

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

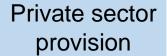






Main Result: Information Search

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





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

