

DESCRIPTION OF THE PRACTICE

1. Title of the practice

Social participation and integration: empowering people with learning disabilities in Galicia

2. Organisation responsible for the practice

Down Ourense Association – the Down's Syndrome Association of Ourense, Spain

3. Contact person(s)

Name /

E-mail

policy@esn-eu.org

4. Summary of the practice

Down Ourense has been developing its work in Ourense [a city in the Region of Galicia, in the north of Spain] for 12 years, **focusing on improving the quality of life of people with Down's Syndrome or intellectual disabilities and their families.**

For this purpose, we deploy a **normalisation** process that seeks the social **participation and integration** of the participants by bringing the necessary support to achieve greater autonomy and an independent life. Priority is given to the individual and their interests when designing individualised programmes. Down Ourense also offers **mediation** services to help people with Down's Syndrome when making decisions. For example, they have developed a programme to **self-manage spare time**, in which a monitor proposes several activities to do on the weekend. Participants then choose the activity in a process where the opinion of each of them is taken into consideration.

The main lesson learned: During this 12-year period, we have observed the feasibility of the full inclusion of people with intellectual disabilities or Down's Syndrome in regular community activities such as studying, working or improving their skills in various environments.

5. National/regional/local context of the practice

Associations are formed by people with intellectual disabilities or by their families on their behalf. They mostly belong to a regional or national federation, which at the same time belongs to other organs of representation of disability involved in the development, design and programming of social policies of the regional or national governments. The entities are bodies representing persons with disabilities to the administration in the last 25 years, legislation has been transformed into a more inclusive reality for people with disabilities.

The initiative came from the Galician Federation of Institutions for Down's Syndrome (Down Galicia), who made a speech in Ourense looking for a group of parents who were interested in creating a partnership. The creation of Down Ourense was made possible thanks to a group of parents of children with intellectual disabilities/Down's Syndrome due to the lack of inclusive associations in the area. The specific associations (occupational centres) existing at the time did not provide inclusive services (we developed different programs to ease the participation of the users in society, for example, working in regular companies or attending regular schools), and the parents wanted their children to participate as regular members of the community with the support needed throughout their lives.

6. Staff involved

See section 13

7. Target group

The association develops programmes for people with intellectual disabilities or Down's Syndrome for all age groups. There are different programmes and individual activities focused on improving the quality of life and autonomy of the participants, allowing them to be part of the community more easily. They are included in the **Service of personal autonomy promotion (SEPAP)**.

8. Aims of the practice

- Improving the quality of life of people with Down's Syndrome or intellectual disabilities and their families
- Improving their social inclusion and freedom of choice.

9. Issues for social services

Service Integration/ Cooperation across services		Service Planning		Contracting	
Technology		Skills development (of the workforce)		Quality of services	x
Others:					

ANALYSIS OF THE PRACTICE

10. Status

Pilot project (ongoing)		Project (ongoing)	x	Implemented practice (restricted areas)	
Pilot project (terminated)		Project (terminated)		Widely spread practice/rolled out	

11. Scope of the practice

Describe the setting of the practice, considering the following criteria:

- *Micro level practice:* practice that involves individuals at local level
- *Meso level practice:* practice that involves organisations or communities
- *Macro level practice:* practice that involves large population groups

Meso level (communities around parents and people with Down's Syndrome)

12. Leadership and management of the practice

Description of the leadership of the practice, considering the following criteria:

- *Collaborative management:* shared between large partnerships, often of central, regional and local representation
- *Organisational management:* by one organisation
- *Professional management:* managed by a single person
- *Shared management:* shared with no defined leadership

Down Ourense is managed by a group of parents. Together, they form the management board. In addition, Down's Galicia (a branch of the regional association) is responsible for the joint effort and general representation alongside other Down's institutions. Down's Galicia has 7 branches in the whole region.

13. Engaging stakeholders in the practice

Description of the engagement of stakeholders, considering the following criteria:

- *Individual practice:* individuals have sought practice change
- *Network approach:* one or more organisations develop a network
- *Collaborative approach:* large collaboration with relevant stakeholders

Partnerships exist with Down's-Spain, Xunta de Galicia [Galicia's regional government], Ourense council, as well as with other social institutions, several private companies, kindergartens, schools, and others. These are more occasional partnerships.

