to a "personal budget" to be used to pay for services under normal business arrangements, replacing a patchwork of state-by-state prerogatives [46]. The main objective is to support the social and economic participation of people with disabilities; also, the programme aims at increasing "men at work". This scheme intends personalisation as social investment that transfers fiscal commitment that the reform needs in social and human capital in order to enhance global competiveness (Needham and Dickinson, 2018). However, since 2012, the Australian government set up a series of reforms and phased in a universal delivery of "Care package", which was formalised in February 2017 under the Increasing Choice in Home Care policy [47]. Consumer-directed care is here defined as when "you (and your carer) have more choice and control over what services are delivered and where and when they are delivered" [47]. The aim is to give patients greater freedom of choice by providing them with the opportunity to decide about the provision of their health care.

### *Italy. The social and health integration policy*

In Italy, the first steps towards a policy of social and health integration started with the reform of the National Health System [48] and the DPCM February 14, 2001 [49]. Article 3 septies of Decree-Law 229/1999 defined social and health services as: "*all activities aimed at satisfying, through integrated care pathways, the health needs of the person that requires unitary health services and social protection actions, capable of guaranteeing, also in the long term, the continuity between the care and rehabilitation actions*". The same decree divided the social and health services into health-related social service (health promotion activities, prevention, and removal of invalidating pathologies) and social-related health service (support activities for the person in need). Thus, since 2001 the Italian National Health System recognised the close correlation between health and social services, which must satisfy the multidimensional needs of citizens (health, social, relational, and economic needs). To the services already identified, it added the health and social services with high health integration, i.e., services in which health and social aspects are closely linked. In addition, by the Law 328/2000 [50] "Framework law for the realization of the integrated system of interventions and social services", Italy introduced the personal plan as integration of social and health care. This reform increased the leading role of the local institutions and civil society. Furthermore, it specified that social and health integration should be the "synthesis of the economic, professional and human resources necessary to start a process aimed at restoring the person to an acceptable social functioning, through an individual rehabilitative therapeutic project, produced and participated by the patient, his family and its community" [51, 10, 9]. It is important to highlight that in Italy, in the field of mental health, the idea of integrated care was previously defined in continuity with the legacy left by Franco Basaglia by the Law 180/1978 [52]. This law enforced the closure of the mental hospital, which restored dignity to people with mental problems, and promoted the role of the therapeutic community within an "ecological" perspective. This innovative reform imprinted in the Italian society a new direction in the mode of care, and encouraged a higher level of integration between social and health care [53].

In planning the integration of health and social services, one has to rely on every area of human daily living and more recently an interesting application has been given with the approach of the quality of life (QoL) [54]. The main areas are: 1) learning/communication; 2) training/work; 3) home/social habitat; 4) affectivity/sociability [9]. The Individualized Therapeutic Plan [55] builds on these areas and relies on a tailored financial support to make on a "personal health budget". A wide spectrum of people is eligible for the health budget, such as persons with disabilities, both physical and mental, in either acute or chronic condition; ex-prisoners and drug users; or, more generally, people with social marginality and exclusion for whom the rehabilitation process must include both health and social aspects. All this requires a strong integration of human and financial resources to support autonomous life by creating an articulated network of agents that involves both public sector organizations and private actors, including the person and his family, local health units, municipalities, and voluntary and charitable organizations. The health budget assumes different intensities according to the health condition and level of social functioning of the patient [51, 9, 56]

Because of health reforms that in Italy have established the importance of integration of the health and social services, some regions have adopted the health budget as an integrated tool for managing social-

**Table 1**
Italian regional health and social integrated care programmes

| Region | Target population | Use | Operative tool | | | Financial / funding tool | | Co-design | Regional law |
|---|---|---|---|---|---|---|---|---|---|
| | | | PUA | UVM | PTI/PAI | BdS | Voucher | | |
| Piemonte | Psychiatric patients | | x | x | x | x | | x | DGR n. 29/3944 del 2016,<br>DGR n. 41 del 2018,<br>DGR n. 355/1817 del 2019 – "Piano d'Azione per la Salute Mentale (PASM)" |
| Lombardia | Psychiatric patients,<br>fragile people,<br>persons with very serious disabilities (i.e. ALS, vegetative state),<br>persons with severe disabilities and reliant from other persons, persons with disabilities | Affection/ socializing<br>Training/work<br>home/social habitat | x | x | x | x | x | x | DGR n. 7/12902 del 2003,<br>DGR n. 23 del 2005,<br>DGR n. 79156 del 2008,<br>DGR n. 10/74027 del 2013,<br>DGR n. X/7600 del 2017-Regole 2018 |
| Veneto | Psychiatric patients,<br>fragile people,<br>disabilities (i.e. ALS, vegetative state),<br>persons with severe disabilities and reliant from other persons, persons with disabilities | | nd | x | x | nd | nd | x | DGR n. 2372 del 2011<br>LR 23 del 2012<br>DGR 975 del 2013 |
| Friuli-Venezia Giulia | Families, minors,<br>elderly,<br>end-of-life care,<br>people with disability,<br>drug users,<br>people with chronic and chronic degenerative,<br>HIV patients | Living<br>Training/ working<br>Socializing | x | x | x | x | | x | LR n. 6 del 2006, art. 5 (progetto assistenziale personalizzato) art. 41 (Fondo per l'autonomia possibile) |
| Liguria | People with fragility condition,<br>not self-sufficiency | | x | x | x | dote di cura | | x | DGR n. 446 del 2015 - Sistema integrato sociosanitario disabilità |
| Emilia-Romagna | People with mental disorders temporary<br>Project on fragile people | Home/habitat<br>Affection/ socializing<br>Training/work | x | x | x | x | | x | DGR 478/2013;<br>DGR 805/2014<br>DGR 1554/2015 "Linee di indirizzo piano sociale e sanitario Emilia-Romagna 2017-2019" |
| Toscana | People with disability | Health and social, school and work, environmental / domestic and socio-relational | x | x | x | x | | | DGR n. 1449 del 2017 |
| Lazio | Families, children and adolescents with disabilities, people with disabilities, elderly, migrants and other minorities, disadvantaged people, prisoners, homeless people, psychiatric patients, drug users | Learning/ affection/ socializing<br>training/work<br>home/ social habitat | x | x | x | x | x | x | LR n. 15 del 2016<br>LR n. 11 del 2016 -Sistema integrato degli interventi e dei servizi sociali della Regione Lazio, art. 53 e capo VII<br>DGR n. 326 del 2017 - Linee guida in materia di co-progettazione,<br>DRG n 149 del 2018,<br>DGR n. 259 del 2018 - Vita indipendente |

*Continues*

**Table 1**
Continued

| Region | Target population | Use | Operative tool | | | Financial / funding tool | | Co-design | Regional law |
|---|---|---|---|---|---|---|---|---|---|
| | | | **PUA** | **UVM** | **PTI/PAI** | **BdS** | **Voucher** | | |
| Campania | People with mental disorders, social disability, and chronic or degenerative disease | Learning/ affection/ socializing<br>Training/work<br>Social habitat | x | x | x | x | | x | LR n. 11 del 2007,<br>LR n. 1 del 2012 art. 46,<br>DGR n. 483 del 2012 - Linee Guida,<br>LR n. 5 del 2012 (art. 3 agricoltura sociale)<br>LR 7 del 2012<br>DGR n. 478 del 2013,<br>DGR n. 805 del 2014 |
| Sicilia | Psychiatric patients<br>Non-self-sufficient elderly<br>Persons with disabilities | Learning/ affection/ socializing<br>Training/work/ income<br>Home/social habitat | x | x | x | x | x | x | GURS n. 24/2012- Piano Strategico Salute mentale<br>GURS n.32/2017-Piano Regionale socio sanitario<br>GURS n. 53/2002-Linee guida per l'attuazione del piano socio-sanitario,<br>GURS n.30/2005- Definizione dei criteri per l'erogazione del buono socio-sanitario a nuclei familiari con anziani non autosufficienti o disabili gravi<br>Agreement Protocollo di intesa tra Ministero Salute e Regione Sicilia sull'agricoltura sociale (21/02/2014)<br>Legge n. 17/2019 art. 24 |
| Sardegna | People cared for by mental health services (social disability or fragility), including drug users | Affection/ socializing<br>training/work<br>home/social habitat | x | x | x | x | | x | DGR n. 35/6 del 2007 e allegato,<br>DGR n. 10/24 del 2010 e allegato,<br>DGR n. 50/19 del 2015 e allegato,<br>DGR n. 26/5 del 2018 e allegato |

*Italian definitions and acronyms legend:* PUA: single point of access; UVM: Multidimensional assessment unit; PTI/PAI: Personal therapeutic plan/personal assistance plan; BdS: personal health budget; Voucher: direct payment; dote di cura: personal health budget; DGR: Regional Council Law; LR Regional Law; GURS: Official Journal of the Sicily Region.

health interventions. *Table 1* shows the main operational, financial and legislative measures implemented by some regions. The areas of application are mainly in the field of mental health (Lombardia, Piemonte, Friuli-Venezia Giulia, Liguria, Emilia-Romagna, Toscana, Lazio, Campania, Sardegna, and Sicilia) and disability (Friuli-Venezia Giulia, Lombardia, Toscana, Lazio, Campania, and Sicilia), but there are also practices in other fields of fragility, such as older people, drug users, child protection, and people with chronic degenerative diseases (Lombardia, Veneto, Friuli-Venezia Giulia, Emilia Romagna, Toscana, Lazio, Campania, and Sardegna). Common objectives include supporting active and autonomous life, stimulate the inclusion, and promote independent living. In some regions (Friuli-Venezia Giulia, Lazio, Campania, and Sicilia) health budgets have also been applied to social farming. Also, in a number of regions the health budget is provide by means of direct payment (Lombardia, Lazio, and Sicilia), which consists to provide vouchers through the local health units or the Municipalities. In this case, the economic contributions can be used to buy assistance services in public or private, profit or non-profit subjects and are independently managed by the users under the assumption that they have all information necessary to choose the best service for them. To detail some applications of the regional legislation, *Table 2* summarises programs adopted by local health units in order to implement health budget and personal plan design.

### *Benefits and drawbacks of personal budgets*

The welfare system must deal with the current high unpredictability of economic systems and the recurrent crises that have characterized the last decades. In this new context, as introduced above, the welfare system turns towards the notion of social investment where, instead of social assistance, capacitation of social and economic capital are the main effects of the welfare costs. In order to reach sustainability of welfare, there is a need of capacitating people by means of social services, thus transforming their abilities into positive resources to generate a cohesive and dynamic society [56, 57]. This increases human and social capital, and

**Table 2**
Some applications of socio-health integration policies in Italy

| Local health unit | Objectives | Governance structure | PTRI (Italian acronym for Personal therapeutic rehabilitation plan) | Professionals involved | Case manager | Agents | Financial tools |
|---|---|---|---|---|---|---|---|
| Torino (TO4 district) | Reorganization of psychiatric residency, appropriateness of hospitalizations, and organization of the home care model (oriented to the health budget model)<br>Overcoming the use of control techniques<br>Participation of users and their family members in the Construction of Care Project (Piedmont Mental Health Plan, 2019) | CPI (Italian acronym for Individual Project Commission) composed of Mental Health Units professionals, which supports the teams of the CSM (Italian acronym for Mental Health Centre) in preparing individual residential, home, and integrated community support projects<br>UVM (Italian acronym for Multi-dimensional Assessment Unit, which evaluates the project, assesses the clinical appropriateness, defines the resources, establishes the level of intensity, and identifies the co-producers)<br>Assessment tools<br>GAF: psychological and adaptive functioning<br>Mini Icf-app: functioning and disability<br>HoNOS: for efficacy evaluation<br>Recovery Star: to measure progress | PTRI assessed by UVM<br>Objectives:<br>•social habitat<br>•work<br>•socializing | UVM<br>Fixed members: President (appointed by the Director of the Complex Structure), psychiatrist, case-specific staff members, patient<br>Variable members: defined by the President of the UVM in agreement with the patient (representatives of Local Health Units, of the social worker's units, and/or other public bodies of the patient's informal network, associations, third sector, any other person useful for carrying out the project) | Professional of the patient's referral team | Social and business agents chosen from a public call for tender | Co-participation of the Municipalities to the health budget |
| Pordenone | Welfare community: promotion of a network that integrates social-health resources with those of the territory<br>Continuity in the transition (through services from childhood for adulthood)<br>Construction of adult life projects in a community context. | Social health head office: governance and management<br>Transition Unit assessment/diagnosis, transition planning; highly complex interventions (e.g. challenging behaviour); interventions for the construction of a network (e.g. job inclusion)<br>Assessment tools<br>-BasiQ: generic QoL scale<br>-SPAID: psychiatric traits<br>HoNOS: functional assessment<br>Disabled advanced medical assistance (DAMA) dedicated access to hospital diagnosis and relationships with general practitioners (GPs)<br>Multidisciplinary team for the handicap (Italian acronym: EMDH) personal plan definition, assignment of interventions and responsibilities, approval of the funds | Three dimensional PTRI:<br>• to be (who the person is);<br>• to belong (relationship with other people and environment);<br>• to become (what the person does and what he or she would like to become) | Transition Unit<br>Social workers, neuro-psychologists (specialist in neurodevelopment disorders), social educators, occupational therapists, dedicated psychiatric and neurological counsellors, professional dependent on social-health office<br>EMDH:<br>GPs, professionals of the health district, professionals of the Municipality social service, users, families, and other specialists (e.g. psychiatrist, neuropsychiatrist, psychologist, etc.) | Psychologist or educator (to design the plan).<br>Social worker and EMDH (to realize the plan) | Accredited or community agents (cultural, sports, voluntary associations, social agriculture network, etc.) interventions/actions have to be activated according to the definitions given in a Local Health Unit list of interventions<br>Public Health services (local health unit care, primary, specialist and hospital care) if defined in the project | Regional funds (for residential, semi-residential, and work integration services)<br>Regional Health Fund (to the coverage of major health interventions).<br>Funds of the municipalities social services (to personalized educational interventions on the territory)<br>Fondo per l'autonomia, i.e., Autonomy Fund (to customize projects to support independent living and home care) |

*Continues*

it avoids "dependence trap" and social isolation. It can be debated whether that the efficiency of personalized services depends on enabling users' choice and control, or instead on capacitating users' collaboration and response. Several scholars share the opinion that users have to engage personally in order to experience better outcomes, and ways to discover and satisfy unmet needs include activating people's potentialities by co-planning and co-production [7, 56]. The criticisms towards the diffusion of direct payment as welfare solution [13, 20]

**Table 2**
Continued

| Local health unit | Objectives | Governance structure | PTRI (Italian acronym for Personal therapeutic rehabilitation plan) | Professionals involved | Case manager | Agents | Financial tools |
|---|---|---|---|---|---|---|---|
| Piacenza | Taking care of the patient: not only health needs but also relational and communicative aspects of the treatment project | PDTAs (Italian acronym for Integrated Care Pathways). The Local Unit defined 9 PDTAs depending on condition, i.e: Fragile people Management Commitee<br>Director of Social and Health Local Unit, Director of Mental Health/Dependence Unit, Transition Psychiatry, District Directors, Director of District Plan Office<br>Operative territorial groups<br>Mental health professionals: social workers, psychiatrists, educators, professionals of the Mental Health Unit and of the Dependence Unit, social workers of the Municipality<br>Conductor group<br>Mental Health/ Dependence Unit and social services of Municipality co-conduct personal plan | Biography of the patient<br>Definition of: objectives, professionals, other informal operators and funds<br>Electronic Tools<br>Unified Electronic archive of PTRI.<br>EFESO Programme.<br>From 2020 personal dossier (Regional) and Social Folder | Fragile people PDTA<br>Transition Psychiatry Social Service of the Municipality, users, family, professionals of the voluntary sector in collaboration with the Social Service of the Municipality | PDTA fragile people: case manager for mental health sector and for social service of the Municipality<br>In particular instances, psychiatric counselling is provided | Local Health Unit, Social Service of the Municipality, agreement with voluntary sector | Fragile people PDTA Human resources of the Mental Health Unit and of the Municipality social services.<br>Dedicated fund (Zone Plans, approximately € 9000/year).<br>In some cases of psychiatric comorbidity, the Health Budget can be used |
| Caserta | De-institutionalisation: household placed in civilian homes (without health personnel, with social and health workers 24-hour coverage, and with case-specific staff members at the Health Mental Unit | Social-health coordination with administrative delegation to the Local Health Units<br>Local social and health offices (single point of access)<br>Local Integrated Evaluation Units: evaluation, planning<br><br>Assessment tools<br>VADO: for skills and goals;<br>HONOS: for efficacy evaluation;<br>ABC: for user satisfaction evaluation | PTRI is built on three objectives:<br>•home/social habitat<br>•training/work<br>•affection/ socializing | • The user and his or her family members<br>• The Local Health Unit, through the services directly involved (Mental Health Unit, etc.)<br>• The Municipality, through its social services<br>• The private co-producers subjects (non-profit but also private profit organisations) | A psychologist with a coordination function. | Co-production public/ private. Social and business agents chosen with regional public call for tender. | Local Health Unit: conversion of performance and redundant costs<br>Municipalities: part of the resources of 328/2000 Law |

suggest that enabling users and enhancing their abilities to self-manage their health and social status would produce better outcomes as compared with initiatives that focus only on patients' freedom of choice. The latter, indeed, can include simply being involved in selecting the preferred health treatment to meet one's own health-related needs, with the risk to develop consumer rights instead of citizen rights [29]. On the contrary, co-planning or co-producing services with users implies promote a full engagement of several agents, i.e., the users themselves and the public and private allies involved in building the personal plan at the local level [51, 58-60].

The studies that directly investigated the outcomes of increased choice found that choice is most beneficial when it enables enhanced-care relations. Gill *et al.* [61], for example, reported that older people emphasised the importance of individualised services that encouraged front-line service providers to develop personalised relationships with them. In this example, "choice" becomes a mechanism for enhancing care relations, and the significance extends beyond simply choosing how to spend the money. Similarly, it has been reported that for people with mental health difficulties a key factor in enabling personal budgets to support empowerment and recovery is the quality and continuity of the professional relationship, a finding that raises particular implications for the organisation of mental health social work and the organisational cultures within which this is situated [62]. However, both self-direct and personal health budget have been reported to result in positive outcomes. A report of the Commonwealth fund described that in the USA (in particular Florida and Texas programs) the users with severe mental illness had a positive shift toward prevention and early intervention, associated with improved outcomes, including more days in the community, higher scores on the Global Assessment of Functioning Scale, and greater percentage of participants in paid employment and training as compared with inpatient settings [23]. In 2013, the In-Control UK Agency reported a second phase survey on more than 2000 personal health budget holders [63]. The findings suggested that the personal health budget had a positive impact on independent living, the service access, and the control on one's own life. In addition, a large majority of personal health budget holders reported that their views were "very much" or "mostly included in their support plan" (older people 85%; people with learning disabilities 85%; people with mental health problems 81%; and people with physical disabilities 87%), with no differences across social care need groups, demonstrating a change towards a more participative welfare.

The introduction of greater choice, however, raises many concerns: the clarity on the available services, the information asymmetry between users and professionals also referred to the professionals' feelings about taking into account patients' preferences, the service quality actually chosen, and the meaningfulness of users' choice. Several scholars argued that the introduction of personal budget, especially when it is self-managed by direct payment, should pay attention to the balancing between taking risk and empowerment. In fact, in the personalisation model, increased choice comes with increased legal responsibilities and administrative tasks that many people and their supports find burdensome [26]. Furthermore, as in the case of mental health practitioners, people with enduring mental health problems [64] and people with dementia [65] are usually seen as incapable of managing personal budgets, and thus as subject to risk of financial abuse. However, a recent study by the UK National Institute Health Research Council evidenced that such concerns might be overstated [66]

### *Key factors for the success of personal budget within the Italian context*

In order to properly support people to re-establish a fulfilled life, the administrative "silos" imposed by government funding and bureaucratic processes should be forced to pursue improvement in outcomes. Overall, greater emphasis should be placed on personal outcomes such as housing, friends, social networks, education, and employment alongside clinical care and treatment. The integrated care should involve the formation of multidisciplinary teams, such as multidisciplinary ambulatory outpatient care; cross-professional care; home rehabilitation; greater involvement of the community; improving family and community-based care; applying a community-based mental health model; training community-orientated primary care [3]. The challenge is getting agencies to work together across the divide, and also to involve the non-profit voluntary sector (called "Terzo Settore", i.e., Third Sector, in Italy), which comprises bodies that rely for funding on charitable donations [8]. However, it is crucial to reflect on the most appropriate way of delivering personalised and integrated care. Indeed, it appears of paramount importance to modulate the ways to organise integrated care respecting the benefits of enhanced choice and involvement for people, without the added responsibilities of fully managing budgets. Personalisation should vary in proportion to the degree to which the person's involvement, knowledge, or leadership adds value to the quality of healthcare decisions and the outcomes achieved. This will require greater coordination across public services, as well as greater flexibility in the way health systems and social care resources are managed. Likewise, both universal services and community resources that promote inclusion and social connection should be 'patrolled' when services are offered, to avoid segregated settings [67, 7]. Finally, in order to design personalisation schemes that ensure health equity and outcome improvement, it appears necessary to take into proper account the existing structural social inequalities in the design of policy delivery systems [26]. Some parents and carers reported that they would need convincing evidence that the level of funding of personalisation scheme would be equivalent to what is already available. Some parents were also concerned that personalised demand for services may result in high demand for some services and a consequent reduction in those services that were "less popular", which may be particularly relevant where resources are already scarce, as is the case with rehabilitation therapies [14, 68]. To address the risk management of personalisation, some types of preventive practices have been suggested: first, exploring the protective value of increased choice; and second, developing risk assessment and risk management techniques to detect abuse or make it more difficult to occur [66]. Especially in the case of self-managed supports, users' preferences can conflict with workers' preferences; in this case, seconding users' choice alone disregards the labour rights and economic issues of carers. However, a more balanced approach that includes preferences of both of clients and workers may result in tensions [10]. Working conditions such as precariousness, invisibility, lack of "back up" workers for sick days, split shifts, and unpaid transportation to rural locales, and so on, should be faced and policy should offer solutions as well as standardise care worker credentials and education [69]. In this framework, training the professionals involved is a central issue when implementing personalised social care services [70].

In the previous section, we described the main welfare policies in the field of integrated care and personal health budget that were introduced in the last few decades in Italy. As compared with the international picture, the piece of legislation produced in Italy on this topic appears in agreement with the principles of person-centred care, community welfare, and 'more choice and control' for the users. Specifically, the regulation of social health integration shares, across regions, a similar overall formulation of the welfare system as well as a convergent definition of the strategic 'pillars' of the regional welfare scheme. Access, assessment, planning, and monitoring are the steps of the path governing the individual care, and they may represent the solutions for the interconnectivity between social and health functions and territorial resources within the local environment, which is the place of implementation of the individual path. Prandini [10], in agreement with others scholars [18, 29, 46], argues that personalisation will be attained if developed within an appropriate context, including new type of professionals, users' led associations, and a new governance's architecture. If the public role is to shape freedom and control, help people to exercise choice in a collectively responsible way and, consequently, to participate in creating public goods, then it would be necessary to offer listening, supporting in decision-making processes, flexibility, balancing between support and self-management, and monitoring responsibility [19]. Unfortunately, in Italy few data are available concerning the impact of the recent welfare innovations. Prandini and Orlandini [56] reported a case study focused on the Sardinian disability policy. They showed how social policy's morphogenetic cycles affected the governance of personalized disability plans, and they highlighted the consequences of policy implementation. Some relevant findings emerged: i) users' pressure played a vital role in the switch from standard to personalised welfare strategy; ii) additional funding have to be paralleled with target professionals' training and introduction of new professionals; iii) the implementation could be enlarged (i.e. addressing more than one group of needs) only if the welfare system is resized to face the increased demand for plan design and implementation. In addition, the Sardinian case study shows that co-design and co-production modality survive if counselling provision capacity follows a rigorous programming. Otherwise, the public role comes down to a simple provider of monetary benefits, renouncing to play the generative role that the personalisation model is expected to play on welfare as social investment. A further case study recently reported concerns about the implementation of the personal health budget in a local health unit in the Campania region [51]. Finding from the first year of a pilot program that started on 2005 showed that the health budget methodology in Caserta led to significant cost savings, mostly associated with the reduction of institutionalized cases and the higher appropriateness of health care services. Besides, patients who qualified for the health budget methodology accessed more timely and suitable health treatment, and they showed an improvement on some items of the Health of the Nation Outcome Scales. In addition, families and patients reported a good level of satisfaction with the program.

