Leonardo Partnership N. 2012-1-FR1-LEO04-35551:
'Adapting services for persons with disabilities to new users'

Summary report on the causes of the diversification of users

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Introduction

The objective of the questionnaire on challenges has been to identify and better understand the causes of the diversification of users of service providers traditionally supporting persons with intellectual disabilities.

"Current users" are persons with an intellectual disability (= learning disability, incl. persons with multiple disabilities).

"New users" are:

- Persons with a mental disability (= mental health problems, mental illness)
- Persons with a dual diagnosis (= persons with an intellectual disability and a mental disability)
- Persons in a situation of social exclusion (= persons who do not fall neatly into a diagnosis of intellectual disability, or mental disability, or dual diagnosis, but who are vulnerable, distant from the labour market, and who need to be supported by services in order to be socially included)

This project has been funded with support from the Lifelong Learning Programme.

1. Respondents

1.1. Participating countries

A total of organizations from eight countries completed the questionnaire.

1. Austria
2. Belgium
3. France
4. Hungary
5. Netherlands
6. Poland
7. Portugal
8. Wales

1.2. Participating organizations

In total, ten organizations filled in the questionnaire.

1. ASBL Le Huitième jour (Belgium)
2. Cartrefi Cymru (Wales)
3. C.E.C.D. MIRA SINTRA (Centro de Educação Para o Cidadão Deficiente, Portugal)
4. Hand in Hand Foundation (Hungary)
5. Jugend am Werk Begleitung von Menschen mit Behinderung GmbH (Austria)
6. Polish Association for Persons with Intellectual Disability Branch in Jarosław (Poland)
7. Stichting IZAH (Netherlands)
8. Unapei (France)
9. Verein zur Schaffung alternativer Beschäftigungsmöglichkeiten für psychisch Kranke (Austria)
10. Wiener Sozialdienste Förderung und Begleitung GmbH (Austria)

Note to the reader:
While some respondents are umbrella organisations for their sector at regional or national level, other respondents are individual service providers whose response is based primarily on the situation in their services. The analysis below should therefore be considered as primarily informative rather than fully representative of the situation in the participating countries.

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2. Summary of responses

2.1. In your country, are service providers for persons with intellectual disabilities also now supporting and caring for: persons with dual diagnosis? Persons with mental disabilities? Persons in a situation of social exclusion?

Country	Dual diagnosis	Mental disabilities	Social exclusion
Austria	◆	◆	◆
Belgium	◆	◆	◆
France	◆	◆	◆
Hungary	◆	◆	◆
Netherlands	◆	◆	◆
Poland	◆	◆	
Portugal	◆		
Wales	◆	◆	◆

In all eight countries, service providers for persons with intellectual disabilities also now support persons with dual diagnosis. In Austria, as there are no specific services for persons with dual diagnosis, these persons are supported either by services for persons with intellectual disabilities, or by services for persons with mental health problems, depending on which disability is considered as prevailing. In Hungary, there are special institutions for these users, nevertheless services for persons with intellectual disabilities get to support them more and more based on their specific expertise (e.g. supported employment services). In France, service providers for persons with intellectual disabilities are supporting persons with dual diagnosis whatever the prevailing disability is. On the contrary, in Portugal, the diagnosis with more weight should be intellectual disability.

In seven countries, service providers for persons with intellectual disabilities also support persons with mental disabilities. The exception is Portugal. In France, even though service providers for persons with intellectual disabilities are also now supporting and caring for persons with only a mental disability, it remains quite marginal.

In seven countries, service providers for persons with intellectual disabilities also support persons in a situation of social exclusion. This is not the case in Poland and Portugal (in Portugal, persons in a situation of social exclusion have priority, however they must have a diagnosis of intellectual disability or dual diagnosis to access these services). In France, persons in a situation of social exclusion who are supported by service providers for intellectual disabilities are mainly persons who also have an intellectual and/or a mental

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disability. Sometimes, users combine a mental disability, an intellectual disability and social exclusion, which often is a challenging situation (e.g. Belgium).