The team consists of the following staff:

- one programme coordinator,
- two social educators,
- two special education teachers,
- one speech therapist,
- one labour counsellor,
- two psychologists, and
- one legal advisor.

14. Involvement of service users and their families

Description of the involvement of service users, considering the following criteria:

- *Team involvement:* service users and carers were part of the practice team
- *Consultative:* a consultative body of users was set up for an on-going dialogue and feedback
- *Involvement in care:* person-centred approaches to care/support

n. a.

15. Costs and resources needed for implementation

Description of how the practice is financed, considering the following criteria:

- *Within existing resources:* staff time and other resources are provided 'in-house'
- *Staffing costs:* costs for staff investment
- *Joint/Pooled budgets:* two or more agencies pool budgets to fund services
- *Funded project:* external investment

The entity is financed by the regional government of Galicia, the national Ministry of Health and Social Affairs and the Municipality of Ourense.

Moreover, users pay a fee, and donations are received. The association is maintained with its own resources (for example, families' quotes) and public and private funding. Currently, the association has 55 people with intellectual disabilities and their families. Last year's cost was EUR 174,048.45.

16. Evaluation approaches

Description of the evaluation method of the practice, considering the following criteria:

- *Multi-method:* use of both a qualitative and a quantitative approach
- *Single method:* qualitative or quantitative approach
- *Audit:* looks at data sources such as existing medical records and/or other routinely collected service data.
- *Informal:* refers to in-house service evaluation using locally designed tools and/or collecting opportunistic feedback
- *No evaluation*
- *An evaluation is planned*

Existing quality systems contain various indicators such as the number of people engaged in ordinary activities, companies, regular schools, etc. These data are collected throughout the year and reflected in the annual report.

Down Ourense also uses a quality management system called ISO 9001.

All gathered information is then used to improve practices and services.

17. Measurable effects of the practice and what it has achieved for...

Service users	<p>The results obtained in the implementation of programs in the association over the last 12 years were as follows:</p> <ul style="list-style-type: none"> • Participation of all children with intellectual disabilities or Down's Syndrome Association in regular non-specific schools (teaching support and adapted material is provided by Down's Ourense) • Participation of people over 21 years in companies using the so-called 'supported employment method' - 47 employment contracts were signed for people with intellectual disabilities or Down's Syndrome. • Involvement of each participant in external activities (non-specific to people with disabilities) according to their tastes and hobbies, such as painting, dancing, workout and outdoor activities, etc.
---------------	--

Formal care givers	n. a.
Informal carers	n. a.
Organisations	n. a.
Other	n. a.
18. Anticipated or ‘aspirational’ effects of the practice and what it has achieved for... <i>This category can include outcomes which are not documented, quantified or properly evaluated. They can include such elements as improved knowledge, quality, workforce, etc.</i>	
Service users	Increased autonomy, self-confidence and social participation. Users are now capable of going to work on their own with no supervision.
Formal care givers	n. a.
Informal carers	For families, these programmes offer support during all important stages of their children’s lives.
Organisations	For organisations, these programmes show a new, positive perspective in regard to the skills of people with disabilities in various environments (schools, companies, etc.).
Other	n.a.
19. How the practice has changed the way the service is provided (lessons learned)	
People with disabilities are more integrated into the community and participate in regular activities. Down Ourense offers support when needed.	
20. Sustainability of the practice <i>Description of whether the practice is sustainable, considering the following criteria:</i> <ul style="list-style-type: none"> • <i>Potential for sustainability:</i> practice was newly started or is on-going/not yet mainstreamed. How could the practice be sustained (in terms of resources)? • <i>Organic sustainability:</i> service users have been empowered to take the practice forward • <i>Established:</i> the project has been operational for several years 	
These programmes have shown positive results over the past 12 years. The only critical requirement to keep it going on is to obtain the appropriate funding.	
21. Transferability of the practice	

Description of whether the practice has been transferred, considering the following criteria:

- *Transferred:* transfer to other regions, countries, service user groups, etc.
- *Potential for transferability:* there is interest from the outside; elements of the practice have been taken up and used elsewhere; material for transferability (for ex. training material) has been developed

All institutions of the Down's Galicia federation work with similar programmes.

Programmes run over several years. Dossiers, brochures and flyers with information on the different programmes are available in Spanish.