## CONCLUSION

Overall, the available data on the new welfare strategies that are geared more to social investment than to social protection corroborate the need to monitor national, regional, and local programs more systematically, and to undertake a comparative analysis of their governance strategies in relation to users and, hopefully, to selected outcome indicators. This is particularly true for Italy, where a national program aimed at applying and verifying the outcome at macro, meso, and individual level of a specific model of "personalisation" does not exist. First, we need to clarify differences and commonalities across the regional/local programs that promote a personal health budget scheme. An analysis involving at least two levels is desirable: i) analysis of regional legislation, population target, governance structure (nodes and agencies' role), professionals involved, funding strategy, and method of personal health planning; ii) analysis of individual outcomes in different groups with different needs. A further level that might carry substantial information would include the analysis of users', professionals', and stakeholders' perspective of the impact of the health budget implementation on their own life and organisations. Both strengths and limitations coming from these analyses can be of help to understand the 'determinant' factors that may allow to scale this welfare model at national or at least multiregional level. It is worth noting that the available Italian models of personal health budgets represent, as well illustrated by Adinolfi *et al*. [51], an advanced model of personalisation involving high intensity of co-design, and in some case co-production, which offers a wide spectrum of welfare solutions. Unfortunately, there are only few experiences. Interestingly, in Italy there is an increasing, though preliminary, interest of the private [71, 72] and non-profit sectors [73] to create partnership with people with disability, suggesting that there is an action field to promote social investment and inclusion, which represents two markers of innovation to which the public sector should pay attention both at the local and national level.

Though decentralisation is one of the new modes of care [3], the central govern plays an important role for guiding processes and locating investments and infrastructures suitable to guarantee quality, equity, and equal opportunities to people with long-term and chronic care needs. In Italy, policies addressed to harmonise welfare rules and opportunity, and to promote social investment and a stable monitoring framework, are urgently needed.

***Acknowledgments***

The Authors thank Corrado Cappa (ASL Piacenza), Carlo Francescutti (ASST Pordenone), Massimo Rosa (ASL Torino) and Fabrizio Starace (ASL Modena) for providing us data relative to the characteristics of the main Italian local programs of personal health budget, the manuscript could not have been completed without their collaboration. We would like also to thank Nadia Francia for her very useful assistance during the collection of grey literature and the editing of the manuscript.

***Conflict of interest statement***

There are no potential conflicts of interest or any financial or personal relationships with other people or organizations that could inappropriately bias conduct and findings of this study.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 206-214
DOI: 10.4415/ANN_20_02_10

# Social farming as an innovative approach to promote mental health, social inclusion and community engagement

**Marta Borgi[1], Barbara Collacchi [1], Cinzia Correale[1], Mario Marcolin[2], Paolo Tomasin[2], Alberto Grizzo[3], Roberto Orlich[3] and Francesca Cirulli[1]**

[1]*Centro di Riferimento per le Scienze Comportamentali e la Salute Mentale, Istituto Superiore di Sanità, Rome, Italy*
[2]*E-labora, Pordenone, Italy*
[3]*Azienda per l'Assistenza Sanitaria ASS 5 "Friuli Occidentale", Pordenone, Italy*

**Abstract**

Nature-based contextual factors are being recognized as fundamental for mental health prevention and promotion. Rural areas, indeed, are increasingly recognized as an elective place for the promotion of mental health. In recent years there has been a surge of rurally-based hybrid governance models in which public bodies, local communities and economic actors join forces to create innovative welfare solutions to facilitate the financial (and organizational) challenges faced by the National Health Systems. Using agricultural resources, such as animals and plants, social farming is able to address specific social needs, including rehabilitation, sheltered employment, life-long education and other activities that contribute to social inclusion. At the same time social farming is able to strengthen the economic and social viability of rural communities. We have been studying the factors underlying the potentiality of social farms to provide job placement programs and rehabilitation for people with mental disorders. Using novel methodologies and appropriate tools, we have been collecting data indicating the positive effects of farming activities on individual's social functioning, as well as the impact of farms' networking on system's sustainability.

**Key words**

- social farming
- rural areas
- mental health
- job placement
- social innovation

## INTRODUCTION

In October 1986 the Ottawa Charter for Health Promotion has "put health on the agenda of policy makers in all sectors and at all levels" [1]. The charter defined a number of action strategies used as guide for health promotion and that rely on the following principles: i) build healthy public policy; ii) develop personal skills; iii) create supportive environments; iv) reorient health services; v) strengthen community action and people's ability to manage their own health and collaborate towards such a goal. The Jakarta Declaration on Health Promotion has gone even further in emphasizing the need for intersectoral collaboration, suggesting breaking traditional boundaries within government sectors, between government and nongovernment organizations, and between public and private sectors [2]. There was a specific emphasis on working collaboratively, creating horizontal collaborative action within government departments and organizations and between competencies, such as policy, practice and research.

Following the Ottawa Charter, the WHO's Mental Health Action Plan 2013-2020 [3] has been the first formal action plan focusing on mental health prepared by WHO and, as such, is considered a landmark [4]. The plan has indicated that, at the world level, health systems have not being able to respond effectively to the burden of mental disorders and that there is an important gap to be filled between the need for treatment and its delivery. One of the objectives of the Action Plan is to promote community-based mental health and social support services, which need to encompass a recovery-based approach emphasizing the promotion of human rights, such as employment, housing, educational opportunities and participation in community activities, for individuals with mental disorders and psychosocial disabilities, ultimately supporting them to achieve their own aspirations and goals [3]. This can be achieved by shifting the place where care is provided from mental

*Address for correspondence:* Marta Borgi, Centro di Riferimento per le Scienze Comportamentali e la Salute Mentale, Istituto Superiore di Sanità, Viale Regina Elena 299, 00161 Rome, Italy. E-mail: marta.borgi@iss.it.

hospitals towards non-specialized health setting, using "a network of linked community-based mental health services", including comprehensive mental health centers and types of housing such as living with family, independent living and supported accommodation. A second main concept that has to be put in action has to do with the provision of "integrated and responsive care" meeting both mental and physical needs, and promoting the right to employment, housing and education. In order to implement these actions, the Plan underlies the importance of establishing interdisciplinary community mental health teams. Advocating with different sectors (housing, education, employment, and social welfare) becomes fundamental for the inclusion of people with psychosocial disabilities in services and programs.

## MENTAL HEALTH DETERMINANTS IN THE CONTEXT OF HEALTH PROMOTION

Our understanding of the impact of social, economic and physical environments on mental health has grown over the past decades [5-9]. Environmental factors – such as low educational attainment, material disadvantage, unemployment, inequity and discrimination – are known to contribute largely to shape mental health and many common mental disorders, and to play a major influence on physical health [10-12]. Hence, reflections on the determinants of mental health and mental disorders should include "not only individual attributes such as the ability to manage one's thoughts, emotions, behaviors and interactions with others, but also social, cultural, economic, political and environmental factors such as national policies, social protection, standards of living, working conditions, and community social supports" [12]. As an example, exposure to adversity at a young age is an established preventable risk factor for mental disorders. Depending on the local context, certain individuals and groups in the society may be placed at a significantly higher risk of experiencing mental health problems. These vulnerable groups may (but not necessarily) include members of households living in poverty, people with chronic health conditions, infants and children exposed to maltreatment and neglect, adolescents first exposed to substance use, minority groups, indigenous populations, older people, people experiencing discrimination and human rights violations, LGBT population, prisoners, and people exposed to conflict, natural disasters or other humanitarian emergencies.

The current global financial crisis provides a powerful example of a macroeconomic factor leading to cuts in funding despite a concomitant need for more mental health and social services because of higher rates of mental disorders and suicide, as well as the emergence of new vulnerable groups, such as the young unemployed. The need for collaborative practice in mental health promotion is firmly established by the sociopolitical and economic determinants of health. That is, influencing the determinants of health, such as enhancing social connectedness, ensuring freedom from discrimination and violence, and workplace and physical environmental change, will not be achieved by the health sector alone, but rather through an intersectoral approach, as emphasized by the WHO [3]. Reducing socioeconomic inequalities is one of the first steps towards building equity in public health [13].

### *Natural environments as protective factors for mental health*

In the prevention of mental disorders and the promotion of mental health, priority should be given to the environmental determinants of health, including the physical environments in which people live. Indeed, assessing the impact of a rapidly changing society and environment on (mental) health is essential to ensure benefits to the health of the public. As an example, city life has a well-established influence on mental health. Psychiatric disorders are highly frequent in urban areas, which provide an environment that can affect processes of attentional selection, including the orienting of mental processing [14], and challenge the capacity of vulnerable individuals to cope with complex psychosocial stressors, such as disintegration of family networks and discrimination [15-18]. This is of particular relevance considering that more than half of the world's population currently live in an urban environment [19]. Although the majority of the research in this field has typically focused on the identification of adversity-related factors, more recently the role of protective factors, that may promote resilience and adaptation to stress and negative events, has been highlighted [18, 20-23]. Among these, access to the natural environment and outdoor spaces has begun to be considered vitally important for mental health. Exposure to natural landscapes or their composite features, such as plants and animals, have indeed been found to have beneficial effects on stress, anxiety and depression and to promote physical activity [24-33], with cascading effects on immune functioning and general physical health [34-40]. Natural environments – including urban green spaces – also provide opportunity for social engagement and are indeed increasingly recognized for their role in contrasting isolation and loneliness and promoting social integration [24, 33, 37, 38, 41-43], all factors playing a beneficial role in the maintenance of physical and mental health [44-47]. This is of particular importance since the social environment is identied as one of the most important risk/protective factors for all-cause mortality which exceeds many well-known risk factors, such as obesity or physical inactivity [44, 46-48].

Since people and their environment are profoundly interrelated, the overall guiding principle for nations, regions and communities should be to encourage "reciprocal maintenance", that is, taking care of each other, our communities and our natural environment [1]. The conservation of natural resources should thus be set as a top-priority responsibility, together with commitments to public health, which include actions to counteract the pressures towards harmful products, resource depletion, unhealthy living conditions and environments. Addressing the link between people and their environment and the overall ecological issue of our ways of living constitute the bases for a socioecological approach to health and for creating supportive environments [1].

## PROMOTING MENTAL HEALTH TROUGH SOCIAL AND EMPLOYMENT OPPORTUNITIES: THE CASE OF SOCIAL FARMING

Stigma and social exclusion both limit the extent to which people affected by mental illness are able to get a job or to engage in lifelong learning. As a vicious cycle, being unemployed, a low educational attainment and social exclusion have all a detrimental effect on mental health and increase the risk for mental disorders [49-51]. Moreover, people with mental health problems are more likely to experience physical health problems [52, 53], which can further compromise their social participation. Hence, measures and interventions based on education and employment, community engagement and salutary activities, can trigger a virtuous circle in which improvements in mental health and resilience further impact on social inclusion.

Increased awareness and understanding of mental health should coincide with increased allocations of financial and human resources towards tackling mental disorders, not only by providing an equal access to care and treatment, but also through actions aimed at contrasting stigma and social exclusion and reducing inequalities, particularly related to unemployment. Considering the financial and organizational challenges faced by the national health and social systems, the creation of hybrid governance models in which public bodies, local communities and economic actors work together to co-produce health and social services appears crucial to offer innovative solutions while increasing economic sustainability.

In this context, *social farming* (SF) is playing a growing role in creating an independent local network of social support that, as a consequence, may sustain healthcare institutions through practices embedded in local social communities [54-57]. The term SF is based on the concepts of multifunctional agriculture and community-based social and health care. It describes any use of agricultural activities – such as horticulture, food processing, selling of products, animal care, and management of the farm-restaurant – to address specific social needs, including rehabilitation, sheltered employment, life-long education and other endeavors that contribute to social inclusion [54, 58]. The aim of SF initiatives is to increase social and/or professional skills of people with physical or mental disabilities, long-term unemployed, or, more in general, people experiencing social exclusion, while promoting their integration into society and the labour market. SF programs have also been successful in engaging older patients and in motivating them to go outside and participate to farming activities such as gardening or taking care of animals, with beneficial effects on perceived stress, mood disorders, behavioural problems and social interactions [59-61].

By providing de-institutionalized care, SF is increasingly recognized as an innovative way to respond to the cultural shift from institutional psychiatry to community-based mental health care, in line with the recommendations of the WHO's Mental Health Action Plan [3]. Considering the recent surge of interest in the potential of natural environments and nature-based interventions in contributing to the prevention and mitigation of mental disorders or states, SF is also viewed as an "open-air" laboratory to further explore evidence of an association between contact with nature and mental health [34, 42, 62, 63]. Moreover, the promotion and strengthening of bottom-up approaches able to create social and economic networks of local communities have been pointed out as an essential element to contrast vulnerability and fighting poverty in rural areas [64]. Rural areas are indeed highly vulnerable to poverty resulting from inequality in the access of groups, households and individuals to resources such as income, land, health services, and education. In particular, rural exodus and youth drain, geographical isolation, low educational attainments, scarcity of public resources, workforce shortages and lack of appropriate models of health care, all represent considerable challenges to deliver appropriate health and social services for rural residents and to foster entrepreneurship in traditional rural domains [65-70]. Being able to promote and generate social services to local communities [55, 71], SF has the potential to foster the farming sector [72, 73] and, more in general, to strengthen the economic and social viability of rural communities [54]. Moreover, SF provides new sources of income for the farming households, by allowing farmers to broaden and diversify their scope of activities [74] and helping them to become more integrated into local communities [58, 72, 73, 75].

Although SF has the potential to address the current and future societal challenges in terms of provision of primary products and public goods, environmental sustainability and improved social well-being for people with (or at risk of developing) mental disorders, research providing a quantitative assessment of the benefits of SF is still in its infancy. There is currently a lack of agreement on the indicators that could be used to measure outcomes of SF (e.g. its impact on users in terms of independence, participation, health, inclusion), as well as on the most effective protocols to be implemented (e.g. in terms of staff employed, type of activities and hours of service delivered). Moreover, there is still very little knowledge on the network of alliances to be built with local actors in order to promote SF and on the appropriate measures needed to strengthen relations and networks at the local level. This is of particular importance since partnerships among public bodies, economic actors and local communities are crucial to sustain SF initiatives. Last, very little is still known on the benefits of SF for rural development, on the comparative cost of social farming and on the social return on investment.

## MEASURING SF OUTCOMES: THE FRIULI VENEZIA GIULIA CASE STUDY

The Friuli-Venezia Giulia region, in North East Italy, is increasingly viewed as an interesting case study to observe how bottom-up SF initiatives rooted in local contexts are able to produce a process of change affecting policies at regional and national level. This region – which is mostly rural (with agricultural areas covering almost one third of its territory) – includes many farms dealing with social inclusion and may represent a model of promotion of self-organized SF initiatives through the support of specific regional policies and institutional framework.

In 2010, a public-private collaboration between the Healthcare Authority AAS 5 "Friuli Occidentale" (who sponsored the project), the Italian National Institute of Health ("Istituto Superiore di Sanità", the leading technical and scientific public body of the Italian National Health Service) and the local Consortium of Social Cooperatives "Leonardo" was established. In the context of the collaborative project, different actions were taken, with the final aim of strengthening local SF initiatives and providing a methodological framework to explore the benefits of SF relatively to its impact on participants with mental disorders and, more in general, on the farming sector. In the following two sections, preliminary results collected in the context of the project are briefly described.

### *Benefits of SF for participants: ameliorating social and professional skills of people with mental disorders*

Notwithstanding the potential of SF, there is still very little evidence on its effects in tackling behavioral problems and social skills, and in promoting social and work inclusion. Evidence for the benefits of SF has so far been predominantly qualitative (e.g., [76, 77]). Common challenges in proving the effectiveness of SF to the healthcare sector through quantitative methods are the difficulties in designing interventions with a comparative method (that is, using a control group) and with blind participants [55, 57], as well as the high heterogeneity of participants (e.g. in terms of diagnosis, age and severity of symptoms) and of the activities proposed. Although subjective perceptions are key to understanding modifications in health and well-being, more quantitative methods should be adopted to reach a consensus on which activities more effectively engage participants and produce benefits in a wide range of domains (e.g. physical, mental, social, educational and vocational). To this purpose, collaborations among professionals involved in SF, healthcare institutions and researchers in disciplines such as health care, psychology and occupational therapy can play an important role in developing replicable protocols and explore SF outcomes.

In the context of the collaborative project carried out by the Healthcare Authority AAS5 and the Italian National Institute of Health, a questionnaire was developed to assess the effects of SF activities on participants' different area of functioning, including social competences (e.g., social rules) and professional skills (e.g., tools and equipment use, knowledge of plants). The questionnaire was used to assess the effect of SF in a sample of adults with a diagnosis of psychosis in charge of the mental health services of the province of Pordenone. Main aim of this pilot study was to explore whether the engagement in SF activities is able to ameliorate behavioural competence and professional skills (e.g., autonomy, motivation/engagement). To this aim, a sample of 25 individuals with a diagnosis of psychosis were selected by the Healthcare Authority ASS5 and were involved in SF activities such as horticulture, food processing, selling of products, and domestic animal care. Six farms were selected among those already involved in SF in the province of Pordenone. The Healthcare Authority ASS5 was responsible for patients' recruitment and monitored their engagement in the farming activities. A territorial facilitator was in charge of connecting social/health services with the farms. Preliminary data were collected at the beginning, after a training period, and at the end of the project.

Results indicate improvements in different areas, including social competence, autonomy, and motivation/engagement, as indicated by scores computed by means

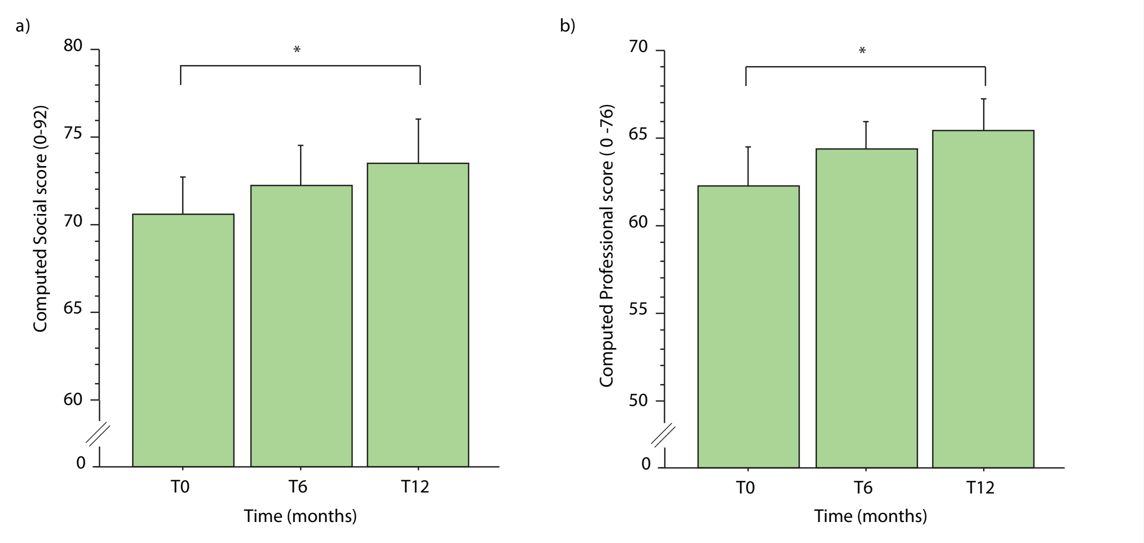

**Figure 1**
Changes in social skills (a) and professional skills (b) in a sample of 25 individuals with a diagnosis of psychosis involved in social farming (SF) activities. The graphs represent the mean (and standard error of mean) of scores computed by means of the questionnaire at baseline (T0), after 6 months (T6) and after 12 months (T12). *Wilcoxon test, $p < 0.05$.

of the questionnaire. More in detail, an improvement in social skills (Friedman test, chi$^2$ = 6.791, p = 0.033; *Figure 1a*) and professional skills (chi$^2$ = 11.256, p = 0.004; *Figure 1b*) was observed after one year of involvement in SF activities.

Although SF has the potential to address specific needs of mentally ill persons, including fighting the stigma, rehabilitation, sheltered employment, life-long education, all contributing to social inclusion, data are not yet conclusive on the outcomes of SF for people with mental health issues. Preliminary data indicate that SF is able to ameliorate social and professional skills in people with psychosis, although further research is needed to develop protocols and to pilot the design and tools for studies to understand the impacts of SF.

A great variability in the severity of symptoms is commonly observed in people included in SF programs. Moreover, farms differ in terms of the type of activities proposed (e.g., horticulture, animal care, woodwork) and skills/interventions provided (e.g., health promotion, counselling and skills qualifications). An easy tool that could be administered by non-clinicians and able to capture this heterogeneity, as well as improvements in diverse areas of functioning, is needed. Our questionnaire is currently undergoing a validation procedure using representative samples of adults with psychosis and with autism spectrum disorder. Open questions still remain as to the training of professionals involved in these activities and long-term sustainability of the system.

A research effort in this field is warranted since SF provides a great opportunity to be in – and to interact with – nature, for social interaction, skills building and purposeful work, all elements contributing to improve physical and mental health, ultimately promoting well-being and quality of life of those vulnerable and disadvantaged. Attempting to unpick the mechanisms underlying observed changes is also challenging and requires further studies [78].

### *Mapping social and economic ties of social farms through social network analysis*

One of the main objectives of the project was to map and describe the social and economic relationships of a sample of farms involved in SF and operating in the province of Pordenone. To this aim, the nature of the networks among farms – and between farms and both public and private actors – were analysed using Social Network Analysis. The impact of dissemination and promotion actions on farms' networks was also explored by collecting quantitative network variations over a period of 10 months.

Results of the study show an entrepreneurial/business vocation (e.g., production and direct sale or marketing of products and/or services) of the selected farms [79]. The aim of rural production appears to be well conjugated with the pursuit of social ends, at least in the case of social cooperatives. However, results also show a number of weaknesses characterizing the relational system in which participating farms are embedded. Indeed, differently to what expected, interactions among farms involved in social activities appear extremely weak. As pointed out by Bassi *et al.* [80] consolidated links between social farms could contrast entrepreneurial vulnerability. Relational variables (i.e., social, economic and other relationships) affect the ability of the farms to implement social activities, including the engagement of disadvantaged people, and are directly and positively related to their ability to cope with market problems. By creating networking opportunities and providing access to new resources, relations with other farms might thus support the smallest (and more vulnerable) social farms and help them to improve their performance [43].

Moreover, most of the participating farms reported a very low proportion of partners active in the education sector, as well as a low proportion of links represented by educational activities [79]. This can be viewed as a limit considering that promoting (or generating) education services represent an important step towards the inclusion of people with "low contractual capacity" as those with mental and physical disabilities. SF programs have the potential to represent a driver for the provision of suitable local training for disadvantaged people, as well as for professionals potentially involved in SF (e.g., health care professionals, psychologists and occupational therapists). Strengthening relationships between farms and educational institutions can indeed result in the growth of the SF context, increasing its ability to develop more structured programs and methodological protocols, allowing the evaluation of the outcomes, at the same time contrasting low educational attainments and youth exodus characterizing rural areas. The latter appears of particular relevance in a region like Friuli Venezia Giulia, in which rural areas, especially close to the mountains, are affected by population decline and increased population age, as well as by an increasing need for basic services and social services.

Interestingly, the exploration of quantitative network variations over a period of 10 months, has indicated that, in order to sustain SF initiatives, more emphasis should be given to the critical role played by network facilitation in diversifying actors, promoting heterogeneous relationships, and, in turn, system complexity. In the context of the abovementioned project different actions were taken, namely the engagement of both private and public institutions (health, civil authorities, and socio-economic actors) in SF programs, as well as dissemination and community engagement strategies. These actions resulted in an enlargement and diversification of social farms' networks and were able to create a greater number of shared contacts among the farms and much more complex territorial inter-relationships. Changes were observed both in the networks' structure and in the flow within the networks and appear to be in the direction of a greater balance between economic and social activities [79].