2.2. Please, describe the phenomenon (e.g.: typical or marginal phenomenon? For how long have you been supporting new users? Is it something constant or a changing situation? Are the numbers of different users increasing? Etc.). If you have figures, please share it with us.

In France "new users" are actually not so new. Service providers have been supporting them since several decades. However the phenomenon has increased due to the closing of psychiatric hospitals in the 1990's, and due to the legal recognition of mental health problems as a mental disability (more and more persons newly recognised as mentally disabled are referred to service providers for persons with intellectual disabilities). Besides, the acknowledgement of this diversification is quite new.

Quite similarly, the situation is not new in Austria and Portugal either. Service providers have been supporting persons with dual diagnosis for several decades. However, like in France it seems that the number has increased with the closing of the health services dedicated to mental disability. There was also an increased in the number of persons with a formal diagnosis of dual diagnosis.

In Wales, support for persons with dual diagnosis has been happening for some years now. One of the growing fields is the number of people with both dementia and intellectual disabilities.

In Hungary, in the field of supported employment services, new users have appeared more or less since 2010. The number of persons with mental illness is increasing.

In Poland, diversification is becoming a typical phenomenon. There is a growing number of persons with dual diagnosis, and of persons with mental disabilities.

In the Netherlands, the need for supported living structures for persons with dual diagnosis is increasing.

The Belgian respondent did not provide an assessment of the phenomenon.

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2.3. According to you, what are the causes of this diversification?

Causes	AT	BE	FR	HU	NL	PL	PT	Wales
More persons with ID also experiencing MHP	◆	◆	◆	◆	◆	◆	◆	◆
More persons with a MD also experiencing an ID		◆	◆			◆		
Lack of diagnosis		◆	◆		◆	◆	◆	◆
Better diagnosis	◆		◆		◆		◆	◆
Lack/poor assessment Lack of care plan	◆			◆	◆		◆	◆
Closing of psychiatric institutions	◆		◆				◆	
Recognition of mental disability	◆		◆	◆	◆	◆		
Shortage of services for PWMD	◆		◆			◆	◆	◆
No /shortage of services for persons with DD	◆		◆			◆	◆	◆
Shortage of services for persons in a SSE					◆		◆	◆
High unemployment	◆				◆		◆	
Policy by authorities to mix users	◆					◆		
Policy by service providers to mix users	◆					◆		
Bridge-building health sector/ social care sector		◆			◆			
Cost shunting			◆					◆
Changes in families' level of care	◆	◆		◆	◆			◆
Others	◆		◆	◆	◆			◆

Only one cause is shared by all **eight** countries: the fact that more persons with intellectual disabilities are also experiencing mental health problems.

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Some causes are shared by half or more of the eight countries:

- lack of diagnosis : **6** countries (BE, FR, NL, PL, PT, Wales);
- better diagnosis: **5** countries (AT, FR, NL, PT, Wales);
- lack of poor assessment / lack of care plan: **5** countries (AT, HU, NL, PT, Wales);
- recognition of mental health problems as a disability: **5** countries (AT, FR, HU, NL, PL);
- no services or shortage of services for persons with dual diagnosis: **5** countries (AT, FR, PL, PT, Wales).
- shortage of services for persons with mental disabilities: **5** countries (AT, FR, PL, PT, Wales);
- changes in families' level of care: **5** countries (AT, BE, HU, NL, Wales);

Other causes are shared by less than half of the eight countries:

- more persons with a mental disability also experiencing an intellectual disability: **3** countries (BE, FR, PL);
- closing of psychiatric institutions: **3** countries (AT, FR, PT);
- shortage of services for persons in a situation of social exclusion: **3** countries (PL, PT, Wales);
- high unemployment: **3** countries (AT, NL, PT)
- policy by authorities to mix different types of users: **2** countries (AT, PL);
- policy by services providers to mix different types of users: **2** countries (AT, PL);
- bridge-building between the health sector and the social care sector: **2** countries (BE, NL);
- cost shunting: **2** countries (FR, Wales)

