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## 2019 ANNUAL EDSA SURVEY .

## INDEPENDENT LIVING

*Dear EDSA members,*

*like in the last years we will combine the next AGA with a seminar day. This time the topic is independent living and autonomy.*

*In 2017 we asked you to answer a few questions about school inclusion, in 2018 about job inclusion.*

*This time our survey deals with independent living and autonomy.*

*Anna Contardi has prepared this survey. Below you will find the questionnaire.*

*We kindly ask you to answer the questions and send the form **back directly to Anna Contardi**, [annacontardi@aipd.it](mailto:annacontardi@aipd.it), before **30 July 2019**.*

*Anna will present the results at our seminar day in Rom, 16 november.*

*Thanks and regards*

*Cora*

**EDSA - SURVEY ON Education to AUTONOMY and INDEPENDENT LIVING****What do we mean for independent living:**

In 2016, EDF adopted the following definition of **'Independent Living'**

"Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the **combination of various environmental and individual factors that allow persons with disabilities to have control over their own lives**. This includes the opportunity to **make real choices and decisions regarding where to live, with whom to live and how to live**. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing persons with disabilities flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent living is for all persons with disabilities, regardless of the gender, age and the level of their support needs."

## Inclusion Europe adds

“What independent living looks like **depends on the needs of the individual person**. For example, one person may need someone to come in once a week to do budgeting, or access to a support number or warden. Another person might need support workers/personal assistants working with them all the time. Someone else may just need support to access employment or to help them work out how to do something new or different.

There are many different approaches to support independent living for those with intellectual disabilities:

One example is **supported housing**, where a person chooses where they live and who they live with, but has support from staff to carry out household tasks.

**Peer support** is a key element of disabled people living independently. Many people with intellectual disabilities choose to access peer support through self advocacy and people first groups, which are run and controlled by people with intellectual disabilities who then employ non-disabled people to support them.”

**We ask EDSA members to complete this short questionnaire by July 30<sup>th</sup>.**

The results will be presented at the Education to AUTONOMY and INDEPENDENT LIVING Workshop to be held in Rome on 16 November at the AGA.

NB: we are aware that there are no statistical data on these issues neither at European level nor at national level but we kindly ask you to fill in the questionnaire based on your organisation’s perspective.

Please send the questionnaire to [annacontardi@aipd.it](mailto:annacontardi@aipd.it) .

Thanks for your cooperation.

Anna Contardi

Edsa Vice President

### Questionnaire

**Country**.....

**Association** .....

### STATE OF THE ART IN YOUR COUNTRY

**1. In your country, adults with DS over 30 live ... (give us a prevalence order: 1, the majority, 2, ...):**

- With their families

- On their own
- With a partner
- In a residential house (max 8 persons)
- In independent small groups within an institution
- in institution

- .....

**2. Is there a law that promotes solutions and services for independent living** YES NO

**3. If yes, which of the following solutions/services are provided by the national or local authorities?:**

- Consultancy services to families
- housing for small groups
- Institutionalization
- Preparatory actions (eg: autonomy courses, short periods out of the family, holidays far from families in small groups...)
- Home personal assistance
- economic support

others (specify)

.....  
 .....

**4. Which is the role played by people with DS living in residential houses?**

- Just users
- Take part in some daily life decisions (meals, free time, )
- Main decisions are taken by people with DS with the support of professionals, if necessary.

**5. Why do people with DS leave their family home?**

- Absent or insufficient family support
- Absent or insufficient support services to the family
- Their own choice

- -.....

## 6. Who manages what?

Residential houses

- > public authorities
- > religious institutions
- > private organizations

Institutes

- > public authorities
- > religious institutions
- > private organizations

7. **Is home automation applied in such environments?** ( Environment control, smart technological solutions for independent living - eg: electronic pantry, easy shopping list on smartphones and other home management apps).

YES NO

8. **In your point of view, what is the main obstacle to the Autonomy and independent living of people with SD in your country (1 answer)::**

- Lack of legislative support
- Support services shortage
- Prejudices / resistance of public opinion
- Poor preparation of young people with sdD
- Resistance of families
- Other (specify).....

## YOUR ASSOCIATION AND INDEPENDENT LIVING

9. **Does your association directly implement services for Autonomy and independent living?**

YES NO

**10. If YES, which kind of services:**

- Consultancy services to families
- Preparatory actions (eg: autonomy courses, short periods out of the family, holidays far from families in small groups...)
- Home personal assistance
- Housing for small groups
- .....

**11. What does your association offers in terms of preparation to independent living?**

- Personal autonomy, self-care
- Domestic skills (kitchen, cleaning, etc.)
- Use of money/purchases
- Orientation and behaviour on the road
- Communication with unknown people
- Ability to make choices, organize one's time
- Assertiveness
- Relational affective dimension
- .....

Questionnaire filled in by:

(First name, Family Name, role in the Association).....

been fine-tuned;

As in 2016 and 2017, the 2018 Programme Guide places a special focus on encouraging projects supporting social inclusion (notably of refugees and migrants), as well as preventing radicalisation.

## EDSA AGA IN ROME

### 15-17 November in Rome

More details.....