This information contributes to our understanding of how and to which extent social farms become embedded in the local network of actors and may help policy makers and practitioners to promote SF initiatives. Considering that the relational system in which farms are embedded is crucial to enhance social farms' performance and, thus, to the functioning of the system itself [80-82], agricultural innovation policies should foster the emergence and functioning of connections among different actors involved in SF, in order to build appropriate linkages and facilitate multi-stakeholder interactions [83, 84]. Network of alliances built with local actors have the potential to promote entrepreneurial dynamism and represent an advantage from the point of view of strategic autonomy and sustainability [85].

## DISCUSSION AND FUTURE PERSPECTIVES

There is an increasing need for actions aimed at the promotion of mental health and the prevention of mental disorders: "*A historic opportunity exists to reframe the global mental health agenda in the context of the broad conceptualisation of mental health and disorder envisioned in the Sustainable Development Goals* (SDGs)" [85]. Indeed, the WHO's Mental Health Action Plan, the ratification of international conventions protecting the rights of people with disabilities (such as the UN Convention), as well as research advances on the determinants of mental health problems, all support the central SDG principle to leave no one behind and its notions of human capabilities and human capital.

Ensuring that people with mental health problems have equal access to care and treatment and basic human rights (such as employment, education and social activities) is of vital importance, but should also go hand in hand with the awareness of the diversity and complexity of mental health and welfare needs of the general population, particularly those at risk of poor mental health, such as disadvantaged and discriminated groups. Rights-based approaches to protect the welfare of people with (or at risk of) mental disorders should be grounded on efforts to enable social and physical environments that promote mental health for all [85].

A number of components of SF may help to explain its potential to improve mental (and physical) health of vulnerable members of the society benefiting from these initiatives. These include the promotion of physical activity, exposure to the natural world (e.g. Biophilia hypothesis), the opportunity to undertake tasks as part of daily and seasonal cycles, to be engaged in meaningful activities for the development of new personal and/or work skills, as well as positive social relationships and interaction with animals [86, 87]. Moreover, the small scale of many social farms allows participants working alongside the farmer and other members of the farm, thus representing a model of "socially embedded care" in which people are integrated in communities and avoid the stigma of care services [19, 55].

Representing a hybrid governance model in which public bodies, local communities and economic actors work together to meet social needs, SF may also offer innovative solutions to buffer the financial (and organizational) challenges faced by the National Health Systems, at the same time helping in diversifying the rural economy with new job creation and income generation opportunities, ultimately increasing economic sustainability. EU policies in the context of the rural development programmes (RDP) have recognized the importance of SF and multifunctional agriculture, also offering different options for funding SF projects.

Support for training for SF actors and for the establishment of SF networks and support centers appears of particular relevance to strengthen SF initiatives. In order to promote bottom-up approach and locally-led SF initiatives, the development and application of appropriate regulations also appears critical. In 2015, the first Italian National law on SF was approved by the Italian parliament (Law n. 141, 8 August 2015; www.gazzettaufficiale.it/eli/id/2015/09/8/15G00155/sg), providing a framework to support cooperation among health services, farmers, social cooperatives and voluntary associations, with the aim of promoting shared planning for the provision of services such as rehabilitation, education, training, employment, therapy and social inclusion.

In Italy, SF has strong links with social enterprises and has been traditionally associated with social cooperatives, including Type A (i.e., those producing goods of social utility) and Type B (i.e., those providing economic activities for the integration of disadvantaged people into employment) [85]. The Friuli-Venezia Giulia case study represents a model in which the health sector has approached social cooperatives or private farmers, locally active, to provide activities for their service users, at the same time facilitating collaborations of the private sector with health, education and other public institutions. This Italian Region has developed a regional framework to support SF through local legislation. Moreover, the Health Authority of the province of Pordenone has promoted welfare measures to support Sf initiative, including the personal budget, a form of contribution that can be directed to different activities, including re-habilitation and sheltered employment, according to the need of the end-user [87]. This program has been overseen for quality and effectiveness by the Health Authority, in collaboration with research institutions such as the Istituto Superiore di Sanità.

Contributions to the current special issue [88-91] all emphasize the importance of taking a person-centred approach in service provision for people with disability, with a strong emphasis on supporting their life-long planning and community participation and improving their quality of life. Opportunities to engage in meaningful activities and occupational status are important determinants of mental health and key elements to strengthen skills and confidence that may be part of the recovery process in the majority of mental disorders. Provide vocational rehabilitation interventions and cost-effective supported employment initiatives, train employment service staff to better understand the needs of jobseekers with mental health needs, as well as support employers in recruiting people with mental health issues, represent essential actions towards the integration of vulnerable populations into society and the labour market. Incentives that encourage innovation and create a more competitive market for services and that can help supporting SF initiatives, such as personal budgets [87], should also be encouraged. The final aim is to innovate the disability sector by adding community-based services to the existing range of supports and by facilitating service users to exercise choice and control over their health and their life planning.

### *Conflict of interest statement*

The Authors declare that they have no conflict of interest.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 215-221
DOI: 10.4415/ANN_20_02_11

# Stress and wellbeing among professionals working with people with neurodevelopmental disorders. Review and intervention perspectives

**Mauro Leoni[1,2], Laura Alzani[1], Davide Carnevali[1,2], Roberto Cavagnola[1], Giuseppe Chiodelli[1], Serafino Corti[1,3], Francesco Fioriti[1], Maria Laura Galli[1], Giovanni Michelini[1,2] and Giovanni Miselli[1]**

*[1]Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro (Cremona), Italy*
*[2]Sigmund Freud University, Milan, Italy*
*[3]Università Cattolica del Sacro Cuore, Milan, Italy*

**Abstract**
Supporting individuals with NDD is extremely demanding, with significant exposure to critical contexts and events, and painful ongoing experiences. Stress and burnout condition is a main concern with growing interest in research, despite the lack of consensus on theoretical explanatory models and modification standards.

The paper provides an up-to-date review of risk factors and involved processes, and presents evidence-based procedures and protocols to implement effective preventive actions addressing both organizational and individual factors. The aim is to offer a global understanding of the subject and offer examples of practical plans to increase the impact on the quality of life of clients and staff members.

**Key words**
- staff
- stress
- neurodevelopmental disorders
- autism spectrum disorder
- applied behavior analysis

## INTRODUCTION

Psychological stress and associated medical illnesses are significant problems amongst those working with individuals with neurodevelopmental disorders (NDD). Potential implications on the quality of life of clients and staff members are significant: psychological condition of professionals is always (to some extent) impacting the quality and quantity of given supports and human interactions. Furthermore, organizations have a moral and legal duty to ensure the welfare of their employees [1].

The present paper is presenting an up-to-date overview of the above topics, and describe the main intervention perspectives.

## STRESS CONDITION IN STAFF WORKING WITH NEURODEVELOPMENTAL DISORDERS

Burnout is a job-related illness, considered a consequence of chronic work-related stress related to factors related to work and private events.

Maslach and Jackson [2] original definition of burnout included three distinct elements: feelings of being exhausted emotionally, loss of feelings of accomplishment on the job, and negative, cynical and depersonalizing attitudes towards service users. It is nowadays considered a label for a broader set of psychological processes, where initial feelings of stress lead to a longer-term sensation of exhaustion and ultimately to a more stable change in behavioral patterns. This change is often described as "coping style", and is associated with negative attitudes towards people with NDD (e.g. treating clients in a mechanical or detached way).

These models have been widely studied and applied, since they allow to make specific predictions about emotional, behavioral and attitudinal change, and to make modifications both from the individual and organizational points of view.

Empirical and theoretical research on stress and burnout among professionals working with people with NDD is limited, but the interest is growing [3]: their impact on staff and clients' wellbeing is acknowledged and review and clinical papers are retrievable, although there still is no consensus on the dimensions of these topics and how to deal with them appropriately (e.g. lack of reliable assessment tools, longitudinal and controlled studies, standardized intervention protocols, etc.).

Staff members working with persons with NDD (including, for instance, intellectual disabilities and autism

*Address for correspondence:* Mauro Leoni, Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Piazza Libertà 2, 26048 Sospiro (Cremona) Italy. E-mail: mauro.leoni@fondazionesospiro.it.

spectrum disorders, often in comorbidity with psychiatric disorders) usually faces in their daily job emotionally and physically challenging situations [4, 5]. Significant levels, between 25 and 32 percent, of work-related stress and burnout, is reported in the literature [1, 6] even if the level of burnout among workers in the field of NDD is not necessarily higher than in other helping professional groups [6].

## REACTION TO STRESS AND IMPACT OF WELLBEING

Supporting a person with NDD is extremely demanding. Both professionals and caregivers are exposed to critical contexts and events, and live painful experiences extended on time.

Studies exploring the consequences of stress and burnout in professionals working with NDD report a variety of outcomes [5, 7] including: lower levels of production, lower quality of direct support and interaction [8]; higher absenteeism and turnover [9]; negative emotional reactions [10]; unhealthy lifestyle [11], mental health problems, physical issues and chronic diseases [12]; higher risk of physical and mental abuse towards clients [13]. Burnout has been specifically associated with increased job turnover and lower level of direct support and interactions [14]: a recent survey of 21 US states reported an average annual turnover rate of 46% in 2016 [15].

Panicker and Ramesh [16] recently studied the psychological status of caregivers of individuals with intellectual disability and psychiatric illness. All the participants (N = 120) experienced depression, anxiety and stress symptoms. These symptoms were found to be significantly higher among caregivers of individuals with intellectual disabilities than those with psychiatric illness.

## RISK FACTORS

The common understanding of stress and burnout are usually based on a supposed causal relationship between the complexity of the job (particularly challenging behaviors of clients) and staff well-being, and the implication that these kinds of job are "burning" professionals over time. There is no empirical support for these hypotheses. A deeper examination of the interaction between multiple factors is needed.

Risks factors have been studied and reviewed (e.g. [7]). Considering specific literature [4, 10, 17-20], these could be summarized and clustered as follows: a) client factors (poor functioning, challenging behaviors, frequency and chronicity of problems; atypical attitudes); b) job factors (work load, work shifts, perception of relationships and received support, low salary, injuries risk); c) organizational factors (low occupational status, role ambiguity and limited job autonomy); individual (staff) factors (psychological).

Finkelstein *et al.* [3] in a sample of 199 professionals, found no significant differences in burnout levels when related to socio-demographic factors and to professional characteristics. Most of the predictors (46.8% of the variance) were indeed organizational measures: role ambiguity, perceived overload, care-recipient group and job involvement.

Emotion-focused coping has been associated with greater burnout and work stress [21, 22]. Michelini *et al.* [23] found burnout as significantly depending on both organizational and individual factors (specifically "psychological flexibility"), with strong independence of those variables.

As a consequence of the above data, interventions aimed to promote stress reduction and wellbeing should be provided at two levels: organizational and individual. The following sections present a summary of the emerging evidence from the two perspectives with examples aimed to support clinicians and managers to introduce supported interventions in their organization.

## INTERVENTIONS AT THE ORGANIZATIONAL LEVEL

As said, challenging behaviors probably are the most impacting factor associated with stress and burnout, with an extremely high prevalence within the population of individuals with NDD (e.g. rates over 60% in children [24]; in adults average estimates of 18.1-18.7% or 50-80% in studies looking at specific settings, subpopulations, or behaviors [25]).

Applied behavior analysis, with a variety of treatment models, has the solidest evidence in terms of efficacy and cost-effectiveness [26-28] for the treatments of challenging behaviors. We must actually consider that applying evidence-based treatment procedures presents significant difficulties in terms of willingness, consistency, accuracy, alignment with changing needs, etc. This concern has been explored by behavior analysis itself: training and management of the treatment-related performance of human service personnel represent one of the core areas of applied behavior analysis named organizational behavior management (OBM) [29]. Therefore, OBM procedures are considered the current standard to change contextual factors impacting on stress and burnout.

Accordingly to OBM, when professionals don't apply behavioral interventions correctly, it means they are not addressing challenging behaviors as required. This could increase the frequency and severity of challenging behaviors, and consequently the exposure to stressful conditions and the risk to develop burnout [30]. Usually, this happens for two main reasons [31]: 1) lack of specific skills; and 2) lack of motivation. OBM indicates two areas of intervention to address these variables: one dimension dedicated to the organizational factors, and one dimension focused on the professionals as individuals.

In order to impact on the organization, research points out the main core tasks to address [32]:

a) clarify roles, responsibility, and duties with a precise schedule;
b) train (and refresh) all staff members on:
  - general rationale;
  - protocols;
  - specific skills *in vivo* (i.e. behavioral skills training);
  - direct modeling and feedback;
c) observe, measure, and analyze data;
d) provide feedback:
  - on the required skills;

  - on the personal attitude and performance using collected data;

e) give direct support to professionals:
  - corrective actions (make professionals aware of errors and provide ethical and approved forms of punishment);
  - reinforcement processes (related to skills and attitudes).

The best prevention for stress and burnout can be provided when implementing the above tasks using a precise behavioral methodology. In *Figure 1* the core tasks are summarized and referred to basic behavioral procedures.

Motivation is usually considered [31] defined by two factors: a) the willingness to apply the required skills; b) the satisfaction in doing a specific activity. The former has a higher risk of failure, is strongly related to the job environment, and it is always fluctuating. The satisfaction in doing a specific activity constitutes an essential factor and should always be addressed since punishment by itself is not effective in a long term perspective. Increasing the access to positive consequences of job activity means reinforcing positive behaviors: staff is progressively less involved in avoiding efforts and more committed to an active search for positive/preferred consequences.

The procedures summarized above stimulate changes in learning processes used by staff members and constitute the base for implementing interventions at the individual level.

## INTERVENTIONS AT THE INDIVIDUAL LEVEL

Accordingly with literature, an intervention at the individual level should be provided and combined with those at the organizational level [5].

Richardson and Rothstein [33] showed how classical interventions for work-related stress were based on psychoeducational training with elements of cognitive behavior therapy (CBT) or cognitive therapy (CT) emphasizing problem-solving. Beyond the usefulness of these approaches and treatment, the limitations are known: the nature itself of challenging behaviors (i.e. cognitive limitations, behavioral deficits, learning history, the inadequacy of environment) make changes and predictability poorly effective or short-lasting.

As a consequence, carers of individuals with NDD develop ineffective emotion-focused coping strategies (avoidance of negative perceptions and thought suppression), increasing paradoxically their risk of experiencing burnout and stress [21, 34, 35]. The importance of individual's responses (i.e. coping resources) associated with the permanency of stressors related to NDD, increased the interest of psychological approaches to treatments aimed to increase resilience [36]. Within these, the third wave of behavior therapies (for a review see [37]) applied to carers of individuals with NDD is growing rapidly [7, 20]. Mindfulness and acceptance are key constructs of 3rd generation behavioral approaches, describing psychological processes confirmed to be effective at reducing occupational stress responses and increasing psychological resilience [20, 38, 39].

Mindfulness-based interventions (MBI) and acceptance and commitment therapy (ACT) can produce positive outcomes for individuals with ID and challenging behaviors [40, 41], and increase the wellbeing of support staff [22, 35, 42]. Protocols based on these processes reduce the efficacy of ineffective coping strategies, and increase the willingness to experience difficult thoughts and feelings ("avoiding the avoidance"), reducing the stressful impact of uncomfortable thoughts and sensations and increasing flexible attitudes towards the events and awareness on individual reactions and responses [5]. A recent study [36] on ninety-seven direct support professionals, confirms Noone and Hast-

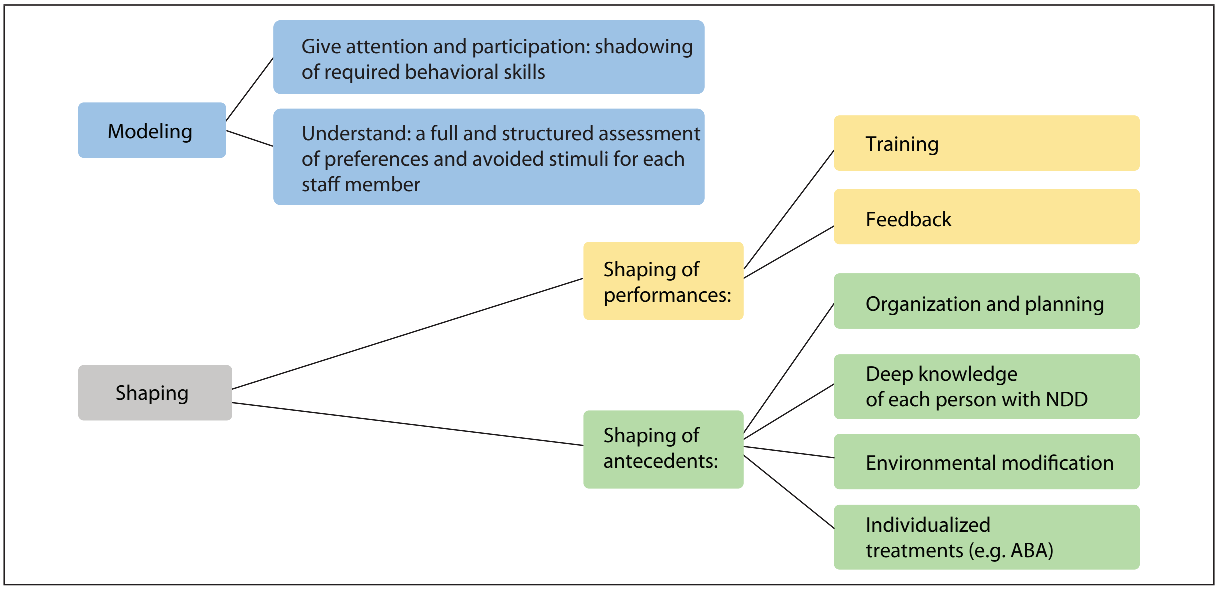

**Figure 1**
Behavioral procedures used in the core organizational behavior management (OBM) tasks for increasing skills as prevention of stress and burnout.

ings findings on the importance of mindfulness as a cognitive mechanism in protecting against negative outcomes. Mindfulness practices operate as a protective factor against burnout and emotional discomfort (e.g. psychiatric symptoms and neuroticism), and associates with adaptive attitudes.

Mindfulness-based and ACT interventions recognize the reality of the challenge that professionals and caregivers of individuals with NDD face day by day. The psychological processes involved help to overcome the limitations of classical CBT and problem-solving approaches: they support learning processes in professionals and caregivers, increase being present in one's discomfort, and foster acceptance and values-oriented behaviors. These approaches will play an important role in disability services as a whole [43]: clinicians and service leaders should explore these opportunities and plan training and implementation in their own work context.

An example of these training is the promotion of acceptance in carers and teachers (PACT) [22], the first treatment protocol based on mindfulness and ACT (acceptance, mindfulness, and values), designed to help

**Table 1**
Workshop modules with descriptions

| Day | Module | Description |
|---|---|---|
| **Day 1** | Introduction | Overview, introduction, schedule and expectations<br>Discuss how people react to challenging behaviors<br>Stress and burnout processes and prevalence<br>Introduce "psychological flexibility": ACT matrix and mindfulness practices |
| | Thoughts and reality | Video metaphors (e.g. Russ Harris, Happiness Myth)<br>Exercises (break into pairs) to describe unpleasant thoughts and feelings and important things we care into our lives |
| | Introduction to the Matrix | Clinical examples assessed using a simplified Hexaflex model (e.g. Polk's Matrix) |
| | Mindfulness | Guided experience (plus homework) |
| **Day 2** | Mindfulness | Group members are leading the guided experience |
| | Processes awareness | Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning) |
| | Matrix | Break into groups and apply to their stressful experiences |
| | Sharing | Each group presents their case<br>Combining ABA (functional approach) to the matrix<br>People describe experiences |
| | Values | Introduction and assessment (VLQ and VQ) [47][48]<br>Feedback on the individual scoring<br>Eye contact exercise |
| | Mindfulness | Homework |
| **Day 3** | Mindfulness | Group members are leading the guided experience |
| | Processes awareness | Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning) |
| | Defusion | Metaphors and exercises (e.g. chessboard, observer self) to help people get a sense of the part of them that just observes |
| | Committed action | Individual use of the Matrix<br>Mindful exercise to visualize values-oriented actions |
| | Matrix | Break into groups and implement their cases with left-to-right and up-to-down processes (e.g. making lists of contents, observing and linking factors to experiences)<br>People describe experiences |
| | Mindfulness | Homework |
| **Day 4** | Mindfulness | Group members are leading the guided experience |
| | Processes awareness | Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning) |
| | Matrix | Break into groups and implement their cases with committed action plans for the group and each participant<br>People describe experiences |
| | Processes awareness | Assessing preferences and avoided stimuli using a structured questionnaire (SSPAQ)<br>Feedback on the individual scoring |
| | Committed action | Individual paper activity, describing a committed action plan, with details on problem-solving (for aversive stimuli) and enrichment (for appetitive stimuli) |
| | Closing | People have an opportunity to share their reactions to the workshop |
| | Mindfulness | Homework |

care staff. The training is working on different tasks: 1) to promote a willingness to experience the full range of emotional responses (including aversive ones); 2) to corroborate the use of flexibility when judging "personal progress", driven by the level of alignment to one's values; 3) to reduce the control of thoughts through mindfulness practices [20]. The authors of PACT recently reported results when using mindfulness-based practices with family carers of adults with learning disabilities and challenging behavior [44]: data show that mindfulness/ACT can change long-standing response behaviors, build personal resilience, and improve mental health.

The authors (within Fondazione Sospiro Onlus, Cremona, Italy) tried to explore these contributions and introduced and adapted these approaches since 2006 in their facilities, developing a protocol for a training workshop dedicated to all staff members, as part of its multi-component organizational reform package [45]. The constant collection of data related to organizational processes, clinical treatments, and staff stress/wellbeing [23] confirmed the importance to address individual factors and to promote psychological flexibility, in combination with planning, support, and intervention at the organizational level. Consequently, the training protocol has been shaped during time (based on outcomes and feedback), and now it's planned 2-4 times every year to members of all residential facilities for adults with NDD and challenging behaviors. The training's aim is to improve the quality of life of those supporting people with NDD. The training workshops are split into four meetings (four hours each; once a month), for groups of 15-20 professionals (with different role and experience). Schedule, components, and descriptions are listed in *Table 1* below, as an example (consistent with the literature, [46]) to be considered and adapted for every type of service.

The training is focused on psychological processes, and uses metaphors, video examples, individual/pair/group exercises (experiential, paper and verbal), to work on the following objectives: a) to increase awareness of staff on how they are using inflexible responses; b) to clarify personal and shared values; c) to plan and make commitments (dedicate time to activities meaningful for them); d) to increase opportunities to access available reinforcements, increasing the chance to live positive (and less painful) experiences (at work and in their daily lives); e) to increase global awareness of their life and to get the best they can from it.

The effectiveness of ACT for work organizations in terms of reducing stress, raising psychological wellbeing, and increasing workers' willingness to use innovative practices is confirmed [46]: organizations should take into consideration how to implement specific support plans aligned to these processes.

## CONCLUSIONS

The quality of life of clients and staff members should be a main concern for organizations and professionals involved in the planning and evaluations of services offered to people with neurodevelopmental disorders (NDD).

Despite the paucity of empirical and theoretical research on stress and burnout among professionals working with people with NDD, the interest is growing. We have now a better understanding of the variety of factors impacting stress and increasing the risk of burnout and its negative consequences (including malpractice and abuse).

Behavioral sciences and applied behavior analysis offer procedures and protocols based on evidence, to implement effective preventive actions, addressing both the organizational and the individual factors. Research should definitely grow and improve, but service providers can have access to this body of science and start to have a higher impact of contexts and people's wellbeing.

### *Authors' contributions*

The first Author reviewed literature and wrote the paper; the remaining Authors collaborated with the revision of the paper.

### *Compliance with ethical standards*

The Authors, in accordance with the policy of their institutional review board, obtained the approval of the research by the Internal Scientific Committee.

### *Conflict of interest statement*

The Authors declare that they have no conflict of interest.