Some respondent have identified other causes:

- longer life expectation of persons with intellectual disabilities (AT, FR, PT, Wales);
- lack of specific services in general (AT);
- more places are available in services, there more users in general, included "new users" (FR);
- the kind of intellectual disabilities is changing (e.g. less persons with Down syndrome, and more with autism) (FR);
- impoverishment of families (HU);
- lack of efficiency of the mainstream basic social care system (HU);
- no offer of fitting services, to be distinguished from a shortage of services: existing services still have a medical approach, instead of a social approach which would better match the needs of new users (NL);

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2.4. Mental health problems experienced by persons with intellectual disabilities

Mental health problems	AT	BE	FR	HU	NL	PL	PT	Wales
Dementia	◆			No reply	◆		◆	◆
Mood disorders	◆	◆	◆		◆	◆	◆	◆
Schizophrenia	◆		◆		◆	◆	◆	
Anxiety and stress related disorders	◆	◆	◆		◆	◆	◆	◆
Eating disorders								
Attention-deficit hyperactivity disorder					◆	◆		◆
Autistic spectrum disorders		◆	◆		◆	◆	◆	◆
Personality disorders	◆	◆	◆		◆	◆	◆	

The Hungarian respondent did not provide an answer to this question. Therefore only seven countries are represented.

Mood disorders and anxiety and stress related disorders are reported in all **seven** countries.

Some mental health problems are in half or more of the seven countries:

- autistic spectrum disorders : **6** countries (BE, FR, NL, PL, PT, Wales);
- personality disorders: **6** countries (AT, BE, FR, NL, PL, PT);
- schizophrenia: **5** countries (AT, FR, NL, PL, PT);
- dementia: **4** countries (AT, NL, PL, PT, Wales)

Attention-deficit hyperactivity disorders are reported in only **three** countries (NL, PL, Wales).

Eating disorders are not reported.

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Conclusion

In all countries, service providers for persons with intellectual disabilities are also supporting persons with dual diagnosis. However, in some countries they support all kind of persons with dual diagnosis, and in others only persons for whom intellectual disability is prevailing, depending on the admission criteria.

In all countries, except Portugal, service providers for persons with intellectual disabilities also support persons with mental disabilities only. However, the extent of this diversification varies from one country to another, and even from one service provider to another.

In all countries, except Poland and Portugal, service providers for persons with intellectual disabilities also support persons in a situation of social exclusion. Obviously though, in all countries they support persons with disabilities in a situation of social exclusion.

In some countries (France, Austria, Portugal), "new users" are actually not new, especially when it comes to persons with dual diagnosis. However the figures are increasing. In other countries the phenomenon is more recent.

When looking at the causes of diversification, one is common to all countries: more persons with intellectual disabilities are also experiencing mental health problems. These mental health problems are mainly autistic spectrum disorders, personality disorders, schizophrenia, and dementia.

Other widely spread causes are the lack of diagnosis, a better diagnosis, a lack of/poor assessment or a lack of care plan, the recognition of mental health problems as a disability, the absence or lack of services for persons with dual diagnosis, a shortage of services for persons with mental disabilities, and a change in families' level of care.

While for some causes it seems possible to categorize countries according to their history or approach (e.g. closure of psychiatric institutions in some Western Europe countries), other causes can be found in countries with different histories or approaches (e.g. lack of diagnosis). This is consistent with the fact that the phenomenon is occurring in all countries.

The findings of this survey strengthen the need for an exchange of good practices at European level. Countries where diversity has been a reality for a while might hold some proven best practices, but also interesting insights on persisting pitfalls. Countries where diversity is newer might show us the way for innovative practices in line with the UNCRPD and its social model.

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