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Autism Spectrum Disorders in the European Union

AUTISM IN ADULT AND OLDER LIVES

An EU Strategy for Autism to Leave No One Behind

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Work Package 3 Goal:

Create a framework to improve care for autistic adults and elders

- **Information Search: services organization**
- **On-line survey: local services provision**

CHILDREN WITH
AUTISM BECOME
TEENAGERS,
ADULTS AND
SENIORS
WITH AUTISM.

Help us act now.



Main Result: Information Search

Key feature of services organization for adults on the autism spectrum in the EU → *private versus public sector balance*

Private sector
provision



Public sector
provision

Private organizations:

- core knowledge base
- often main providers of services

On-line survey

Goal: Better understand local services provision

How closely does the experience of services users and providers 'fit' published recommendations?

3 target groups (N=2009)

- professional in adult services (N=751)
- adult with ASD (N=667)
- family/caregiver of autistic adult (N=591)

11 languages

Completely anonymous



Main Results: On-line Survey

Alignment between recommendations and actual experience:

- evolving positively in some service areas, but not all
- much room for improvement

Alignment is especially poor in:

- Services staff training in autism
- Basic customer service practices
- Post-diagnostic support
- Adolescent-to-adult services transition



Main Results: On-line Survey

Services areas that appear to be doing best (although room for improvement):

- residential services
- diagnostic services for autistic adults

Services areas that appear to be doing less well:

- adolescent-to-adult services transition
- healthcare
 - e.g., health care professionals' understanding of risks for poor health conditions and behaviors in autistic adults is uneven

Recommendations

Support:

Activities to reduce gaps between services recommendations and actual community practices

Activities to reduce uneven capacities and gaps in adult services, especially

- Healthcare
- Managing transitions, especially the adolescent to adult transition

Training programs in autism for adult services staff, including health care

Important to seek input from all 3 respondent groups for a complete view of adult services in local communities.

- ***different perspectives on service needs***