### *Informed consent*

Informed consent has been obtained by the Authors, for the patients involved in the study, and no reported data can be referred to individual identity.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 222-229
DOI: 10.4415/ANN_20_02_12

# Individual planning starts at school. Tools and practices promoting autonomy and supporting transition to work for adolescents with autism spectrum disorder

**Fiorenzo Laghi**[1] **and Barbara Trimarco**[2]

[1]*Dipartimento di Psicologia dei Processi di Sviluppo e Socializzazione, Facoltà di Medicina e Psicologia, Sapienza Università di Roma, Rome, Italy*
[2]*Cooperativa Sociale Integrata Agricola Giuseppe Garibaldi, Rome, Italy*

**Abstract**

There is an increasing need for effective services and strategies to favor the transition from school to post-school/working experience for individuals with disabilities and specifically with autism spectrum disorder (ASD). Post-school options are still limited, and most adults with ASD struggle in finding adequate and stable job opportunities. This work analyzes the increasing number of laws issued in Italy in the last decades in order to improve social and working inclusion. The central role of the individual educational planning (IEP) as part of the broader individual project is discussed. Also the potential of pathways for transversal skills and orientation for future employment outcomes is taken into consideration. Good practices promoting autonomy and supporting transition to work starting from school years are reviewed. The international literature shows different models and tools, which could be applied to the Italian school. The COMPASS consultancy model could favor the achievement of individualized transition IEP goals. Peer mediated intervention could improve social skills, a core weakness in ASD, though a central element for success in the workplace. Another key element is the parental involvement in the construction of the future of their children with ASD.

**Key words**
- individual educational planning
- transition outcomes
- peer mediated intervention
- autism spectrum disorder
- adolescence

## DISABILITY AND ITALIAN EDUCATIONAL POLICIES

Since the 1970s, Italy has initiated a process of inclusion of students with disabilities in mainstream schools and abandoned segregated educational practices. This change begins with Law 517/1977 [1] which establishes the right of students with disabilities to attend common schools and introduces a new philosophy of integration. Social debate begins to focus on the principles affirmed by the Italian Constitution [2]: equal social dignity (article 3) and the universal right to education (article 34). Fifteen years later, Law 104/1992 [3] is approved: this law becomes the main regulatory frame of reference for disability and is focused on assistance, social integration and the rights of people with disabilities. It reaffirms the importance of social and school integration for the protection of the human dignity of individuals with disabilities. The State is considered responsible for removing the obstacles to the individual's development and for providing (re)habilitative interventions. This law considers the individual educational planning (IEP) and the dynamic-functional profile (PDF) as the expression of the right to education of the person with disability. Therefore, Law 104/1992 [3] emphasizes the principle of individualization in education and learning. In 2014, the Italian Government starts a renovation of the educational system, following the directives of the Convention on the Rights of Persons with Disabilities (article 24) [4]. Legislative Decree 66/2017 [5] on inclusive education is adopted in Italy in April 2017. This decree applies to all children with a certified disability from nursery school to secondary school.

According to this decree, schools can achieve inclusive education through educational and didactic strategies aimed at developing the potential abilities and aptitudes of each person. It promotes the definition and

*Address for correspondence*: Fiorenzo Laghi, Dipartimento di Psicologia dei Processi di Sviluppo e Socializzazione, Facoltà di Medicina e Psicologia, Sapienza Università di Roma, Via dei Marsi 78, 00185 Rome, Italy. E-mail: fiorenzo.laghi@uniroma1.it.

sharing of the individual project among school, family and other public and private subjects, operating in the local area. The decree considers the participation of the family as fundamental in the school and social inclusion processes. Educational inclusion was originally born to guarantee the right to educational success of children with disabilities and today it represents a fundamental value of the identity of the educational institutions.

Legislative Decree 66/2017 [5] reaffirms the role of the IEP as one of the main inclusion tools. The IEP identifies tools, strategies and methods to achieve an optimal learning environment in the following dimensions: relationships, socialization, communication, interaction, orientation and autonomy. It also contains educational and evaluation methods in relation to individualized programming and defines the tools for the actual realization of "school-work alternating system". The IEP is co-constructed, according to the individual functioning profile, by the student's class teachers, the family and the specific professional figures inside and outside the school. The IEP is an integral part of the broader Individual Project (Law 328/2000 [6]), developed by the local authority to tailor social and health services to the specific needs of the person with disability. Therefore, the decree considers inclusive education as part of a broader individual strategy aimed at promoting social inclusion and autonomy for people with disability. School is formally integrated as part of the life project of the individual, endorsing a life course perspective.

In this decree, there are two main points which may play an important role in promoting independent living and supporting transition to work. First of all, the integration of the IEP in the broader individual project might facilitate the planning of the abilities which will be necessary in the working environment and should be developed starting from the school phase. Secondly, the definition of specific and individualized strategies and tools for the success of the school-work alternating system, included in the IEP, may allow an initial contact with work contexts.

When requested by the individual with disability or his/her parents or legal guardian, the city council and the local sanitary district cooperate to create the Individual Project, aimed at the full inclusion of the person with disability in family and social life, as well as in educational and working pathways. The local authorities activate the individual project, according to the available resources, on the basis of a diagnostic-functional evaluation. The individual project includes several services, i.e. care and (re)habilitation services, direct and indirect economic measures aimed at overcoming poverty and, when necessary, at recovery and social inclusion. Support can also be provided for the family of the individual with disability. This important document can be defined and implemented with the contribution of specific professional figures (i.e. psychiatrist, psychologist, social worker in the case of mental disability) who cooperate in order to guarantee the continuity of the habilitative process, especially during critical phases through the life of the individual, such as the transitions from a school level to another, or from school to work.

School-work alternating system (Legislative Decree 77/2005 [7] and Law 107/2015 [8]) is an innovative education method, addressed to students of upper secondary schools, that allows them to "alternate" periods of training in the classroom and inside work contexts (i.e. companies). The law establishes the minimum duration of these periods of training, leaving to the school the decision on the possibility to extend their time.

Article 4 of the Legislative Decree 77/2005 [7] requires that working pathways for individuals with disabilities should be carefully tailored in order to promote their autonomy and to prepare them to enter the world of work. Moreover, article 6 of this law highlights the importance of evaluating and certifying the skills acquired by students with disability during the school-work alternating system, according to the principles of Law 104/1992 [3] in order to facilitate future employability. School-work alternating system has been recently renamed as Pathways for transversal skills and orientation (Law 145/2018 [9]).

The recent Legislative Decree 96/2019 [10] integrates and modifies Legislative Decree 66/2017 [5]. The new decree affirms the role of the multidisciplinary evaluation unit of the local health services, that elaborates the functioning profile (which integrates the previous functional diagnosis and the functional dynamic profile), together with the family and a special education teacher of the school. The functioning profile follows the criteria of the bio-psycho-social model of the International Classification of functioning, disability and health (ICF) of the World Health Organization (WHO) [11]. The IEP is now exclusively defined as part of the individual project, ratifying the role of the individual project as an all-inclusive document of the interventions designed for the life project of the person with disability. Additionally, this legislative decree clearly affirms the importance of the active participation of the student with disability during the development of the IEP, in line with the principle of self-determination. The inclusion process is now considered, even more than before, as the product of a network action between the different local institutions.

The creation and development of this network, together with a detailed and updated functioning profile, may represent an essential link between childhood/adolescence and adult age, facilitating the transition from school to work.

## GOOD PRACTICE SUPPORTING TRANSITION TO WORK FOR STUDENTS WITH AUTISM SPECTRUM DISORDER

The prevalence of ASD reported by Fombonne [12], in an analysis of epidemiological studies published between 1966 and 2001 was around 36/10 000. Reviews of Fombonne [13], Charles, Carpenter, Jenner and Nicholas [14] and Rapin and Tuchman [15] show an increase in the prevalence of autism spectrum disorder (ASD): around 60-70 cases in 10 000 people. A global review [16] confirmed this data, establishing a prevalence of 62/10 000. This increase in the number of individuals with ASD leads to a need for more services, especially as this population becomes older. Post-school options are still limited, and most adults with ASD struggle in finding adequate and stable job opportunities. Additionally, studies conducted in various countries (the US, the UK, Australia and Canada) [17-20] showed high rates of unemployment in ASD compared to other disabilities.

Bennett and Dukes [21] analyzed studies focused on teaching employment skills to secondary students with ASD between the ages of 14-22. They found few studies targeting job specific skill instruction and no studies targeting social abilities necessary for employment. Much of this research examined strategies to increase independent employment skills through self-management packages or video modeling with promising results [22-24]. Another study with encouraging results [25] described an intervention package comprised of behavior skills training and text message cueing. Additionally, highly preferred items were more effective than less preferred items as a maintaining variable of task completion [26]. Bennett and Dukes [21] concluded that the paucity of research on secondary special education programming applied to students with ASD may contribute to their poor employment outcomes.

In their systematic review, Hedley *et al.* [27] analyzed a number of studies that, overall, supported the use of technological aides and behavioral strategies in improving workplace skills in adults with ASD. Nevertheless, the large range of skills taught in the studies considered in this review and the reduced number of individuals involved limit the generalizability of these results.

An important point to address is the lack of evidence-based transition interventions to improve post-school outcomes and the absence of transition planning processes with empirical support [28]. Therefore, the need for studies of empirically-supported approaches for improving transition planning and outcomes for students with ASD is a critical issue, as observed by the Interagency Autism Coordinating Committee [29].

To help improve transition planning and outcomes, Ruble *et al.* [30] designed a randomized control trial (RCT). These authors adapted the Collaborative Model for Promoting Competence and Success (COMPASS) [31], a consultation intervention [32, 33] that has proved to be successful in improving achievement of goals in pre-school and elementary school. In this RCT, twenty teachers and 20 students and their parents participated; 11 dyads were assigned to the experimental group and 9 to the comparison group. The teachers in the comparison group received online training on three evidence-based practices in autism. The results showed that Individualized Education Program goal accomplishment was higher for students in the COMPASS group. This indicates that COMPASS was able to support teacher-student dyads to achieve transition goals.

Social and interaction deficits are a core aspect of ASD [34] and represent one of the main obstacles to community inclusion, including finding and maintaining a gainful job [35, 36]. Among the strategies used to improve social skills in ASD, Peer mediated intervention (PMI) is a promising practice that can be conducted in meaningful real-world contexts. In this approach, typically developing peers are taught effective strategies to interact with and help children and adolescents with ASD gain social skills by increasing social opportunities. In their systematic review, Watkins and colleagues [37] analyzed fourteen PMI studies which included children and adolescents from preschool to high school age. Most of these studies showed that it is possible for children and adolescents with ASD to make significant changes in their social skills in inclusive settings as reported by parents, teachers, researchers, and children and adolescents themselves. Nevertheless, only few studies specifically targeted middle or high school age children. As the social context dramatically changes between elementary and high school, it would be important to establish specific guidelines for selecting peer buddies for adolescents with ASD.

## HOW COLLABORATIVE MODEL FOR PROMOTING COMPETENCE AND SUCCESS CAN IMPROVE THE TRANSITION OUTCOMES

The international literature shows different models and tools, which could be applied to the Italian school. The COMPASS consultancy model could favor the achievement of individualized objectives as an integral part of the IEP. An extended application of the PMI could equip high school students, strengthening their weaker social skills, which are a central element for success in the workplace. The use of technological tools, such as video-modeling, could favor the acquisition of specific work skills, which could be implemented and tested in the pathways for transversal skills and orientation, during the last high school years.

These elements offered by international literature require more in-depth analysis. It will be important to design and conduct longitudinal studies analyzing the school-work transition and evaluating the effectiveness of the proposed models.

Ruble and colleagues provide a strong rationale for the importance of a collaborative approach to interventions in schools, for improving teaching quality and student learning and transition outcomes [30, 31]. The Compass is a manualized teacher-parent consultation intervention for students with autism that was translated and adapted in Italian context. There is a first step (Step A) of the consultation plan where the consultant meets the teacher and caregivers for obtaining a clear picture of the student with ASD thanks to Compass profile that includes questions about different domains: adolescent's strengths, preferences, fears, frustrations, adaptive functioning, problem behaviors, social and communication skills, and learning skills. In this first phase we added different instruments for identifying in the next step, IEP goals related to the social, communication, and work skills.

Both parents and teachers complete the Social Responsiveness Scale (SRS) [38], that is a 65-item rating scale measuring the severity of autism spectrum symptoms as they occur in natural social settings. The SRS provides a measure of the adolescent's social impairments, assessing social awareness, social information processing, capacity for reciprocal social communication, social anxiety/avoidance, and autistic traits.

The Italian form of the Vineland Adaptive Behavior Scales - Second version [39] is used to assess the adaptive functioning of the student with ASD. Three VABS skill domains are evaluated: communication (receptive, expressive, and written language skills), daily living (personal self-care, domestic living skills, and community living skills), and socialization (interpersonal skills, play and leisure, and coping skills). In order to ensure higher reliability, we prefer administering the interview form. The consultant interviews each participant's parent.

Teachers are asked to complete the Italian form of the ABAS-II [40] to assess the adaptive functioning of their students with ASD. Three ABAS-II skill domains are analyzed: conceptual (communication, functional academics, and self-direction), social (leisure, and social), and practical (community use, home living, health and safety, and self-care).

The TEACCH transition assessment profile (TTAP) is used to evaluate abilities for transition planning from school age to adolescence and adulthood [41]. TTAP test items cover the six functional areas of vocational skills, vocational behavior, independent functioning, leisure skills, functional communication, and interpersonal behavior, with an observation of the performance of students in several tasks, and with an interview for teacher and parents to evaluate abilities related to school and family context. For each ability it is possible to evaluate the performance of the student with a 3-point scale of P (pass), E (emerging), or F (fail).

In the Step B the profile is shared with teachers, parents and paraprofessionals and the aim of the meeting is to analyze the student's current personal and environmental challenges and the personal and environmental supports necessary for success. Then, the consultant, caregiver, and teacher prioritize goals, write measurable objectives, and develop the teaching plan and identify environmental supports for each objective [31-33]. A Goal Attainment Scale is created: the expected outcomes are defined on a 5-point scale from -2 (outcome much less than expected), -1 (less than expected), to 0 (expected outcome) to +1 (better than expected), and +2 (much better than expected). As reported in other studies [42], for vocational skills and vocational behavior, the consultant set the goals for each subject in the areas where the performance of the student is emerging.

The intervention consists of four 1-1.5 h coaching sessions conducted in-person at the school within the first and second semester of the school year.

The application of the COMPASS in the Italian context has shown promising results. After their experience with the COMPASS, most parents and teachers considered Step A very useful to define the objectives of the IEP. The definition of a detailed profile describing the abilities of the students in the different areas was particularly appreciated, as it allowed them to define the goals they wanted to achieve. Additionally, they found the analysis of environmental challenges and resources very useful for the planning of activities aimed at reaching the established goals. The main obstacles were the definition of the objectives according to the Goal Attainment Scale and the planning of the activities after defining the goals. The monitoring of goals can also be considered a critical point: teachers who are not used to being observed, for instance through video units, sometimes experienced the observation as a test instead of a way to think over the process together with the consultant.

In the Italian context, providing training for teachers on targeted intervention practices and on autism is particularly important, because support teachers do not necessarily receive a specific training on ASD and may not be experienced in working with individuals with this condition.

## HOW PEER MEDIATED INTERVENTION CAN HELP THE STUDENTS WITH ASD TO ACQUIRE ABILITIES RELATED TO INDEPENDENT FUNCTIONING AND VOCATIONAL SKILLS

In the literature, peer-mediated intervention (PMI), a treatment approach in which classmates are trained to act as the intervention agents, has been demonstrated to be useful to promote social behavior and enhance scholastic achievement. Inclusive classroom environments may produce positive benefits to social development and adjustment of adolescents with autism. However, the simple exposure to peers' interactions is not sufficient to promote social skills in adolescents with autism, but highly structured training programs with systematic procedures are required.

The benefits of PMI also depend on the strategies used to choose peers. Previous research has provided some support for the use of sociometric status, but some risks need to be understood. Adolescents who engage in antisocial behavior may be popular in the classroom because of their social influence on peers. Hence, new strategies to identify peer buddies are reported.

We ask adolescents to provide their contact information if they are interested in learning what they thought about the possibility to help a peer with ASD in their classroom. Because first session is initiated, permission is obtained from parents. We think that the voluntary adhesion to the project is not enough to guarantee the effectiveness of the intervention program. It is important to evaluate the specific characteristics of peer buddies, to ensure that these are suitable for adolescents with ASD. For this reason, the introduction meeting is devoted to have a deep knowledge of students who want to become a peer buddy for a student with autism. We describe briefly the key variables that we evaluate and may be considered by scholastic psychologists and teachers when a peer mediated intervention is planned: mind reading abilities, prosocial behavior, and peer buddy nomination. We use the Reading the Mind in the Eyes' Test revised version [43], that is a standard test of advanced "theory of mind" which measures the ability to decipher mental states from 36 photographs of the eye region alone. Participants are required to select which of four complex mental state descriptors (one target word and three foil words) best describes the thoughts or feelings expressed by different individuals. Prosocial behavior, a construct that includes behaviors as helping, sharing, cooperating, and comforting, is evaluated with the Italian version of Strength and Difficulties Questionnaire [44]. Peer Buddy Nomination is a technique where adolescents nominate three classmates they would "choose as a peer buddy" and three classmates they would "not choose as a peer buddy" to help the adolescent with ASD in the classroom. Students also circle the person that would make the "best peer buddy".

We think that these constructs are very important because, as demonstrated in previous studies [45], the classmates's social use of their mind reading abilities is recognized by peers but using a measure of prosocial behavior we can analyze the social use of mind reading abilities and understand if the potential peer buddies employ these abilities for prosocial goals. After this phase of knowledge of the classmates, all students are trained in four training session. Each training session is conducted during scholastic period and lasted no more than 3 hours.

In the first session of training students are provided with a rationale for helping a student with ASD and guided in a discussion about "challenges and resources" asking students their strengths, preferences, fears, and frustrations, and the preference, strengths and areas of need of the classmate with ASD. The trainer uses video clip, books and slides to explain the characteristics of autism spectrum disorder. The aim of this phase is to help the classmates that all students have resources and areas of need.

In the second session, following Owen-DeSchryver *et al.* [46], we use the same five central themes, except for the fourth theme that was adapted for work abilities: 1) When can you share activities and talk to (name of the student) at school?; 2) What are some topics you can talk with him/her?; 3) What are some activities that you can do with him/her during the recess?; 4a) How can you help him/her learn to acquire a work skill during activities in laboratory (only for students that attend laboratories at school); or 4b) How can you help him/her learn a social or communication ability (the ability can be chosen thanks to Compass profile administered to parent and teacher); 5) What can you do if he/she doesn't cooperate and shows unusual behaviors?

After the discussion, the trainer shares potential techniques that can be used and facilitate a discussion on times that they can be involved in activities for helping the classmate with ASD. The purpose of this phase is providing meaningful opportunities for students to help the classmate with ASD.

In the third and fourth session, the aims of the training are to discuss any barriers and provide support to students as needed related to the difficulties that they meet during the activities.

The application of PMI in the Italian context [47] has shown that this model was very positively received by both teachers and classmates, who defined the intervention as useful and effective in improving social and communication abilities of students with ASD. The possibility of experiencing this intervention within the classroom was appreciated by students and teachers. In the same research study [47], classmates maintained they felt comfortable in the relationship with the students with ASD and they enjoyed interacting with them, showing that PMI can be considered a successful strategy for inclusion.

## HOW THE PARENTAL INVOLVEMENT CAN BE A SOURCE FOR THE TRANSITION OUTCOMES OF STUDENTS WITH ASD: THE SOCIAL COOPERATIVE GIUSEPPE GARIBALDI

A group of parents of high school students with ASD requiring very substantial support, who later founded the Social Cooperative Giuseppe Garibaldi, started their journey together while their children were attending the Agricultural High School "Istituto Tecnico Agrario (ITA) Giuseppe Garibaldi" in Rome. During high school, this group of adolescents with ASD experienced a school-based intervention aimed at improving working and social skills using behavioral strategies in a peer-mediated model [48]. This PMI intervention, monitored by the Department of Developmental and Social Psychology ("Sapienza", University of Rome), laid the groundwork for the continuity of social and working inclusion during the transition from school to post-school experience.

An important goal of the scientific collaboration between the Department of Developmental and Social Psychology, ITA Garibaldi and Garibaldi Cooperative was to set up a network of services for the inclusion of the students with disability. The Province of Rome, the local sanitary districts, the Municipalities and the associations working for the adolescents with ASD attending ITA Garibaldi participated in the protocol which made the PMI intervention possible. This collaboration also allowed the activation of parent training and self-help interventions for parents and the monitoring of the specific objectives in each area of development indicated in the IEP.

Parents and children obtained the management of a part of the field of their former school ITA Garibaldi, thus they had the chance to develop the Cooperative, where the young adults with ASD, after graduating from high school, can maintain and keep developing the working and social abilities they had started to strengthen during the school years. The Cooperative is a real agricultural and agritourism enterprise. Half of its members are young adults with ASD requiring very substantial support. Together with their individual tutors, they sell agricultural food products in the city farmers markets and serve the tables in the Cooperative restaurant, which allows them to interact with their colleagues and with their clients every day. The creation of urban vegetables garden in the field managed by the Cooperative provides another chance of interaction and social inclusion in the local community. The Cooperative also receives students attending near schools for their pathways for transversal skills and orientation.

Monitored by the Department of Developmental and Social Psychology, the Cooperative has adopted an adapted version for young adults and working contexts of the COMPASS [31]. This model allows an individualized habilitative planning: the goals and the tactics to achieve them are tailored on the specific individual's needs and abilities, considering her/his strengths and weaknesses, and regularly verified and updated. The participation of parents and tutors in the individual planning is a core element of the model. One of the main obstacles in the adaptation of the COMPASS in the working context of the Cooperative is the availability of tutors who are experienced and trained in working with adults with ASD. Specific training on ASD and on intervention practices is often necessary. The active participation in planning and monitoring the habilitative goals can also be challenging for some parents when individuals with ASD become adults.

## KEY ELEMENTS ASSOCIATED WITH A REAL-LIFE PROJECT AND FAVORABLE TRANSITION OUTCOMES

This overview highlights the increasing need for specific services and shared strategies of proven effectiveness to favor the transition from school to post-school/working experience. From a legislative viewpoint, in the last decades, an increasing number of laws have addressed the themes of disability and inclusion in order to improve the quality of life of individuals with different disabilities in Italy. However, the actual school conditions do not always allow a full implementation of the legislation in the interest of the students with disabilities. We try to describe the key elements, in our experience, that are associated with favorable transition outcomes.

The first key element is the involvement of parents and teachers for evaluating strength and challenges and for defining transition outcomes of the student with ASD. We know that parents serve as key support for increasing abilities across life skills that continue long past school age, as reported by Rubles and colleagues [32], and teachers can be a source to teach learning objectives and life-skills. Following the COMPASS model, both parents and teachers are involved in the first phase of consultation, and the discussion on the profile allows the development of an individualized set of goals for each student and a personalized teaching plan for each goal. Parents and the student, when possible, answer additional questions about post high school goals. Thus, plans are also generated for the achievement of post-school goals. After the first consultation, the consultant meets with the parents, the teacher and the student, when possible, for four coaching sessions to review data on the student's progress toward the goals and the tactics to accomplish the goals. Cooperative problem-solving on issues which may obstacle the goal achievement is also an important part of the model. If the students with ASD have the possibility to develop work abilities thanks to the design of high school internships they are more likely to be employed as adults, as reported by Schall *et al.* [49].

The second key element is the power of the classmates, because many activities can be done in general education settings where students with ASD can receive the help of classmates, if they are trained as peer buddies. The school setting can be a fertile ground where adolescents with ASD may experience social interactions in a positive way if structured procedures and training are provided to peers.

The third key element is the parental involvement in the construction of the future of their son or daughter with ASD. The experience of Cooperative Garibaldi is an example of how the individual project (Law 328/2000 [6]) can support an individual with disability, by creating a network among the available health and social services and integrating the specific tools accessible during each life phase. The individual project is also essential for the continuity of the habilitative process during life transitions.