Date: 15, 16 and 17 November 2019

Place: Albergo Etico Roma, Via Pisanelli 39/41, Roma

<https://www.albergoeticoroma.it>

Timetable:

Friday 15 November, 16.00 - 19.30 hrs: first part of the AGA

Saturday 16 November 9,00 - 18.00 hrs: Seminar on independent living and autonomy

Sunday 17 November 10.00 - 13.00 hrs: second part of the AGA

You can also stay overnight in the Albergo Etico. Aipd reserved 10 rooms for EDSA members. You have to book yourself online. Rooms cost 98 Euro (incl. breakfast), plus 3,50 city tax.

If you want to stay in a cheaper or in a different place there are lot of other options close by (see [booking.com](https://www.booking.com) etc.)

How to reach the meeting place?

Albergo Etico Roma is close to Piazza del Popolo. It can be reached by Underground. Line A, Stop: Flaminio

This is four stops from Termini-Station.

Albergo Etico has got some employees with Down-Syndrome and is a member of the Valueable network..

Another Valueable member is the Rome hello hostel, not so far from Termini station. It offers cheap accommodation as well. <https://theromehello.com/>

Saturday night (16.11) a social dinner was arranged in a famous Pizzeria. Up to now 16 persons have reserved for the dinner.

**To better organise the AGA, it is important to know who will attend it and how many people will join the social dinner.**

Please answers directly to [halder.cora@t-online.de](mailto:halder.cora@t-online.de)

## EU OPPORTUNITIES

### Council of Europe - The European Youth Foundation

STRUCTURAL FUNDING FOR INTERNATIONAL YOUTH ORGANISATIONS - DEADLINE:  
1 OCTOBER 2019

Structural funding may be requested to cover part of the administrative costs of managing the activities of organisations at European level.

They are of two types: two-year structural funding is made available for a period of two years and is granted for the long-term strategic planning of organisations. After being granted, it must be renewed the following year. Extraordinary structural funding, on the other hand, can only be applied for once by a single organisation and is not renewable.

#### DESCRIPTION:

The European Youth Foundation was founded by the Council of Europe in 1972 to provide economic and educational support to European organisations active in the youth field. The foundation offers support to youth organisations through different types of calls for proposals that finance initiatives, pilot projects or the ordinary activities of organisations.

The priority areas of intervention valid for the period 2020-2021 include:

Access to rights for young people, i.e. activities involving the removal of legal, political and social barriers. For example, media literacy courses for young people and children, identification of the effects of restricting civic space on young people and youth organisations and possible solutions.

Youth participation and youth work: activities that strengthen young people's political awareness, active citizenship and participation at local and regional level in cooperation with local authorities, as well as the importance of youth work and non-formal education.

Inclusive and peaceful societies: activities promoting social inclusion, active participation, gender equality and combating forms of discrimination with a specific focus on LGBTQ+ minorities, Roma Sinti Camminanti, young refugees, young women; activities enabling young people to play an active role in promoting peaceful societies.

The maximum contribution that can be requested from the Foundation for two-year structural funding is 25,000 euros per year, or 50,000 euros for the two-year period. The amount actually granted will depend on the score obtained in the selection. The Foundation's annual budget for this measure is 630,000 euros.

For the extraordinary financing, on the other hand, a total of 30,000 euros per year is available, which can be allocated for a maximum of 10,000 euros to a single applicant organisation.

#### BENEFICIARIES:

Who can submit projects for two-year structural funding:

- International youth organizations
- International networks of youth associations who have received support from the Foundation for at least three international activities and at least two grants for other reasons in the previous three years (2017, 2018, 2019).

Who may apply for extraordinary structural funding:

- Regional networks of youth associations

Read more: <https://www.coe.int/en/web/european-youth-foundation/structural-grant>



## THE BOOK OF THE MONTH

### Le futur de la trisomie 21



#### **New publication on Down Syndrome.**

A curative perspective is emerging for Down Syndrome, a genetic condition that affects several million people around the world. Genetic therapies in the process of being updated are likely to profoundly modify the development of people with the condition. At the same time, more ambitious cognitive pharmacotherapy is being introduced to improve intellectual development.

Author of the book “Le Futur de la trisomie 21”, Jean Adolphe Rondal returns here with a new book on the subject in which he also discusses the progress of medical monitoring which already makes it possible to counter the effects of certain pathologies associated with trisomy 21. It indicates that effective cognitive rehabilitation exists, which promotes an improvement in intellectual abilities. The pathology of Alzheimer’s disease, which is more frequent in people with Down’s Syndrome 21, is also the subject of multiple studies that will allow a better understanding of the etiology of the disease.

Without being overly optimistic, the book “Le futur de la trisomie 21” documents, analyses and puts all these advances into perspective.

#### **About the author:**

Jean Adolphe Rondal is a PhD candidate from the University of Minnesota, Minneapolis. He holds a doctorate in language sciences from the University of Paris-V-René-Descartes-Sorbonne and is a full professor emeritus at the University of Liège. He has written numerous scientific books and articles in the fields of language and trisomy 21. In addition, he is a founding member and former president of the European Down Syndrome Association.

## MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter?  
Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

### CONTACTS

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