### *Conflict of interest statement*

The Authors declare that they have no competing interests.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 230-240
DOI: 10.4415/ANN_20_02_13

# Neurodevelopmental disorders and development of project of life in a lifespan perspective: between habilitation and quality of life

**Roberto Cavagnola[1], Laura Alzani[1], Davide Carnevali[1,2], Giuseppe Chiodelli[1], Serafino Corti[1,3], Francesco Fioriti[1], Maria Laura Galli[1], Mauro Leoni[1,2], Giovanni Michelini[1,2] and Giovanni Miselli[1]**

[1]*Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro (Cremona), Italy*
[2]*Sigmund Freud University Milano, Milan, Italy*
[3]*Università Cattolica del Sacro Cuore, Brescia, Italy*

**Abstract**

For some years, the term "project of life" has become widely used in the field of neurodevelopmental disorders, and, at the same time, it has begun to make its way in many social and health planning documents. However, beyond its relatively widespread use, this term does not yet possess an adequate and shared frame of the main underlying decision-making processes. In particular, there is a need to identify the crucial questions for orienting the choice of goals within the adolescent transition, which represents the complex hinge between childhood and adulthood. Moreover, adulthood, which is often completely devoid of culturally and socially shared references, is still critical precisely because of the lack of future direction prompts usually represented by the stages of development. In this case, the themes of quality of life functioning as a guiding compass appear pertinent and much more relevant. The present contribution is, therefore, an attempt to present, in a unitary manner, the decision-making processes and questions at the basis of a construct of "project of life" shared within the scientific and associative communities.

**Key words**
- neurodevelopmental disorders
- quality of life
- project of life

## PROJECT OF LIFE DURING DEVELOPMENTAL AGE: INTRODUCTORY CONSIDERATIONS

When analyzing the project of life in children with neurodevelopmental disorders, it is necessary to introduce an important distinction between childhood and preadolescence: they may roughly correspond to the transition period between the end of primary school and the beginning of secondary school respectively.

This distinction seems appropriate precisely in relation to the concept of project of life. As regards childhood in the strictest sense and, in particular, what is sometimes called first and second childhood, (from birth to the first five years of life), we believe that the project of life has, and should have, specific habilitation-based features closely related to the different developmental stages. Indeed, it is during the developmental stages that anything "potentially" relevant for the future life of the child is pursued. In a broad sense, therefore, we speak of project of life as a way of bridging the gap between the skills possessed by the minor and what is typically observed in minors of the same age. The project of life clearly aims to find a connection with the outcomes that the person will have during the course of their life but, on the level of habilitation contents, it is based on "cusp" [1] and "pivotal" skills [2-4]. These skills are important in order to guarantee greater possibilities of development, promotion, and quality of existence in the periods immediately following, such as the one starting with pre-adolescence. Indeed, it is precisely during this period that it is more appropriate to speak of a project of life because what was previously purely potential, now begins to be translated into numerous links which effect what ideally will find full actualization in adulthood, i.e. an existence made up of inclusion, commitment, active recognition within society, and achievement of personal outcomes.

Therefore, the keyword for childhood is "habilitation".

Child habilitation is, by definition, extended to all areas of development. However, primary attention should be given to some repertoires that objectively play a criti-

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*Address for correspondence:* Roberto Cavagnola, Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro (Cremona) Italy. E-mail: Roberto.cavagnola@fondazionesospiro.it.

cal role in the whole process of growth and that, consequently, have an educational centrality.

The relevant areas of intervention in the educational habilitation process can be briefly summarized as follows:

- inter-subjectivity;
- game and free time;
- communication;
- personal hygiene;
- basic autonomous behaviors.

The assessment tools that can adequately support this habilitation practice and emphasize the above-mentioned areas are: Vb Mapp (Verbal Behavior Milestone Assessment) [5], Pep 3 (Psychoeducational profile) [6], Denver Model Curriculum Checklist [7], Ablls (Assessment of Basic Language and Learning Skills-Revised) [8].

In general terms, what may be said about first and second childhood intervention, can be effectively summarized within the so-called triad of intervention.

Firstly, the intervention is defined starting from *precocity*. The precocity of intervention is now considered to be the necessary condition to exploit learning opportunities and maximize the chances of success of the intervention. At the same time, precocity prevents the consolidation of "maladaptive" learning behaviors within the main contexts of interaction.

A second characteristic of the early childhood intervention is the *intensiveness*, which refers not only to the quantitative dimension of the treatment (minimum number of hours per week necessary to support the change), but also to the contextual dimension. Intensiveness indicates the extent of the habilitation action not only centered on the child, but also extended to the context in which the child lives. Special attention is given to the child's family engaged in learning and experimenting with new effective models of interaction. For these reasons, the educational planning implies, from the beginning of the intervention, a guided involvement and participation of the family members in order to create the most favorable conditions to transform every daily moment with their child into an authentic opportunity for learning in a natural environment.

The *curricular character* of the treatment is the third salient feature and it refers to the articulation of the goals linked to the developmental processes. Therefore, this type of intervention must be supported by specific assessment tools, such as those mentioned above, capable of aligning the assessment plan with that of the intervention. The curricular plan must also be pursued with educational procedures that are supported by clear evidence. Hence, we are referring, in general terms, to the complex and articulated contribution offered by behavioral science with ABA and the Denver Model. As already mentioned, it is believed that the project of life begins to acquire shape from the pre-adolescent and adolescent phases. The two main elements that markedly note the distinction between the planning of the first and second childhood are: first, a more precise and punctual identification of concrete and specific community contexts within which to allocate educational interventions to promote the development of the child. Secondly, a stronger emphasis on the set of transitions viewed as a shift to increasingly diversified and specific social roles. The minor begins to enter the peer group, to participate in a more active community life (volunteering, places of entertainment, etc.), to develop the need to move independently in the territory, and to have a more active and collaborative role within the family and domestic context.

If the keyword for childhood was "habilitation", for the adolescent and young adult the keyword becomes "transition". Thus, the assessment process must reflect this change of perspective and adopt this transition to new roles and new areas as a central element of the evaluation.

Useful tools in this perspective are: the Teacch Transition Assessment Profile (TTAP) [9], Community Based Skill Assessment Checklist [10] or the Transition Checklist contained within the VB Mapp [5]. These tools focus, in particular, on the skills needed to adequately perform the complex tasks required by the transitions. The relevant work areas within this life cycle are described in *Table 1*.

In an attempt to summarize in key words the paradigm of the project in a lifespan perspective, it could be stated that the project of the person with neurodevelopmental disorders ideally represents an arc. The starting point of this arc coincides with a strict *habilitation* phase, which is then followed by a planning phase during which the *transitions* represent its main feature. These transitions are the ones that accompany the per-

**Table 1**
Adolescent and young adult task area required by the "transition" phase

| Area | Description |
|---|---|
| Career and employment | Opportunities to learn all the skills needed to enter the world of work in a fulfilling and productive way, while respecting the personal skills and interests, or attitudes |
| Self-determination | Ability to be the primary causal agent of one's choices, and at the same time, the knowledge of how to protect oneself from possible exploitation or deception |
| Health and Safety | Ability to manage one's sexuality, to adequately manage possible pharmacological therapies or practices of self-medication, or know how to move safely in the home |
| Community active participation and access to services | Participate to the wide range of possible activities related to personal satisfaction, such as the cultivation of friendships, the development of hobbies, sports activities, etc. Furthermore the use of public transport is crucial to attend community |
| Role within one's own household | Acquiring an active role, which is that of contributing to the management of the various daily life actions and to the care of the home environment |

son to adulthood where the project takes on a markedly existential connotation.

## THE PROJECT OF LIFE IN ADULTS WITH NEURODEVELOPMENTAL DISORDERS AND DEFINITION ISSUES: INTRODUCTORY CONSIDERATIONS

The previous paragraph has given us a glimpse, in its essential terms, of what could be defined as an itinerary for the development of a project for people with neurodevelopmental disorders in the developmental age. Perhaps, a good starting point is the precise definition of the differences between a project of life for people with neurodevelopmental disorders in adulthood and in the developmental age.

First of all, the project of life for the adult person, especially when compared to the developmental age project, implies fewer shared social expectations. The developmental age consists in stages of development where, regardless of whether the specific child will follow this evolutionary sequence, there is a social consensus on what is important to acquire. At a certain age, a child is typically expected to start speaking, to develop sphincter control during kindergarten, to start learning literacy at the age of six, and so on. Something similar does not exist for adulthood. The cultural and social link that can be the basis for choosing goals for the project of life in adulthood is much more evanescent and nebulous. This becomes vaguer when the functioning of the people with disabilities is low, they require a high degree of support, and there are no credible pathways to employment. Hence, we enter a gray area where "what society expects" appears to be an even more random reference. All this leads us to affirm that, at times, when selecting goals for the adult person with disabilities there are specific reasons why certain goals were chosen to the apparent detriment of others.

Secondly, in simple terms, the project of life for adults should be characterized by a different emphasis within the range of goals. Gardner [11] proposed and distinguished between the following outcomes:

- *clinical*, are the outcomes of interventions aimed at ensuring both good physical health and the reduction of "challenging behavior". Both the former and the latter interfere with the full exploitation of the opportunities offered by the community;
- *functional*, are the outcomes of programs aimed at improving the person's functioning in terms of socially relevant behaviors;
- *personal*, are the expression of what is interesting and desirable for the person.

If we adopt this tri-partition of goals stemming from expected outcomes, we can affirm that planning in the developmental and adult age differs precisely because of the different saliency of these three categories within the individual project. In particular, in a project of life for adults, the functional goals, though still present, will be decidedly less marked than those found in a project for the developmental age. This is not only because of less brain plasticity, but also, and especially, because the greatest concern in adulthood is to enhance and emphasize the learning that occurred in the previous years. This means making the object of learning functional and avoiding maintaining the subjects at the existential register of eternal schoolchildren. Conversely, in adulthood all those paths that put the person in contact with personally relevant and rewarding outcomes will necessarily have to find more space, which is not different from what all adults pursue when attempting to realize their desires and expectations. The potential presence of health issues or behavioral and psychopathological problems may facilitate both in the developmental age and in adulthood, the presence of clinical outcomes *(Figure 1)*.

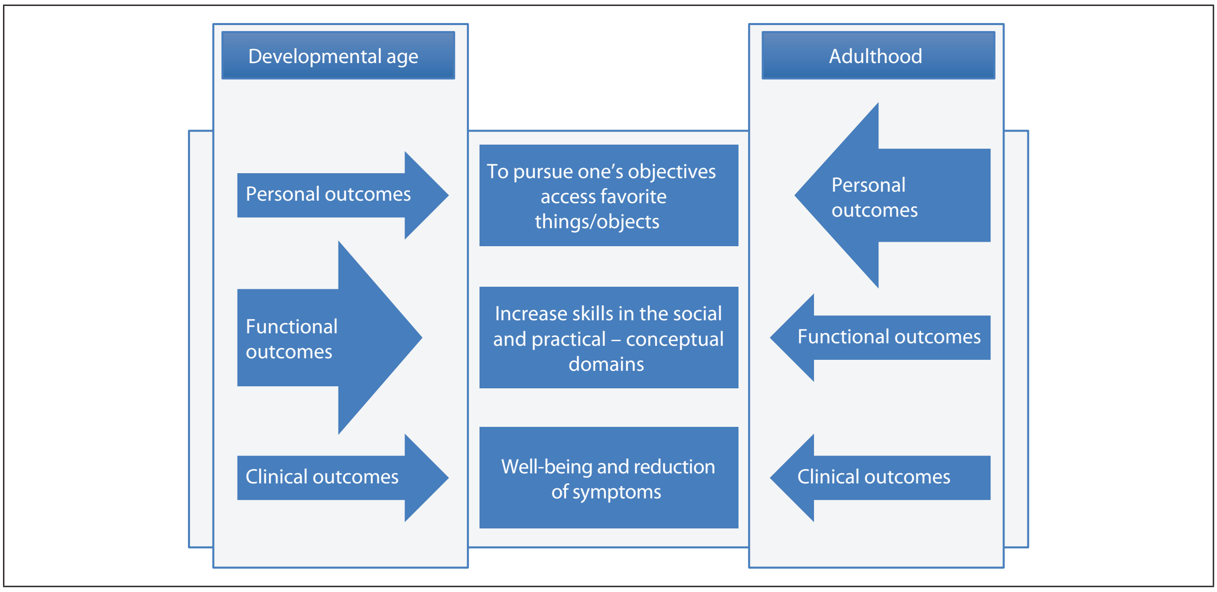

**Figure 1**
Model of the "Project of life" outcomes differentiated by the age of the subject. The size of the arrows indicates the greater/lower emphasis that should be given to personal, functional, or clinical outcomes in the different ages.

Thirdly, we believe that another difference between projects in the developmental age and adulthood lies in the different timespan that characterizes them. Indeed, the goals contained within a project for minors have, legitimately so, a very close temporal projection. On the contrary, those present in a protocol for adults require much more time for their realization. This depends on two factors: the first, which is well known and cited, is the greater brain plasticity during the developmental age, which necessitates intensive and early intervention, with different and operational short-term goals. The second is linked to the common and ordinary ways in which, typically, adults plan their lives. Indeed, the ways to build a career, an independent life, an emotional project are goals that may occupy many years and involve countless and intertwined paths. Thus, a project of life for adults will necessarily require an adequate temporal span within which to unfold and should not have significant repercussions in the short term [12].

### *The assessment of the project of life*

In terms of assessment, it may be useful to start from the five dimensions that characterize intellectual disability and autism according to the multidimensional perspective proposed by AAIDD [13, 14]. This multidimensional approach requires that a comprehensive assessment of a person with neurodevelopmental disorders include five dimensions to be assess:

1. intellectual capacity;
2. adaptive behavior in its three fundamental factors (conceptual, social, and practical);
3. health, physical, and mental condition;
4. participation, interactions, and social roles;
5. the person's life context.

For each of these five dimensions, there are different tools depending on the function the evaluation intends to perform. The functions can be:

- diagnostic;
- classificatory;
- aimed at the programming of plans and individual support systems [14].

For the purpose of this contribution, we think that the main purpose of an evaluation process is to better identify the necessary support systems:

- improve functioning;
- improve outcomes (in terms of quality of life);
- encourage the implementation of individual choices;
- guarantee human rights.

Within the five dimensions, the assessment tools will thus be varied and the short list below has the sole function of indicating, in a concise manner, some of the most useful ones for the development of a project of life. As far as health conditions are concerned, the CIRS (Cumulative Illness Rating Scale) [15] is an easy, but effective tool for the quick identification of the active pathological frameworks and comorbidities present in the individual. The CIRS is a standardized scale for obtaining a measure of somatic health. The questionnaire requires the healthcare professional to identify the clinical and functional severity of 13 categories of pathologies based on clinical history, objective examination, and symptoms. Then, the professional defines the level of severity for each of the categories and a comorbidity index is drafted. With regard to the health condition, the presence of other potential psychopathologies necessarily requires appropriate tests to detect the associated psychiatric pathology, such as SPAIDD-G (Systematic Psychopathological Assessment for Persons with Intellectual and Developmental Disabilities - General screening) [16] or DASH II (Diagnostic Assessment for the Severely Handicapped revised,) [17]. However, it is critically important to have instruments of functional analysis of behavior and, in particular, of experimental functional analysis [18, 19]. Indeed, these may detect the functions of behavior and, consequently, may be the basis for the identification of iso-functional, adequate and effective behaviors, which need to be reinforced in order to replace problematic and dysfunctional behavioral repertoires. As far as the adaptive dimension of behavior is concerned, in addition to the Vineland II Scales [20] – which represent a normative tool – an excellent contribution for the construction of a project of life is provided by other sets of criterion-based tests such as the TTAP (TEACCH Transition Assessment Profile) [9], the EFL (Essentials For Living) [21], the AFLS (Assessment of Functional Living Skills) [22]. In terms of the intelligence dimension, we believe that tests of a normative nature such as the WAIS (Wechsler Adult Intelligence Scale) [23] hardly satisfy the function of programming plans and individual support systems. If the main purpose of this particular type of assessment is to define the project of life, then it may be important to use assessment tools that improve the evaluator's ability to focus on basic learning skills, such as ABLA (Assessment of Basic Learning Abilities) [24] or communication skills, such as the Speaking and Listening scales in "Essentials For Living" [21].

The assessment of the remaining two dimensions, namely participation, interactions, social roles, and the context of life, emphasizes the need to make use of criterion-based and non-normative tools, such as ecological questionnaires to investigate the ecosystems of the person's life and scales for the assessment of support. Furthermore, at least two types of assessment can also be extremely significant: the quality of life and the preferences expressed by the individual. With regard to the theme of quality of life, there are many scales designed for such assessment in people with neurodevelopmental disorders [25-31]. In our working practice, we make explicit reference to the meta-model proposed by R. Schalock [32], who insists on eight domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and mental health, material well-being.

As it has already been anticipated, a second type of assessment plays a crucial role in the development of the project of life. This assessment consists in a set of procedures normally defined as "preference assessment". The assessment of preference is of fundamental importance for a project of life that emphasizes the prominence of personal outcomes, the access to the world of stimuli and, more generally, the events preferred by the individual. This type of assessment can be performed indirectly, that is, the source of access to preferences is not the direct observation of the person with disabilities, but a survey conducted by caregivers who know them best (or by people with disabilities themselves if they are linguistically competent), for example questionnaires such as RAIDS (Reinforcement Assessment for Individuals with Severe Disabilities) [33], the Reinforcement Inventory for Children and Adults [34] or the "values interview" [35]. In general, however, the hierarchies of preferences produced by indirect assessments do not always align with those resulting from direct assessments. Another modality, which could be defined as direct observation, is that of the "free operant" [36], characterized by giving the subject free access to objects or activities and the amount of time spent in contact with the objects (manipulating them, looking at them, paying attention to them) constitutes the criterion for constructing the person's hierarchies of preference. The framework of preference assessment procedures is completed by systematic preference assessments that can range from single-stimulus assessment [37], to paired-stimuli assessment – which is perhaps the most precise way to build a hierarchy of preferences [33, 38] – multiple stimuli assessment with repositioning [39], where the stimulus selected as preferred is reinserted within the range of choices, and lastly the multiple stimuli procedure without repositioning [40], where the selected stimulus is removed from the selection set, thus "forcing" the person to assess the preference within the remaining stimuli. It goes beyond the intent of the paragraph to compare the validity of the different preference evaluation procedures. In the present work, it should be highlighted that there are, in the literature, different ways of assessing preferences and assessment acquires an unprecedented importance in the evaluation phase of the project of life for adults. A person-centered plan without an assessment of what is important and preferred by such individual risks consigning the choice of activities to a philosophical, rather than empirical, principle and this can give rise to innumerable biases [41, 42].

## FROM ASSESSMENT TO ECOLOGICAL BALANCE

The observational and evaluation phase conducted so far should offer the assessor a substantial amount of data and information regarding the five dimensions presented in the previous paragraph. Thus, having a great deal of information available is a potential benefit for a more project-based evaluation, but such an amount of information may be difficult to summarize and it could pose some problems for the development of the project of life. Indeed, assessment is valuable insofar as the data and information collected are instrumental and usable for the development of the project [12]. In order to align the data of the evaluation with the goals and goals of a project of life, it is therefore necessary to have an intermediate process capable of filtering the set of information and data. Such process questions the results of the overall assessment and draws significant information for the development of the project of life.

Consequently, with this intent, we have outlined some questions that could be viewed as special lenses through which to investigate the varied information produced by the assessment. These questions, in line with the initial assumptions, lead to an ecological analysis involving the person and the main ecologies of life within which the person lives (family, service, places, and community services). This analysis should involve all the main caregivers, and, where possible, the people themselves, with the aim of finding a balance among the various ecologies/ecosystems. The questions, which are at the basis of the ecological balance are a means to develop input for the project. The ecological balance is composed of six questions:

### *Preferences and wishes of the person with disabilities (things that are dear and important to the person with disabilities)*

At this level, reference is made to the results of the survey conducted previously with the person with disabilities about their complex system of preferences obtained through the choices assessment procedures. The hierarchy of preferences expressed by the person must represent the fundamental reference point in the definition of the project of life. This hierarchy must then be concretely declined according to the resources and opportunities available. During this process of declination, it is also appropriate to provide for interventions that can change the contexts and beliefs of the ecosystems of life of the person with disabilities. Thus, the questions feeding this category are: "what does the person want?", "what does the person like?", "what does the person declare to be important for them?". A further question that could be proposed at this level is related to the difficulties that this person might encounter in acquiring their favorite things or in achieving what is important to them.

### *What is important for the person (from the point of view of caregivers and the person's background)*

This question leads us to investigate the parts of the assessment related to contexts. Understanding what the different contexts of the person's life represent for them means understanding the expectations and rules of the primary network (e.g. family) and all other networks of support and belonging of the person (friends, services, volunteering...). The choice to investigate the expectations and rules of the networks that constitute the social and affective context, in addition to the person's expectations, stems from the fact that the preferences and desires of the person with disabilities are not always exhaustive of what is important for that individual. It is a trivial consideration, but it implies both ethical and deontological consequences. There are many classes of behavior that appear to be central to ensuring a good quality of life and which, however, are not among the person's preferences and priorities. The answers to this general question can be sustained by a series of other questions, such as: "what do we consider important for this individual?", "what skills are important for this individual in order to improve their quality of life?", "what skills would be useful to improve their quality of life?". It is important that the formulations collected are always expressed in a positive form and not in a negative one. The assessors will therefore express themselves starting from statements such as: "increase their communication"; "increase their personal autonomy skills"; "make them more capable of managing their emotions". The following formulations are not correct: "we would like him not to disturb", "we would like her not to always get into trouble…".

The first question of the ecological balance directly interrogated the set of evaluation procedures related to the preferences of the person, but there is no similar question regarding the process of choice and targetization of goals and objectives. Even in the absence of such a precise reference, however, it is possible to orient this choice by means of a series of further critical questions about activities and goals. These questions can refine the statements stemming, at first, from the different contexts. The following questions draw on two major sources of the literature: on the one hand, the contributions offered by behavior analysis [43, 44, 2] and, on the other, the quality of life studies [32].

*Do the identified goals represent an essential skill?*

McGreevy [21] has listed eight potential "must have" skills also suitable for adults. The lack of these skills could be a factor of serious hindrance for the development of other more important functional and adaptive skills. The skills that are reported at this level are the following:

- making requests;
- knowing how to wait for the delivery of a reinforcing stimulus;
- accepting the delivery of a reinforcement and/or the interruption of a preferred activity;
- knowing how to complete learned tasks;
- accepting a negative answer ("no");
- following health and safety related instructions;
- completing daily life skills related to health and safety;
- tolerating health and safety related situations.

*Is the behavior or activity likely to produce reinforcement in the person's life context?*

The question leads us to reflect on whether the achievement of a goal and/or the performance of a certain activity will have reinforcing consequences for the individual. In this case, an objective or activity is significant and important because of the person's primary interest. When can these circumstances occur? We believe that at least two different circumstances meet the "primary interest of the person" requirement:

a) the first can be considered satisfied when the objective or activity produces automatic reinforcement. In other words, the activity is self-reinforcing. For instance, though they are very different, "reading" or "manipulating stimuli" that produce pleasant tactile sensations are two examples of this;
b) the second refers instead to the possibility that, while the person is carrying out an activity, or at the end of a teaching process, they can get in contact with reinforcements in their natural environment.

Is this behavior (or activity) a prerequisite for a more complex functional ability?

Some behaviors are not significant except for the fact that they are prerequisites of functionally important and relevant skills: for example, grasping a soap bar placed in one box to put it in another could be a meaningless activity if it is not given any function other than changing the location of objects. However, it could be a valuable activity to build prerequisites if it intends to develop the grasp of soap that is an absent behavior within a task such as "washing your hands". In this case, it is worth underlining that if some prerequisites represent the target of the intervention in the context of a project designed for adults, they must be directly connected to a socially relevant skill and not be generic remote prerequisites.

*Does this skill increase the person's opportunity to access environments in which other important behaviors can be acquired and used?*

The question enquires whether the chosen behavior is a behavioral "cusp". To understand what a "behavioral cusp" is, it is worth citing the author who first used these words: it is "a change of behavior that has consequences for the body beyond the change itself, some of which can be considered important" [1]. A classic example, borrowed from the developmental age, is that of a child learning how to walk. The acquisition of the walking skill allows the child to access new contexts and new experiences that can be both reinforcing and a source of new and significant learning. In the developmental age, we can certainly set ourselves a behavioral objective of this kind and be reasonably sure that walking will put the child in contact with countless stimulating contexts. Nothing else is needed. The targetization of a behavior or the selection of an activity, in an adult person with neurodevelopmental disorders, should, in our opinion, imply a greater commitment to identifying the contexts to which we want, realistically, the person to have access. Therefore, the potential cusp function of a behavior does not seem sufficient to target an objective or select an activity without, at the same time, identifying the specific contexts within which the person will experience new sources of reinforcement.

*Will changing this behavior predispose others to interact with the person in a more appropriate and supportive way?*

In this case, the target is not of direct and immediate interest to the person with disabilities. Cooper, Heron and Heward [43] produce a good example of a potential communication target which is suspended in favor of another related to the management of living places (tidying one's own room and helping with the housework) in order to reduce the workload (and stress) of parents. In this case, the authors state that it may be appropriate to teach such skills precisely because the reduced dependence of the children will predispose parents to interact, more and better, with them, also from the point of view of communication itself, which was the initial target of the educator. This question has a certain relevance for people with disabilities in adulthood, whether they are with the family or part of service programs. Indeed, the frequent reduced number of staff creates a condition of real "flooding", that is, the tasks of care significantly saturate the time of the staff. Similarly, this phenomenon tends to reproduce itself in the family, often characterized by a high level of stress resulting from the burden of care of the relative. In this case, a reduction of the burden could turn into a flywheel able to increase the availability of staff or parents, promote training or, more simply, a shared time slot within which to develop more fun and strengthening relationships. The question guiding targetization certainly has its relevance and legitimacy, however, it also presents potential risks. In the previous example, there were two clear aspects:

a) behavioral objective which the educational figure considered of direct utility for the person (e.g. communication);
b) behavioral objective which is primary for other significant people (e.g. parents).

This means that a reduction in the care burden should be matched by an increase in the commitment to the behavioral target of direct interest to the person. In other words, an indirect target should always be paired with the identification of a target of direct interest. Otherwise, there is a risk of identifying targets that completely diverge from the priorities of the person with disabilities.

*Is the behavior or activity generative?*

The generativity of the target behavior occurs when the learned behavior produces changes and evolutions in other behavioral classes without being directly taught. The concept of generativity has been reviewed several times in the analytical behavior literature. It is on these behaviors that the concept of "pivotal behavior" [2-4] focuses, for example, as a skill that produces modifications or covariations in other adaptive behaviors not necessarily taught. For instance, teaching an autonomous and independent approach to other people represents, according to the authors, pivotal behavior because it correspondingly increases other classes of behavior such as "asking questions" or the "quantity" and diversity of speaking and dialoguing with others. There are many activities that develop potentially pivotal behaviors [44]: if one is taught how to play bingo, they will learn a variety of skills beyond the simple game: listening, verbalizing, interacting, taking turns and sitting together with others. It is easy to see how mastering all the fundamentals of a seemingly simple game like bingo could translate into skills needed for other areas of life.

Likewise, the concept of generativity, which is interesting because it creates potential developments that are not the object of direct teaching, thus widening the repertoire of the person, requires specific attention when applied to adulthood. Though it is true that a certain behavior has in itself the potential to broaden a person's repertoire of abilities in certain areas of life, the opposite can be said when that new behavior or activity is not accompanied by an increase in the opportunities needed to activate the generative process. Indeed, it is not uncommon to witness situations in which certain activities are selected for some intrinsic pivotal potential, but, in terms of opportunities offered, the person's life does not change at all and the so-called "other areas of life" simply do not exist. For this reason, developing activities or promoting pivotal behavior must include explicit planning of new opportunities to offer to people with disabilities.

*Does the behavior or activity represent an iso-functional alternative to challenging behavior?*

This question emphasizes the "constructive" approach versus the "eliminatory" approach [45]. Indeed, it is simply unfeasible to eliminate a challenging behavior when this behavior, though socially challenging and dysfunctional, has proved to have at least one or more functions for the person who exhibits it. For this reason, Bosch and Fuqua [44] suggest alternative behaviors as a new frontier of cusp behavior. In this sense, some activities, which apparently may not have any meaning, acquire significance precisely because they are socially and personally more adequate responses to the problems present in the person's repertoire. Behaviors and activities at this level can be very different depending on the level of functioning of the person and the type of challenging behavior subject to intervention. They can range from mand training to manipulation of soft materials to surrogate tactile sensibility stereotypies.

*Is this behavior age-appropriate?*

The question refers to two assumptions. The first is philosophical, so to speak, the second is linked to the actual probabilities a behavior or activity has to be reinforced naturally in the natural context. The philosophical principle is based on the famous concept of "normalization", which emerged during the 1970s. The recommendation is to conduct activities "as culturally normal as possible" [46]. The term "as far as possible" indicates that the principle of normalization should be understood more as a continuum rather than a category. There are different ways to answer this question and, among what is feasible, there is the use of age-appropriate material. Indeed, it is also possible for people with profound multiple disabilities to perform sensory activities with brushes capable of stimulating their touch, rather than with cloth puppets.

*Does the activity or behavior aim to improve important parameters of a person's health?*

Sometimes the activity or behavior to promote is not aimed at the person's immediate behavior. Weight reduction or glycemic values are examples of this. However, activities can contribute to the achievement of adequate physiological parameters through the teaching of a diet, exercise, or other activities that can normalize the parameters. Health issues, which are frequently related to neurodevelopmental disorders, are therefore of co-primary importance within a person's project.

*Is the behavior or activity a direct response to improving some domains of quality of life?*

An expression is often used in reference to behavioral targets: "socially significant". This definition indicates, like that of normalization, what is socially expected, in particular, for an adult person. However, there is a potential range of goals which are not only attributable to socially expected behavior, but also encompass the improvement of quality of life and general well-being. A reference to this level can be represented by R. Schalock's meta-model [32] which, as seen in the previous paragraph, identifies 8 fundamental domains for a good quality of life for all people. This question leads to the identification of "contents" that can be used as the basis of the targetization process. In this regard, it is worth underlining that there are not only goals aimed at increasing adaptive skills, but also others intended to increase the indicators of happiness or, conversely, reduce pain indexes within clinically necessary activities [47, 48], thus generally improving well-being. It should be noted that in adulthood the dimension of personal outcomes should be emphasized and the identification of potential goals balanced by trying to respond to the complex of the eight domains. The breadth of the domains requires that the goals relating to improving the quality of life are clearly defined in terms of expected outcomes and do not constitute generic phrases capable of justifying any activity.

### Challenging behaviors for the environment and concurrently dysfunctional behaviors for the person (which challenging behaviors limit their active participation?)

This question requires the assessor to investigate the existence or non-existence of behaviors that the person exhibits which are challenging for their ecosystems and, at the same time, dysfunctional for the same individual. This operation involves two different moments:

a) the collection and listing of the different behaviors experienced in a challenging way by the contexts;
b) the assessment of challenge severity and hierarchy.

The collection of challenging behaviors must include the contribution of all people who, in different ways, have an important relationship with the person with disabilities. The selection "judges" the degree of challenge, thus including some of these behaviors (which will then be the subject of intervention) and excluding others. The process of selection and hierarchy can be facilitated by the use of questionnaires that can help caregivers to share the judgment of challenge and produce a hierarchy.

In order to understand and evaluate the degree of challenge of some behaviors, it would be better to resort to some subjects before starting any intervention. The first of these should be whether the behavior produces damage to the subject or to other people or things. A positive answer to this should clearly dispel any kind of doubt: the behavior that the person exhibits is truly challenging. The second enquires whether that challenging behavior is an obstacle to the development and well-being of the individual. Indeed, there is a wide range of behaviors that are not "dangerous" either for the person or for others, such as stereotypies.

However, a considerable exhibition of such behaviors can be detrimental to the learning of new skills. In some cases, the frequency of stereotypies is so high that it even seems to shield the subjects, thus making them hostile and extraneous to any proposal. In this case, too, an affirmative answer would legitimize an intervention. Finally, some considerations should be done on "milder" behaviors, configurable as strange or bizarre attitudes. The assessor needs to evaluate whether such behaviors tend to consolidate the social stigmatization and therefore the marginalization of the subject. This evaluation is important because the risk is that of "normalizing" the behavior of the person by annulling what could be defined as the typical dimension of the subject in light of a conformist vision of attitudes and behaviors. Only a pondered and shared positive response among all the people and contexts with which the user is in close relationship can provide a sufficient basis for an intervention.

### The person's performance/skills are not actualized (required) by environmental contexts

This specific question leads to the isolation of the set of skills that the person already possesses within their repertoire and that, for various reasons, are not requested and experienced. It is not a matter of selecting these skills, if there any, and inserting them sic et simpliciter within a new project. However, it is important to understand how much of that person's learning history has settled in order to assess how many of these skills can be appropriately included in an intervention program for the person. The term "appropriately" refers to the role these skills could play in improving one or more domains of the person's quality of life.

Therefore, at this level two steps must be taken: on the one hand, the set of these skills needs to be identified, on the other the skills that are considered "important for the person" for a good quality of life should be selected.

The questions that could feed the information contained in this category are the following: "does the person have any skills that are currently unexpressed?"; "are there any skills that we have seen in the past, or that emerged during the assessment, that are currently not valued?"; "In the person's history, are there any skills that our environment has no longer exercised or requested?".

### Balance between personal performance and ecosystem demands (what significant abilities does the person already express?)

This ecological analysis question attempts to isolate the "balance points" between the abilities expressed by the person and the demands of life ecosystems. Referring to the "old" WHO document, the ICIDH (International Classification of Impairments Disabilities and Handicaps) [49], where there is a balance between environmental demands and skills expressed by the person there is no "handicap". It is ultimately a question of investigating, in the different contexts of a person's life, the strengths of that individual, what makes them particularly “capable” of responding to certain aspects of their daily life in their environment. The questions that call for an investigation in this direction can be: “are there any skills that the person already exhibits that we consider particularly useful in the life they lead within that specific system (family, service, aggregation); “what strikes us most positively among the skills exhibited by the person?”; “what are the skills that make them more adequate and capable than what is typically required in their daily lie?”.

### *Health conditions that can influence the search for the best quality of life (which health conditions could limit the active participation of the person?)*

The sixth category of the ecological balance requires the identification of disease conditions that may impair the achievement of a higher quality of life. It is therefore not so much a question of listing all the pathologies of the person, but of understanding which ones seem to have the most direct impact on quality of life. In particular, we are referring to physical health, since mental health aspects should have already been investigated (in behavioral terms) in the previous analysis question on “environmentally problematic and dysfunctional behaviors for the person”. This part of the analysis should examine: the active pathologies present at that moment; the risk factors (with particular reference to lifestyles) that could give rise to potentially serious disease patterns detrimental to a good quality of life; and the presence of iatrogenic problems arising from the use of psychotropic pharmacology.

## FROM THE ECOLOGICAL BALANCE TO THE PROJECT OF LIFE

The ecological balance we have seen so far should lead to a summary of the salient and representative aspects of the people’s desires and choices, and the different contexts and systems within which the subjects find themselves living.

The ecological balance should provide the “material” with which the “project of life” will be developed and its results represent what could be defined as real project inputs.  From this perspective, the “project of life” is a set of propositions elaborated by the multidisciplinary team and shared with the person, their family, and other significant contexts. Therefore, the project of life must clarify the “general purposes” that inspire the work of the whole team and its different goals must be declined within the eight domains of the already mentioned meta-model of quality of life [32]. As already noted, the project of life must be promoted within an adequate temporal span. This means that the different goals contained in it can guide the educational and clinical work for periods that can be as long as a few years. This does not mean rigidifying the planning or not considering events that can modify the educational clinical and care framework. It only means that the planning, sometimes, should be configured as a necessarily long-term process, similarly to normotypical adults.

In general, this translates to having articulated and coordinated plans that can lead to expected outcomes in a period that is not necessarily measured over a calendar year. It is worth pondering, for a moment, what it could mean to habilitate a person to an independent life, or to activate a path of reintegration in the community of a person suffering from severe challenging behavior. The Project is therefore valid as long as the five dimensions of the evaluation, on which the ecological balance was conducted, do not present significant changes. If this were to happen, for example in the case of an onset of dementia, a major psychiatric problem, or the disappearance of one of the nodes in the person’s network (e.g. the family), this picture would change substantially and the project of life would have to be extensively redefined.

## THE INTERVENTION PROGRAM

The intervention program represents the full operationalization of the goals contained in the project of life and its translation over a short period of one year. The goals contained in the project are, as was said, operationalized and transformed into work goals. The intervention program, precisely because it is inscribed within a complex and articulated project of life, must necessarily develop from different types of objectives. In particular, within the Intervention Program we can distinguish the following five objectives:

1) *constructive type*, that is, the formation of new skills (or increase of the parameters of the same) previously absent from the person’s skills repertoire;
2) *decrease*, aimed at reducing challenging behaviors or behavioral excesses;
3) *maintenance*, intended as actions towards classes of responses, already present in the person’s repertoire, through functional exercise and monitoring. On the one hand, the maintenance goals will therefore welcome the constructive goals that have been achieved and that will have to be included in a functional exercise and monitoring register. On the other, they will be fed by inputs contained in the ecological balance when, for example, the points of “balance between the performance of the person and the demands of the ecosystems” are identified;
4) *environmental change*, as actions directed towards environmental ecosystems in order to make an environment more appropriate to the well-being of the person, and their personal and functional characteristics. The concept of environment used within these goals is “extensive” as it includes physical, organizational, cultural, and relational aspects. In other words, this particular type of goals does not focus on a person’s behavioral repertoire, but rather on the modification of certain aspects of the environment in order to update the skills possessed, increase well-being, or reduce the burden of discomfort and pain;
5) *bio-medical*, are the set of actions and interventions mainly aimed at normalizing parameters (treatment), preventing pathologies linked to specific risk factors, and monitoring the effects of the treatments themselves with the aim of reducing possible iatrogenic conditions.

Each of these objectives clearly has specific ways of articulation and a number of steps that must be followed in order to implement them. However, an analytical examination of these processes within the individual types of objectives goes beyond the scope of this chapter, which has only attempted to outline a possible path for the development of a project of life for a person with neurodevelopmental disorders.

### *Conflict of interest statement*

The Authors declare that they have no competing interests.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 241-246
DOI: 10.4415/ANN_20_02_14

# Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy

**Corrado Cappa, Michela Figoli and Paola Rossi**

*UOC Psichiatria di Collegamento e Inclusione Sociale, DSM-DP AUSL Piacenza, Piacenza, Italy*

**Abstract**
The Mental Health Department of Piacenza has recently activated a special program for persons diagnosed with autism spectrum disorders (ASD). The Program engages a number of stakeholders: the users, their families, social and psychiatric services as well as specific associations for autism. The program is aimed to grant a complete and individualized assistance to people with ASD and it is especially focused on the transition to adulthood. In this period, it is necessary to build the "life project" in order to improve functioning and quality of life of users. The elective areas of the individual plan have to deal on how to reach autonomy in daily living and related skills, obtaining and maintaining a job, as well as starting and reinforcing significant relationships. This paper is especially focused on job placement for people with ASD.

**Key words**
- autism spectrum disorders
- adulthood
- transition
- life project
- job placement
- individualized program

## INTRODUCTION

Piacenza and its region account for about 280 000 citizens. The Mental Health Department serves this population and treats about 2% for mental illness.

The psychiatric unit, called *Psichiatria di Collegamento e Inclusione Sociale* (PCIS), is a Rehabilitation Psychiatric Unit that works like a server for all the other Psychiatric Units of the Mental Department. Its mission is to improve the functioning and the quality of life of users followed by psychiatric services. Then the elective areas of work concern autonomous daily living and related skills, obtaining and maintaining a job, as well as beginning and reinforcing significant relationships. The Psychiatric Unit has in its mission the improvement of physical health of people with serious mental illnesses and the reduction of social stigma through specific interventions in secondary schools.

From 2014, PCIS has started a special program (*PDTA Autismo: Percorso Diagnostico-Terapeutico-Assistenziale Autismo*) for persons diagnosed with autistic spectrum disorder (ASD). This involves all the stakeholders: users, their families, social and psychiatric services and specific associations for ASD persons. The program aims to provide a complete and individualized assistance for people with ASD. The focus is especially on the transition from adolescence to adulthood, when the risk of missing users is particularly high: during the period from 16-18 years users and their families are in charge of both the child neuropsychiatry and the psychiatry unit (autism transition team, ATT). After the age of 18, only the PCIS takes care of these users. In the same period of two years, the team of PCIS repeats a general assessment: diagnostic, cognitive and neuropsychological, and, specially, an assessment of the functioning in the main areas for independent life and the preferences of the user. The repeated questions posed to users from the operator is: "What do you want to do now? And in next ten years from now? The belief is that the age between 18 and 30 is crucial to make the fundamental choices for future life. This is especially true for people with ASD, because they are generally less autonomous, less likely to be employed, more isolated then their peers, also compared to people diagnosed with intellectual disability [1-3]. Practically, this period of transition is dedicated to building up the life project of the user. Of course, this fragile age deserves major attention from the psychiatric service through a holistic approach [4].

In the same period, we divide the ASD population we counsel according to 3 functioning levels, following

*Address for correspondence:* Corrado Cappa, UOC Psichiatria di Collegamento e Inclusione Sociale, DSM-DP AUSL Piacenza, Piacenza, Italy.
E-mail: c.cappa@ausl.pc.it.

the DMS 5 classification: high (level 1), middle (level 2) and low functioning (level 3). In making this classification we use some flexibility with the ultimate goal of directing the users to those activities they are more inclined to. Level 3 users are managed in collaboration with the social service of the local municipality.

From the beginning of the PDTA Autism, we have been aware that there is an underestimated prevalence of ASD in the population in the range 18-30 years. Data suggest that many undiagnosed cases are assessed in the PDTA Autism that have escaped previous assessment by the child neuropsychiatry unit and by doctors from other specialties.

## JOB DEVELOPMENT AT THE PCIS OF THE PSYCHIATRIC UNIT OF PIACENZA

In this paper, we specifically consider the paths and the outcomes of job development for people with ASD in our mental health department.

Only ASD persons in levels 1 and 2 according to DMS 5 have a real job. Those in level 3 do not qualify for a real job, have occupations consisting of a helpful and significant work and a minimum wage. We know that there are a lot of obstacles for people with ASD, like the "benefits trap", rigidity in their preferences and routines, an uncomfortable working time and specially the self-stigma or the lack of trust on their own resources: the family is often the first to report this lack of trust. The operators must be aware that these are real obstacles to habilitation or rehabilitation of the user and must actively recognize and bring about the positive personal resources of each individual. Indeed, special interests represent second core symptoms of the disturbance and they can be a source of desire and development, especially in the job area. Unfortunately, many users with ASD ended the secondary school with the belief that they are less capable than their peers to hold a normal job. Alternatively, in reverse, some people with ASD think that working is not for them because of their differences from "normotypic" people: the consequence of these attitudes will be a progressive marginalization, isolation and, sometimes, discrimination. For many people with ASD the aim of a normal job will not be reached because of the lack of trust in their own capability, despite they might show normal or even higher intelligence, compared to an average person without ASD.

In our psychiatric unit, at the end of the transition period from adolescence to adulthood, we try to offer all ASD persons a variety of working possibilities, respecting the preferences of any user for a certain kind of job.

We have available 3 main paths: a) internship; b) social cooperation and c) IPS (individual placement and support).

The first two are a kind of sheltered route. They are the traditionally paths for people with psychiatric illnesses (and especially for people with ASD) that want to start a job. Actually, it is the mainstream for most of our users.

a) The *internship program*, in particular, takes place in various work contexts, predominantly involving manual work, where there is a lower demand for intellectual performance. This working context could be positive for people with ASD because it is often repetitive and rigid. Many users with ASD do not disdain a working place where they can do cyclic tasks. The limitation of this approach is that the training before the real job is often too long: job recruitment happens many years after the beginning of the internship or does not happen at all. In the last years, the rules for recruitment have become stricter preventing the person to finally gain a real job, a very different condition than in other countries as northern Europe were the path is much facilitated.

b) *Social cooperation* has a long tradition in Italy and in our region; there are a number of social cooperatives: many of these receive users from the mental health services. Normally after a period of internship, the cooperative hires the users who have demonstrated a specific ability in the tasks required. This characteristic allows users with ASD to find a job close to their special interests. The limitation of this approach is that the social cooperative that has to produce goods needs to be productive and follow the hard rules of the free market requiring a good balance between workers with good working skills and workers with disabilities. Notwithstanding these difficulties, the users – especially ASD people who work in the social cooperative find a good social environment that extends their relationship network.

c) *IPS* uses an evidence-based method to job placement for people with mental illness developed in USA by Bob Drake about 20 years ago [5] and later in the last ten years also in Europe [6]. In Italy, IPS has an ongoing development: in our department, the number of IPS users is increasing while the number of internships diminishes. The IPS has actually a few extensions for people with ASD, because this method requires that the potential worker has the ability to search for a job by himself, with the help of a job tutor. The difficulty in social interactions characterizing ASD persons limits this approach and it is mostly people with the highest level of functioning, high IQ users (Asperger syndrome or high functioning autism) that are the recipients. The limitation of this approach is that searching for a job in a labor free market is highly stressful for ASD persons. However, the user can receive the constant help of the job tutor. Furthermore, if the path to obtain a work in the labor market is difficult and long, having a "regular" work with a "regular" wage is a powerful thrust to self-efficacy and satisfaction [7]. In recent literature, there is a proof that a specific cognitive remediation may increase the effectiveness of IPS also in people with intellectual disability and with ASD [8].

The keystone of the organization of every path is the work operator. He suitably belongs to the psychiatric unit and represents a different figure from the case-manager. The latter manages the rehabilitative relationship with the user, including in the housing and social areas, but not the job area. This area is given to the work operator, who's expert both in psychopathology and the labor market. Every work operator is specialized only in

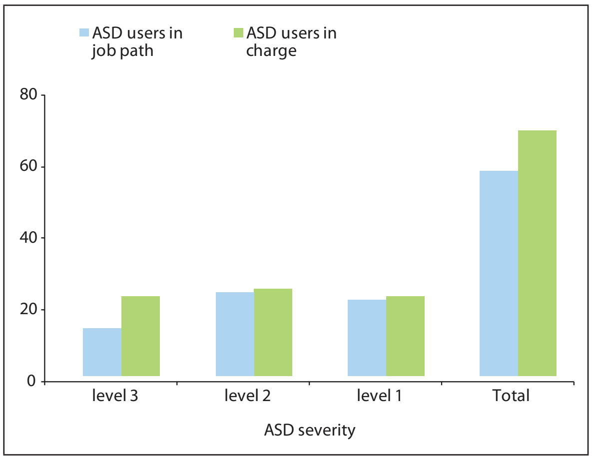

**Figure 1**
Percentage of ASD adult users in-charge of ASL Piacenza attending the job path by ASD severity level (according to DSM 5). Data from December 2018.

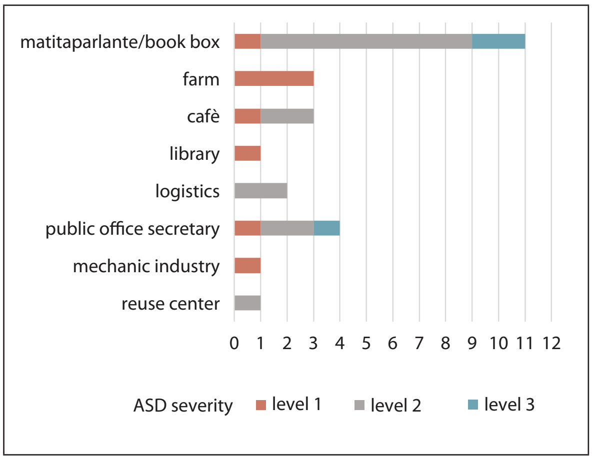

**Figure 3**
ASD users in internship by activity area and ASD severity. According to DSM 5.

one working path: internship, social cooperative or IPS. This is why every work operator must have mastered every method applied to the user. The work operator maintains regular contact with the labor companies and their employers.

In December 2018, there were 89 adult users in charge of the psychiatric unit, 68 of which were in treatment and 21 under the transition team. There was an equal distribution between the three levels of ASD severity (level 1, 22; level 2, 24; level 3, 22). It is important to note that the number of cases not coming from the ATT but directly referred to the adult psychiatric unit are one third (n. 8) of cases referred to ATT.

The main outcome of the PDTA Autism is that most adult ASD users are occupied with some form of job (n. 57; 83%) *(Figure 1)*. These users receive a monthly wage of € 528 (median € 300), with a very high standard deviation because of the high differences in various jobs.

About half of those with a job *(Figure 2)* are employed in sheltered work (internship or social cooperative), while the two smaller groups are engaged in free labor market and in completing educational training. In all these cases, the user has a work operator (or study operator) who follows and assists him to cope with the difficulties of the job (or of the study). A restricted number of users at level 3 (n. 11) have a job and of these only 2 users are paid for their job.

If we analyze the number of users in the internships, we can see the variety of labor contexts *(Figure 3)*: mechanical industry, secretarial, logistics, library, café,

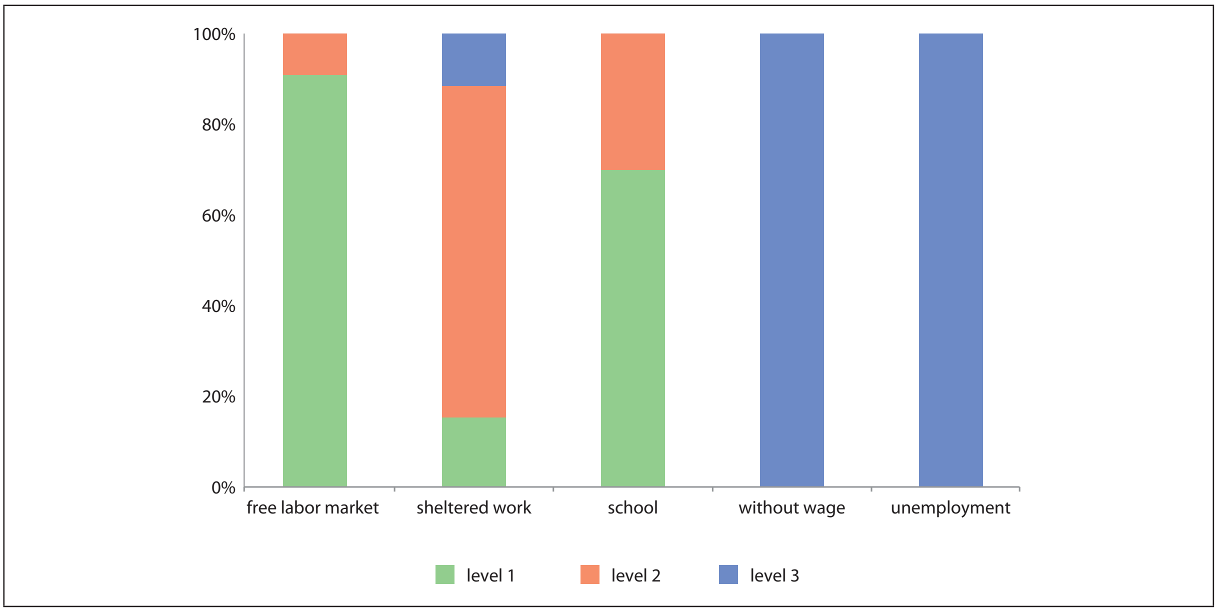

**Figure 2**
Percentage of ASD adult users in-charge of ASL Piacenza by employment and ASD severity level (according to DSM 5). Data from December 2018.

farm, etc., this means that the users may choose the labor context desired and that they often can find it. Furthermore, the average number of hours worked is 20 hours/week, that is quite good and engaging for people with social disabilities.

In this way frequently, the users may take advantage of their special interests, because the job is fit for them *(Table 1)*. Persons with ASD have difficulties in interacting socially. The labor context can cause problems in the relationship with the colleagues, with the employer, or simply with respecting with the rules of cohabitation in the workplace. For this reason, we provide a set of social skills training weekly and the users – if they want – can freely participate. The arguments treated are how to accept criticism, how to manage anxiety or anger, how to be on time, how to ask for help to perform a task, how to dress properly, how to respect roles and hierarchy and – last but not least – how to cope with failures or how to exploit successes. A group leader helps the users to learn adequate behaviors using role-playing.

Between the various work contexts, we have three experiences directly promoted from the psychiatric unit that are important to describe: Book Box, "Matita Parlante", The Perinelli farm.

Book Box (www.bookbox.it/) is a special initiative (conceived from an idea of Marilena Zacchini, which is spreading to many Italian centers): the aim is building a service to provide books in waiting rooms of offices or public places. In these contexts, special containers are placed – they are called book box – where anyone can give away and put their own books. The workers of the Book Box project periodically empty the boxes and change the old books with new ones. Therefore, users of public places or visiting an office can read a new book whenever they come. This work represents a service for the community that allows participation of users with different levels of severity.

"Matita Parlante" (literally The Speaking Pencil, www.lamatitaparlante.it) is another special work initiative: the aim is drawing up book texts, made of symbols instead of words, through the augmentative and alternative communication (AAC, [9]), that is an intervention technique for those who have an inability to communicate vocally). A group of ASD users, with a specific interest for drawing or writing stories, make up the editorial staff. The "Matita Parlante" has already edited some books written with the language of CAA or translated some book from verbal to CAA language. The group has begun to sell some books that have been edited.

The Perinelli farm (www.consorziocascinaclarabella.it/cooperative/i-perinelli) is a social cooperative, promoted and managed directly from the Mental Health Department. The farm is a wine company. The workers grow vines, harvest the grapes and produce excellent quality of wines, which they sell at local markets or to restaurants. The users are hired as agricultural workers, work in a collaborative way and follow the seasonal rhythms that wine production requires.

The challenge, for all the three experiences cited, is to create ex novo a social business, which can satisfy the special interests of the workers and grant them a certain salary. All the three forms of jobs try to deal with the labor market through the production of some new product. This is very difficult but feasible!

To assess the subjective satisfaction of user workers, we administered a simple questionnaire: the Indiana Job Satisfaction Scale [10], of 33 items, that measures 6 areas: general satisfaction, wage, career opportunities, interaction with colleagues and the manager, feelings related to work. The results show that the main reasons for working are: a: the salary which is however judged by many to be not sufficiently high; b. to feel useful; c. to be busy; d. have a good working time. Furthermore, the relationship with colleagues and the manager or the director is judged positively and the workers mostly appreciate when they receive praises for their efforts or positive feedback.

**Table 1**
Special interest of ASD users and current internship (names are imaginary)

| User | Special interest | Internship |
|---|---|---|
| Marco | foreign language | library |
| Federica | english language | library |
| Paolo | tranports (train timetable, bus, etc.) | trade union |
| Riccardo | software programming | IT company |
| Miguel | software programming | IT company |
| Alfredo | agricultural studies | farm |
| Francesco | barman course | café |
| Giovanni | restaurants | ice-cream shop |
| Pietro | agricultural studies | wine farm |
| Simone | interest in order and repetitiveness | megastore |
| Claudio | art historian | café |
| Gabriele | interest in order and repetitiveness | inserting bolt and screws |
| Simone | sport (ping pong, basketball) | sport megastore |
| Bartolomeo | forging knives | blacksmith |

## DISCUSSION

It is known that people with ASD, despite sometimes having good skills and the desire to work [11], continue to remain unemployed or underemployed [12]. Early adult outcome studies have demonstrated a poor employment situation for individuals with ASD. Whitehouse, et al. [13] reported an employment rate of 18% in a UK study. However, Eaves and Ho [14] illustrated that 56% of a Canadian sample had found an employment after reaching adulthood. The Australian Bureau of Statistics asserts that the labor-force participation rate for people with ASD was 42%, compared with the 53% for people with disabilities and 83% for people without disabilities [15]. In conclusion, there is evidence that people with ASD in the world work less than all other persons with mental psychiatric disabilities. This happens because the social context of work is "normotypic" and therefore ASD persons find it difficult to perform and maintain a job. Furthermore, the transition from childhood to adulthood, when most adolescent conclude the course of studies and orientate themselves to some kind of work is particularly tricky. Difficulty in social interaction, specific and rigid interests, or a firm trend to sameness, as well as frequent problematic forms of communication challenge people with ASD in this delicate phase. All these abilities are essential to find and maintain a job. Specific and structured intervention are needed to answer with these difficulties.

Persons with ASD usually don't do as well in school as their cognitive abilities allow and often do not finish the degree course. For this reason, it is important to sustain the user who wants to conclude the course of study or convince him to do it.

Another big concern is the organization of mental health services in Italy. There are different psychiatric services in adolescence and adulthood; this disorientates the adolescent, with the risk of loss of the needed relationship when a new operator ensues. It is for this reason that it is important to share the case between the two teams, in our experience from the ages of 16-18 years.

The cited considerations show that the mental health services attribute an insufficient emphasis on employment for all kind of mental diseases. "Who is not ready?" was the title of an article of 2007 in which the author underlined that the enhancements to supported employment are no doubt needed, such as the additional cognitive intervention [16]. This is even more true for people with ASD, who holds a great potential workforce without being able to express it. In our psychiatric unit, the first question to the user – independently from the problem or diagnosis he has – is "Do you want to work? What kind of work would you like to do?". These questions precede any question about the user's working skills. Motivation is the strongest push to reach the goal of a job. This task involves not only the user but also all the family, who often does not trust the user's possibilities.

Recently some factors that influence the outcome of the employment in ASD people have been highlighted: a more advanced age, a higher level of education, the absence of comorbidity [17]. Therefore, it seems of particular importance to pay attention upon completion of the study course (supported education) and treat as soon as possible the onset of some psychiatric problem. However, mostly it appears important to pay attention and sustain the job search and its maintenance endowing the user with a dedicated operator. He must monitor the work habits of the user with ASD, the working style, his work independence, the sensory responses and needs, the routine daily activities and the interpersonal skills [18]. There is a growing interest for supported employment that can become an important tool through which the person with autism can be brought to work [19]. The key factors to reach these objectives are the matching of the user's skills and the job request; an adequate level of education and training; the employment supported by dedicated and specifically prepared operators [20].

Our Psychiatric Unit, of PCIS, chooses the philosophy of "place and train" opposite to the outdated philosophy of "training and place", that expresses a waiting attitude and is not very promising for those who really want to find a job.

The psychiatric organization however must provide different types of work and the possibility to change from one to another when the user desires it. The transition from one form to another form of work is accompanied by the change of work operator, but not of the case manager, who maintains the reference to the user.

In our recent experience, for people with ASD the more effective type of work is the internship. The social cooperative represents also a valid but less effective tool to gain a job. Finally, the IPS has an undoubted effectiveness for people with high functioning ASD. Our intention is to develop mostly the latter, also through the help of a specific cognitive remediation method [8].

### *Conflict of interest statement*

The Authors declare that they have no conflict of interest.

Submitted on invitation.
*Accepted* on 19 March 2020.

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Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 247-250
DOI: 10.4415/ANN_20_02_15

# The Integrated and Disability Health Program of AUSL Bologna. The Alstom experience for employment access in high functioning autism spectrum disorders

**Rita Di Sarro, Nicola Varrucciu, Anna Di Santantonio and Ingrid Irene Bonsi**

*Dipartimento di Salute Mentale, Azienda USL di Bologna, Bologna, Italy*

**Abstract**

The Integrated and Disability Health Program (IDHP) of Bologna deals with the assessment and treatment of both young and adults with high and low functioning autism spectrum disorder (ASD). The IDHP and Alstom Ferroviaria SPA started a highly innovative project for the employment of young adults diagnosed with high functioning ASD. The project consisted of a six months' internship, for a total amount of 560 hours, and a renewal for another 6 months and involved a group of 5 young adults with high-functioning ASD, aged between 18 and 42 years, coming from Bologna or the suburbs. During the internship, a job coach trained in autism spectrum disorders was provided by IDHP. The intervention was based on Behavioral Skills Training (BST). As a result, the following advantages of BST model were found: very effective in small group; learning occurred by observation and modelling, feedback was received by the trainer and other group members.

**Key words**

- people with disabilities
- autism spectrum disorders

## INTRODUCTION

The term autism spectrum disorder (ASD) refers to a condition characterized by difficulties with social skills, repetitive behaviors, and communication. In recent decades, the number of people diagnosed with ASD has increased significantly. According to the Centers for Disease Control, autism prevalence rate is in 59 children in the United States [1]. The incidence of diagnosed ASD in children appears to be in a range of 6 to 20 per 1000. The over-representation of males (four to one) is a controversial piece of data that may possibly lead to women with high functioning ASD being misdiagnosed. Recent research is highlighting a marked overlapping between high functioning ASD and borderline personality disorders [2].

What we know is that autism is not a single condition with a single phenotype, indeed every person with ASD may be considered as affected by a unique "genetic syndrome", most influenced by a combination of genetic and environmental factors [3]. Therefore, every person has a specific set of features that fit with specific environments, persons and situations. People with ASD think, find new solutions and learn in very different ways, from highly skilled to severely impaired, with variable levels of support needed, ranging from inpatient units to independent living.

In the autism spectrum, there are several factors may affect significantly on daily life. First of all the sensory profile: people with ASD, if overstimulated, may undergo saturation, and this can lead to emotional disorders and challenging behaviors. Furthermore, several medical issues, such as gastrointestinal, sleep and psychiatric disorders can interfere with an effective functioning and reduce life quality. A primary aim for people is to achieve a good quality of life, to live meaningfully, choosing the best for themselves in the areas that each considers as the most significant such as a satisfying job that also in people with ASD can have several meanings: self-determination, independence, social opportunities. Because of its great importance in people's lives, access to employment is a fundamental human right included in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) [4]. Nevertheless, the number of people with ASD who do not have a job is still very high, such as the number of person with ASD who do not have a satisfying job [5]. In fact, people

*Address for correspondence*: Rita Di Sarro, Programma Integrato Disabilità e Salute, Azienda USL di Bologna, Via Castiglione 29, 40124 Bologna, Italy. E-mail: r.disarro@ausl.bologna.it.

with ASD are extremely heterogeneous, very skilled in details identification, testing and in repetitive tasks, but usually impaired in jobs were social skills are needed. Unfortunately, health services do not consider the characteristics and the needs of this population in the job search phase, offering opportunities not matching with their level of functioning, which leads to a high probability of failure.

## THE INTEGRATED AND DISABILITY HEALTH PROGRAM (IDHP)

The Integrated and Disability Health Program (IDHP) was established in 2016 within the Local Health Authority of Bologna: one of the main purposes was to deal with the assessment and treatment of young and adults with high and low functioning ASD in collaboration with disability services, Social Services and Public Mental Health Centers. In 2017, IDHP and Alstom Ferroviaria SPA started a very high innovative project for the employment of young adults diagnosed with high functioning ASD. Alstom Ferroviaria SPA is a multinational company with solid roots in Italian industrial history, with 8 offices throughout the national territory. One of the core activity of Alstom Italia is the development of rail transport in Italy; the Group operates in a high technological sector, strongly innovation-oriented. With 2500 employees in Italy and around 600 in Bologna, it represents one of the leader companies in the Italian railway sector. This project appeared immediately as a good opportunity to help people with ASD to find a qualified job: often these persons, despite their skills, face several difficulties in finding jobs that offer opportunities for professional growth. Usually, at best, people with autism settle for an underqualified job. This must be, at least partly, attributed to the little knowledge on employment-specific support needs, fundamental to start a professional career.

With the introduction of a specific law regulating employment of disabled people (Law no. 68 of 12 March 1999: “Regulations on the right to employment for persons with disabilities”), based on the size of their workforce, both private and public sector employers are required to hire a certain percentage of disabled workers and follow these rules:

- employers with more than 50 employees must meet a 7% disability employment quota;
- at least 2 disabled workers must be hired in workplaces of 36 to 50 employees;
- workplaces of 15 to 35 employees must hire at least one disabled worker if there is an opening for a new job.

Unfortunately, many companies do not fulfill the above-mentioned obligations and prefer paying a fine rather than hiring a disabled person. To change companies’ mind, training sessions on ASD features resulted to be very effective, examining in depth strengths and weaknesses and identifying strategies to deal with this population. Group psycho-educational interventions are then needed to foster social relations in subjects with ASD. We focused on some specific aspects: an increase in knowledge on the specific components of this condition, the identification of specific difficulties in interpersonal relationships (cognitive, emotional and behavioral components). In addition, we taught functional interactive and communicative modes (verbal, non-verbal, implicit behavioral elements).

### *Characteristics of the persons identified for the project*

A group of 5 young adults with high-functioning autism spectrum diagnosis, between 18 and 42 years, coming from Bologna or from the suburbs was selected. One of the 5 boys lived independently, while the others were still with the family of origin. One of them had a bachelor in statistics and now he is successfully enrolled in Drama, Art and Music Studies University of Bologna (DAMS). One is currently enrolled in the Faculty of Statistics. Two trainees had a high school diploma and another one was still attending high school. He was included in this project within a school/work training pathway. Such a training consisted of a specific part (individual and/or group) dealing with job placement and another one on personal and family issues.

### *Description of the project actions and aims*

The project consisted of a six months type C internship, for a total amount of 560 hours, and a renewal for another 6 months. Support actions planned and implemented for the insertion and during the training internship were:

1. cognitive and functional assessments:
   b. WAIS – IV or specific cognitive tools;
   c. AFLS (assessment of functional living skills, ed. 2012) – social skills – basic working skills;
   d. clinical interviews;
2. support meetings with psychologist, and/or social worker and/or educator;
3. information and support meetings with Disability Employment Center;
4. social skill groups;
5. meetings of verification and connection with the services for adults who are in charge of the subjects;
6. parent training;
7. verification group meetings with ALSTOM;
8. specific training for ALSTOM employees.

The general objectives of the project were the acquisition of competences defined in the specific individual project, through a type C internship, (Regional Law n. 7/2013) and placement in the ordinary labor market, through law 68/99, of adults in charge of services, with diagnosis of the high functioning ASD. The specific objectives of the project can be listed as follows:

- exposure to a work environment;
- personal and relational growth;
- acquisition, through practical experience, of knowledge and skills certified by continuous education programmes (issued by a training institution);
- verification and orientation of individual professional choices;
- finalizing the educational experience in a recruitment.

Work and social goals were individually defined on the basis of the personal characteristics and interests. One of the main issues was to find a job that matched both with functioning and interests of the person, to avoid drop out from the project. From our clinical experience, we know that people with autism are less likely to tolerate the frustration of undesirable work or activities; so, with the engineering team we tried to "build" the job step by step, balancing between the needs of the person and the needs of the company.

The training intervention was based on behavioral skills training [6], an effective procedure for teaching social skills and professional skills; the procedure consists of four steps:

1. give clear instructions that describe the appropriate behavior that one wants to be issued;
2. give an observable model (live, video, etc.) of the target behavior;
3. act the target behavior observed;
4. give an immediate feedback to the subject.

During the internship, a job coach trained in ASD was provided. At first, the job coach was present daily in the company with the subjects: the main function was to foster autonomy, self-organization, problem solving and responsibility, but also mediation with the environment, communication, modeling inappropriate behaviors and managing sudden challenging behaviors.

Our training was specifically focused on social skills that is the set of psychological, relational and communicative abilities, which play a fundamental role, from a cognitive and emotional point of view, in the correct interpretation and use of the rules of social interactions. Thus, the focus is on the set of behaviors that make it possible to live well with others. Considering the characteristic profile of people with ASD [7, 8], teaching adequate social behaviors (rule-governed behavior) was extremely important for the success of the whole project [9, 10]. The difficulty in understanding the mental states and the behavioral codes of peers and adults can lead to troublesome behaviors or lack of interest, resulting in a drop out from the project. The group experience, fostering social relations, also encourages communication, sharing of experiences, understanding, awareness and respect for social rules.

## CONCLUSIONS

Overall, the project evidenced specific advantages of the BST model. This can be summarized as follows: it is very effective in small groups, learning occurs by observation and modeling and the participant receives feedback by the trainer and other group members. However, a main disadvantage of this method is that BST is not focused on the individual, so that the rate of participation of each subject could be limited, or on the contrary, one member could predominate on the other.

During the training, immediate feedback was very useful to correct the inadequate behaviors and to foster efficacy and social relations. Furthermore, clinical interviews were conducted to evaluate the progress of the internship and the single expectations, to focus on individual features and needs and quickly intervene, when necessary. Parallel to this project, group interventions on social skills were activated. The group activities focused on main issues of ASD, the identification of cognitive, emotional and behavioral components and relative effects on the environments, and the teaching of functional interactive and communicative modes (verbal, non-verbal, implicit behavioral elements).

In conclusion, this project gave a real opportunity to people with ASD to start a real successful career. Furthermore, it allowed the Alstom offices to better understand the potentialities of this kind of population to improve the qualities of their business.

### *Authors' contributions*

The first Author reviewed literature and wrote the paper; the remaining Authors collaborated with the revision of the paper.

### *Compliance with ethical standards*

The Authors, in accordance with the policy of their institutional review board, obtained the approval of the research by the internal scientific committee.

### *Informed consent*

Informed consent has been obtained for the patients involved in the study, and no reported data can be referred to individual identity.

### *Conflict of interest statement*

The Authors declare that they have no conflict of interest.

Submitted on invitation
*Accepted* 19 March 2020.

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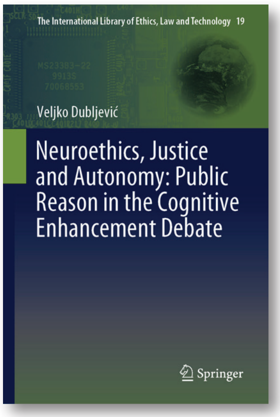
Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 251-253
DOI: 10.4415/ANN_20_02_16

# Book Reviews, Notes and Comments

Edited by
**Federica Napolitani Cheyne**



**NEUROETHICS, JUSTICE AND AUTONOMY. Public reason in the cognitive enhancement debate**
Veljko Dubljević
Springer Nature Switzerland AG 2019.
The International Library of Ethics, Law and Technology, 19.
ISBN 978-3-030-13642-0.
€ 83,19.

In his book, *Neuroethics, justice and autonomy: public reason in the cognitive enhancement debate*, Veljko Dubljević reflects upon the issue of cognitive enhancement technologies, i.e. stimulant drugs or cognition enhancement drugs (CED) and stimulation devices, within the framework of political philosophy, with respect to the risk of violating rights and justice raised by the actual lack of adequate regulation. This focus is particularly relevant in the present society, where, in addition to the ethical and political issues raised by cognitive enhancement technologies, new social and economic pressures raise additional issues deserving a dedicated analysis. To illustrate, pressure to enhance is likely to rise in contexts like the military, the education, and several jobs, with an increasing influence of private business.

The author is right in stressing that CED pose new issues than genetic enhancement, because they target the mind of competent adults making individual choices for themselves, even if it might be objected that competence is a controversial concept. The rationale behind the analysis of the book, which is grounded on Rawls' philosophy, is very clear and agreeable in its simplicity: despite the tendency to see pro-enhancement arguments as liberal and progressive, applying the liberal principles of justice to the discussion on CED leads to the conclusion that, because of the lack of an adequate regulation, cognitive enhancement might be a violation of equal rights and liberties of people preferring not to use it. Moreover CED might violate the principle of equal opportunity. Thus the question why justice did not play a central role in the neuroethical discussion about CED arises.

The question of justice in relation to CED might also be framed in terms of public priorities: given the limited resources available, it might seem unfair to invest money in CED rather than for other health related needs. This is a legitimate concern, even if it might be argued that, at least on theory, the use of CED could be a tool for figuring out new solutions to actual health needs. Yet it is true, as stated by the author, that as a matter of fact CED are used (if not even conceived) as a mean for getting personal advantage. How to react to this state of affairs? The author's suggestion is to use economic disincentives, for both individuals and companies: fees for citizens willing to use CED and special taxation procedures for companies interested in producing them. Economic disincentives would be a tool for the state to exercise its influence, which is justified because unregulated use of CED challenges the principle of justice. First because private interests are fulfilled at the expense of the public; second because cognitive enhancement actually affects the very structure of our society limiting the individual capacity to formulate and revise rational choices concerning their lives.

The second point in particular is related to the indirect coercion exercised on citizens to use cognitive enhancement. If the topic is not new in both neuroethical and political literature, the argument in support of its relevance provided by the author is very interesting, and argued for using the rational choice theory. The conclusion of the argument is that if a sufficient number of people expect others to use cognitive enhancement in a certain competitive context, that is enough to start a chain of reactions supporting the use of cognitive enhancement in order to not be left out. After having highlighted the limits of the two classical models of cognitive enhancement regulation (i.e., prohibition *vs* permissive or *laissez-faire* approaches), the author argues for the Economic Disincentives Model (EDM), which is a sort of middle way approach including forms of taxation and fees, as well as periodic tests about the perils of cognitive enhancement for people using it. The money gained through the application of the EDM would be invested for activities of public utility. I agree that this model basically balances the other two approaches: it allows an active role of the state without denying a liberal organization of society, even though it is not completely clear to me how to balance the prohibition to produce and sell CED with the acceptability of private use by individual citizens.

A key concept of liberal society is autonomy. The third chapter of the book is dedicated to the conceptual analysis of this key notion, arguing against a confusion that has often affected bioethics, neuroethics, and political philosophy, among others, i.e. the confusion between/conflation of the metaphysical notion of free will and the political notion of autonomy. The author rightly stresses that the concept of autonomy embedded in the legal and political system of pluralistic democratic societies does not presuppose any religious or metaphysical doctrine. The political concept of autonomy is open to empirical scrutiny. Particularly interesting is the minimal or basic sense of autonomy, which emerges from the interaction with empirical sciences: it requires only that the agent is able of making rational decisions in accordance with his or her own long-term interests. This is a form of self-determination that should not be conflated with free-will. Three components of autonomy are identified: volitional (agents act voluntarily or intentionally), cognitive (agents have sufficient information and understanding), and liberty (there are no controlling influences on agents, both external or internal). In sum, autonomy presupposes having the power of self-control and self-regulation, not necessarily exercising this power all the time. Both coercive (from external) and compulsive (from internal) influences are possible at different levels of intensity. Since they can diminish the personal capacity for long-term rational and autonomous decisions, both coercion and compulsion justify the intervention of the state without denying individual autonomy.

Highly illustrative is the example of addiction that the author provides: the model of autonomy he developed leads to the conclusion that both the moral and the medical models of addiction are false because grounded on a view of autonomy as not gradual but rather as an all-or-nothing capacity. In fact, addicted autonomy is highly compromised but not totally gone. The misunderstanding arises again from the confusion between the political notion of autonomy and the metaphysical notion of free will: to avoid this confusion precedence should be given to practical application over metaphysical justification. This is the core of the argument developed in the book.

To summarize, the following main points can be identified in the book:

- policy proposals and detailed models (e.g., what is a responsible use of CE) are scarce;
- particularly, regulatory environment for enhancement technologies (e.g.,Transcranial Magnetic Stimulation, transcranial Direct Current Stimulation) is no clear;
- in order to more effectively address the ethical issues raised by CE it is necessary to reflect less on abstract positions and more on concrete proposals to regulate, providing their operationalization in society;
- the EDM argued for in the book is a sort of middle way between *laissez-faire* and prohibition;
- the philosophical engagement with neuroscience and neurotechnologies should be framed as a political neuroethics, i.e. a combination of both practical and theoretical reflections on the basis of political categories (e.g., autonomy), mainly inspired to John Rawls.

This book is an excellent example of political neuroethics, which is a form of conceptual reflection interested in how political categories can help in analyzing the impact of new technologies on society.

Within the contemporary reflection on the statute of neuroethics, three main methodological approaches have been identified [1] eventually calling for a conceptual expansion of the field [2]. A “neurobioethical” approach is primarily normative and prescriptive: it applies ethical theory and reasoning to practical issues arising from neuroscientific research and its applications. An “empirical neuroethical” approach is descriptive and occasionally explanatory: it uses empirical data to inform theoretical (e.g., what is moral reasoning) and practical issues (e.g., who is really a moral agent). A “conceptual neuroethical” approach is primarily theoretical and particularly interested in clarifying fundamental notions. Basically it calls for a conceptual clarification of relevant notions in order to adequately deal with the issues raised by neuroscience. But semantic clarification does not exhaust the conceptual neuroethics work. In fact, at a deeper level, it emphasizes the need to develop and use a methodological *modus operandi* for effectively integrating scientific (e.g., neuroscience) and philosophical (e.g., ethics) interpretations.

Ideally these three approaches, even if distinct, are combined in practice. The political neuroethics argued for by Dubljević is highly illustrative in this respect. In fact, it combines practical, descriptive, and conceptual interests, eventually showing how mature philosophical reflection can help in clarifying the issues raised by contemporary science and technologies, their impact on traditional political categories, and how to deal with them. This approach seems promising also with respect to recent calls for thinking new strategies in order to make neuroethics more effective in dealing with the issues raised by contemporary science and technologies [3], particularly by big international brain initiatives [4]. Last but not least, political neuroethics seems very promising also with respect to one of the pillars of Responsible Research and Innovation (RRI), which is the engagement of citizens for reflecting on science and technologies and anticipating their future impact [5].

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Michele Farisco[1,2]
[1]*Centre for Research ethics and Bioethics,*
*Uppsala University, Sweden*
[2]*Science and Society Unit, Biogem, Biology*
*and Molecular Genetics Research Institute,*
*Ariano Irpino* (AV), Italy
*michele.farisco@crb.uu.se*

**MOSCHE, CAVALLETTE, SCARAFAGGI E PREMIO NOBEL**
**Era solo un ragazzo. L'incontro con Rita Levi Montalcini ha cambiato la sua vita**

Milano: Harper Collins Italia; 2019.
254 p.
ISBN 978-88-6905-417-4.
€ 16,00.

*[Flies, grasshoppers, beetles, and a Nobel Prize. He was just a boy. The meeting with Rita Levi Montalcini changed his life]*

Even if especially intended for young fellows, mainly adolescent and young-adults possibly facing the idea of starting a scientific biomedical career, this lively biography is strongly suggested to anyone interested in how started, developed, florished, and still prosecutes a very peculiar, yet thrilling biographical sketch. Luigi Aloe, born 1943, for decades the strictest collaborator of the 1986 Nobel laureate for Medicine or Physiology Rita Levi-Montalcini, eventually got in 1989 from the prestigious "Alma Mater" University of Bologna, followed by a subsequent laurea *honoris causa* in Medicine at a Bulgarian university. The stubborn, intelligent and very concrete figure of Luigi was born in a very humble family in the small seaside village of Amantea, Calabria, Southern Italy. Starting from being busboy of a spoiled tailor, (where he learned some skills very relevant to his "golden hands" subsequent technological career) he emigrated, as many poor Italians from socio-economical deprived Southern areas, in Germany. Thanks to the fortunate effort of Prof. Armando Rigobello (a philosopher active at Rome Tor Vergata University) he got a secondary school degree while undergoing the hard work of construction worker. But his second important step was when he was enrolled by the neuroscientist Prof. Giuseppe Colombo, Faculty of Medicine, University of Perugia, who introduced in his laboratory the young Luigi as an animal keeper, responsible for a colony of beetles, a task which also included the constant cleaning of their "perfumed" faeces.

When Rita Levi Montalcini came to Colombo's lab for giving one of her magnificent conferences, Colombo boasted of having a genial beetles' keeper who, despite his scientific illiterateness, invented and executed a variety of very clever experiments. Impressed from such a strange story, Rita immediately proposed to Luigi to follow her in her US lab, at one of the most prestigious neuroscience American temples, the Washington University in St. Louis, Missouri. There, Luigi's skills, motivation and innumerable scientific results made the rest. Neuroscience discoveries accumulated. A new, important scientists was born and his exceptional curriculum of publications achievement and prizes today well testifies of his uniqueness. By the way, rumours arise that Luigi Aloe's biography soon could become a television fiction.

Daniela Santucci, Stella Falsini, Enrico Alleva
*Centro di Riferimento per le Scienze Comportamentali*
*e la Salute Mentale - SCIC*
*Istituto Superiore di Sanità, Rome, Italy*
*Enrico.alleva@iss.it*

Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 254-256
DOI: 10.4415/ANN_20_02_17

# Publications from International Organizations on Public Health

Edited by
**Anna Maria Rossi**

## EUROPEAN FOOD SAFETY AUTHORITY (EFSA)

Craig PS, Dujardin B, Hart A, *et al.* **Cumulative dietary risk characterisation of pesticides that have acute effects on the nervous system.** *EFSA Journal* 2020;18(4):e06087 A retrospective acute cumulative risk assessment of dietary exposure to pesticide residues, supported by an uncertainty analysis based on expert knowledge elicitation, was conducted for two effects on the nervous system: brain and/or erythrocyte acetylcholinesterase inhibition, and functional alterations of the motor division. The pesticides considered in this assessment were identified and characterised in the scientific report on the establishment of cumulative assessment groups of pesticides for their effects on the nervous system. Cumulative exposure assessments were conducted through probabilistic modelling by EFSA and the Dutch National Institute for Public Health and the Environment (RIVM) using two different software tools and reported separately. These exposure assessments used monitoring data collected by Member States under their official pesticide monitoring programmes in 2014, 2015 and 2016 and individual consumption data from 10 populations of consumers from different countries and different age groups. This report completes the characterisation of cumulative risk, taking account of the available data and the uncertainties involved. For each of the 10 populations, it is concluded with varying degrees of certainty that cumulative exposure to pesticides that have the acute effects on the nervous system mentioned above does not exceed the threshold for regulatory consideration established by risk managers.

EFSA Panel on Biological Hazards (BIOHAZ), Koutsoumanis K, Alvarez-Ordóñez A, Bolton D, *et al.* **The public health risk posed by Listeria monocytogenes in frozen fruit and vegetables including herbs, blanched during processing.** *EFSA Journal* 2020;18(4):e06092 doi: 10.2903/j.efsa.2020.6092 A multi-country outbreak of Listeria monocytogenes ST6 linked to blanched frozen vegetables (bfV) took place in the EU (2015-2018). Evidence of food-borne outbreaks shows that L. monocytogenes is the most relevant pathogen associated with bfV. The probability of illness per serving of uncooked bfV, for the elderly (65-74 years old) population, is up to 3600 times greater than cooked bfV and very likely lower than any of the evaluated ready-to-eat food categories. The main factors affecting contamination and growth of L. monocytogenes in bfV during processing are the hygiene of the raw materials and process water; the hygienic conditions of the food processing environment (FPE); and the time/Temperature (t/T) combinations used for storage and processing (e.g. blanching, cooling). Relevant factors after processing are the intrinsic characteristics of the bfV, the t/T combinations used for thawing and storage and subsequent cooking conditions, unless eaten uncooked. Analysis of the possible control options suggests that application of a complete HACCP plan is either not possible or would not further enhance food safety. Instead, specific prerequisite programmes (PRP) and operational PRP activities should be applied such as cleaning and disinfection of the FPE, water control, t/T control and product information and consumer awareness.

EFSA Panel on Biological Hazards (BIOHAZ), Koutsoumanis K, Alvarez-Ordóñez A, Bolton D, *et al.* **The public health risk posed by Listeria monocytogenes in frozen fruit and vegetables including herbs, blanched during processing**. *EFSA Journal* 2020;18(4):e06092 doi: 10.2903/j.efsa.2020.6092 A multi-country outbreak of Listeria monocytogenes ST6 linked to blanched frozen vegetables (bfV) took place in the EU (2015-2018). Evidence of food-borne outbreaks shows that L. monocytogenes is the most relevant pathogen associated with bfV. The probability of illness per serving of uncooked bfV, for the elderly (65-74 years old) population, is up to 3600 times greater than cooked bfV and very likely lower than any of the evaluated ready-to-eat food categories. The main factors affecting contamination and growth of L. monocytogenes in bfV during processing are the hygiene of the raw materials and process water; the hygienic conditions of the food processing environment (FPE); and the time/Temperature (t/T) combinations used for storage and processing (e.g. blanching, cooling). Relevant factors after processing are the intrinsic characteristics of the bfV, the t/T combinations used for thawing and storage and subsequent cooking conditions, unless eaten uncooked. Analysis of the possible control options suggests that application of a complete HACCP plan is either not possible or would not further enhance food safety. Instead, specific prerequisite programmes (PRP) and operational PRP activities should be applied such as cleaning and disinfection of the FPE, water control, t/T control and product information and consumer awareness.

## FOOD AND AGRICULTURE ORGANIZATION OF THE UNITED NATIONS (FAO)

Ulrichs M, Costella C, Holmes R, *et al.* **Managing climate risks through social protection - Reducing rural poverty and building resilient agricultural livelihoods.** Rome: Food and Agriculture Organization of the United Nations, and Red Cross Red Crescent Climate Centre ( The Hague, Netherlands) 2019; 64 p. ISBN 978 92 513 1884 3 FAO recognizes that those living in rural areas whose livelihoods depend heavily on natural resources, are disproportionately affected by climate risks because of their great likelihood of living in high-risk geographical locations as well as their high vulnerability to, and limited capacity to cope with, climate hazards due to low incomes, lack of savings, weaker social networks, low asset bases and heavy reliance on agriculture and natural resources. Protecting poor and vulnerable small scale producers from the negative impacts of climate risks is an imperative in order to reach FAO's strategic objectives and achieve Sustainable development goal one and two. Managing climate risks through social protection sheds light on social protection as an effective investment to safeguard the livelihood of small scale producers and strengthen their essential role in ensuring food security across the globe.

Bracco S, Tani A, Çalıcıoğlu Ö, et al. **Indicators to monitor and evaluate the sustainability of bioeconomy. Overview and a proposed way.** Rome: Food and Agriculture Organization of the United Nations 2019; 127 p. (*Environment and Natural Resources Management – Working Paper; 77)* ISBN 978 92 513 1796 9 FAO has been working for many years on non-food biomass products (including sustainable bioenergy) and biotechnology, and it received a mandate to coordinate international work on "food first" sustainable bioeconomy by 62 Ministers present at the Global Forum for Food and Agriculture (GFFA) 2015. Moreover, FAO has received support from the Government of Germany to develop guidelines on sustainable bioeconomy development (Phase 1: 2016; Phase 2: 2017-mid 2020). This involves work on the bioeconomy monitoring, including the selection and use of indicators. The ultimate aim of FAO's work on sustainability indicators is to provide technical assistance to countries and stakeholders in developing and monitoring sustainable bioeconomy, more particularly on identifying suitable indicators in line with the Sustainable Bioeconomy Aspirational Principles and related Criteria, agreed upon in 2016 by the International Sustainable Bioeconomy Working Group created in the context of FAO's project on Sustainable Bioeconomy Guidelines. These indicators shall help both policy makers and producers/manufacturers in monitoring and evaluating the sustainability of their bioeconomy strategies and interventions. In order to cover all the relevant aspects and issues for a sustainable bioeconomy, our approach identifies impact categories from the sustainable bioeconomy principles and criteria. The monitoring approach suggested is balanced, since it considers the three sustainability dimensions (social, economic and environmental); at the same time, it proposes to use a limited set of core indicators, to keep the monitoring feasible and cost-effective. The suggested methodology starts with a review of existing monitoring approaches to identify already available indicators, from which the authors.

## INTERNATIONAL SCIENCE COUNCIL (ISC)

**Review of the Urban Health and Wellbeing Programme.** Paris: International Science Council (ISC). 2020; 20 p. doi: 10.24948/2019.01 The report documents the independent mid-term formative review of the International Science Council (ISC) Urban Health and Wellbeing (UHWB) programme, established in 2014. The review was carried out by an independent panel of five experts. As the review is intended to inform the next phase of the ten-year programme, the review panel purposefully focused its work on identifying critical areas for growth and direction. The review panel's overall assessment is that the International Programme Office (IPO) has developed an ambitious "science plan" and an impressive steering committee, as well as local hosts. In the first three or so years, the IPO has experienced several challenges in meeting its goals and objectives as set out in the plan. These challenges, expected with any new IPO, range from issues related to language and staffing to clarity of expectations. The review panel is of the opinion that the core idea for the programme – to produce policy-relevant research – was ambitious, and that given limited resources, it requires careful re-thinking on how to go forward. The plan for the coordination of research projects has not been realized. In the considered opinion of the review panel, the programme is not on course to achieve the objectives as stated in the original science plan.

**Frameworks for understanding transformations to sustainability – the "Multi-Level Perspective" in socio-technical transitions research. A Transformations to Sustainability knowledge brief.** *Knowledge Brief* 2019;3 Addressing persistent and worsening global environmental problems, such as climate change, biodiversity loss and resource depletion, will require socio-technical systems such as energy, transport and housing to undergo fundamental change, and, in some cases, total transformation. This knowledge brief presents the "Multi-level perspective" (MLP), which is an analytical framework that provides a "big picture", integrative approach to understanding how transitions come about as co-evolutionary processes. It is based on a peer-reviewed article which synthesizes recent literature on the MLP approach in socio-technical transitions research, including criticisms and recent elaborations. It is part of a series of knowledge briefs which synthesize findings from recent research papers on transformations into an accessible format, with the aim of opening up the latest transformations research to a wider audience. The MLP has shed light on transitions in energy, transport and food systems, and has explained why some innovations were adopted quickly in some places, but not in others. MLP research suggests that policy makers can actively nurture the emergence of conditions that favour stronger policies for sustainability.

Handmer J, StevanceA, Rickards L, *et al.* **Achieving risk reduction across Sendai, Paris and the SDGs**. Paris: International Science Council (ISC). 2019; 8 p.The ISC's newly published policy brief provides a crucial set of key messages for policy-makers based on the synergies and coherence between the major global agreements of the Sendai Framework on Disaster Risk Reduction, the Paris Agreement and the 2030 Agenda with specific reference to systemic and cascading risks. This focus is because of the extreme widespread and long-lasting potential impacts of such events, which could have long-lasting negative effects on the livelihoods and well-being of people, economies and countries, undermining development and the achievement of the Sustainable Development Goals (SDGs). This brief should be read as complementary to material dealing with frequent, smaller events and the day-to-day emergencies that affect hundreds of millions regularly.

## WORLD HEALTH ORGANIZATION (WHO)

Fancourt D, Finn S. **What is the evidence on the role of the arts in improving health and well-being? A scoping review.** Geneva: World Health Organization. 2019; p 142 (*Health Evidence Network Synthesis Report*; 67) Order no. 13400211 Sw.fr.25.00/ US $ 25.00ISBN 978 92 890 5455 3 Over the past two decades, there has been a major increase in research into the effects of the arts on health and well-being, alongside developments in practice and policy activities in different countries across the WHO European Region and further afield. This report synthesizes the global evidence on the role of the arts in improving health and well-being, with a specific focus on the WHO European Region. Results from over 3000 studies identified a major role for the arts in the prevention of ill health, promotion of health, and management and treatment of illness across the lifespan. The reviewed evidence included study designs such as uncontrolled pilot studies, case studies, small-scale cross-sectional surveys, nationally representative longitudinal cohort studies, community-wide ethnographies and randomized controlled trials from diverse disciplines. The beneficial impact of the arts could be furthered through acknowledging and acting on the growing evidence base; promoting arts engagement at the individual, local and national levels; and supporting cross-sectoral collaboration.

**The selection and use of essential medicines. Report of the WHO Expert Committee, 2019.** Geneva: World Health Organization. 2020; p 677 (*WHO Technical Report Series*; 1021) Order no. 11001021 Sw.fr.90.00/ US $ 90.00 ISBN 978 92 412 1030 0 This report presents the recommendations of the WHO Expert Committee responsible for updating the WHO Model List of Essential Medicines and WHO Model List of Essential Medicines for Children. It contains a summary of the evidence presented and the Committee's consideration, justifications and recommendations for additions, deletions and changes to medicines on the Model Lists. Annexes to the main report include the 2019 WHO Model List of Essential Medicines (21st edition) and the 2019 WHO Model List of Essential Medicines for Children (7th edition). In addition, all medicines on the Model Lists are presented according to their Anatomical Therapeutic Chemical (ATC) classification codes.

Wild CP, Weiderpass E, Stewart BW (Eds). **World Cancer Report. Cancer Research for Cancer Prevention.** Geneva: World Health Organization. 2020; p 612 (*IARC Non Serial Publications*) Order no. 17600041 Sw.fr.60.00/ US $ 60.00 ISBN 978 92 832 0447 3 This is a multidisciplinary publication, with leading international scientists as authors and reviewers. More than 60 different chapters describe multiple aspects of cancer prevention and the research that underpins prevention, focusing on research activity during the past 5 years. Starting with the latest trends in cancer incidence and mortality worldwide, this publication provides wide-ranging insights into cancer prevention based on the known causes of cancer, factors that determine how cancer develops, and the behaviour of different tumour types, and presents a broad scope of interventions to reduce the cancer burden from a global perspective, including addressing inequalities that affect cancer prevention. The electronic version is available for free at: http://publications.iarc.fr/Non-Series-Publications/World-Cancer-Reports/World-Cancer-Report-Cancer-Research-For-Cancer-Preevention-2020.

# Instructions to Authors

***Annali dell'Istituto Superiore di Sanità*** is a peer reviewed quarterly science journal which publishes research articles in biomedicine, translational research and in many other disciplines of the health sciences. The journal includes the following material: original articles, reviews, commentaries, editorials, brief and technical notes, book reviews. The publication of Monographic Sections on Annali ISS has been discontinued. In case you wish to present a limited number of coordinated contributions on specific themes concerning priorities in public health, please contact the Editorial office. *Annali* follows the Recommendations for the Conduct, Reporting, Editing, and Publications of Scholarly Work in Medical Journals, issued by the International Committee of Medical Journal Editors (ICMJE) www.icmje.org.

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- author's contribution statement (individual contribution to the manuscript);
- conflict of interest statement (a conflict of interest exists when authors or their institutions have financial or personal relationship with other people or organizations that could inappropriately bias conduct and findings of the study);
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Receipt of author's paper will be acknowledged by an e-mail containing an identification number which should be used in future correspondence.

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- once the paper has been accepted, authors will receive proofs from the editorial office, which should be corrected and returned (usually within three working days).

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Tables and figures should be kept to a minimum and be presented only if necessary.

Authors should deal responsibly and effectively with security issues that might be raised by their papers (see: Statement on Scientific Publication and Security *Science* 2003;299:1149).

This journal has adopted the SAGER reporting Guidelines for Sex and Gender Equity in Research.

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The name of the bioresource (and identifier, if available) which provided samples/data useful for the conduct of the study should be reported in extense, either in the Material and methods section or in the Acknowledgements.

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- the *brief note*, 3000 words, including about 15 references, one table and one figure;
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They should be understandable also without reference to the text and should be numbered in Arabic numerals in a consecutive and independent way according to their citation within the paper.

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Figures should be loaded as separate files. The following file formats are acceptable: JPEG, TIFF or EPS. Vectorial images (graphs, flow charts, schemes, and other non bitmap material) should be in Excel, Adobe Illustrator, Microsoft Power Point so as to allow the editorial formatting of the material.

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### Articles in journal

Bozzuto G, Ruggieri P, Molinari A. Molecular aspects of tumor cell migration and invasion. Ann Ist Super Sanità. 2010;46(1):66-80. doi: 10.4415/ANN_10_01_09

### Books and chapters in a book

Godlee F, Jefferson T. Peer review in health sciences. London: BMJ Books; 1999.

Van Weely S, Leufkens HGM. Background paper: orphan diseases. In: Kaplan W, Laing R (Eds). Priority medicines for Europe and the world – a public health approach to innovation. Geneva: World Health Organization; 2004.

### Proceedings

Fadda A, Giacomozzi C, Macellari V. Comparative measurements to validate a new telemetric pressure insoles system. In: 2. International Symposium on measurement, analysis and modelling of human functions. 1. Mediterranean Conference on measurement. Workshop on evaluation check of traceability. Proceedings. Genova: June 14-16, 2004. p. 425-7.

### Technical reports

Della Seta M, Di Benedetto C, Leone L, Pizzarelli S, Siegmund U. ETHICSWEB technical guides. Manual for the creation of standards and guidelines for sharing information about knowledge organization systems on ethics and science. Roma: Istituto Superiore di Sanità; 2011. (Rapporti ISTISAN, 11/32).

### Legislation

Italia. Decreto legislativo 29 ottobre, n. 419. Riordinamento del sistema degli enti pubblici nazionali, a norma degli articoli 11 e 14 della legge 15 marzo 1997, n. 59. Gazzetta Ufficiale – Serie Generale n. 268, 15 ottobre 1999.

US Social Security Administration. Evidentiary requirements for making findings about medical equivalence. Final rules. Fed Reg. 2006 Mar 1;71(40):10419-33.

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