

CH 6: Community-based rehabilitation for adults with developmental disorders including intellectual disabilities and autism spectrum disorders. [New 2015]

SCOPING QUESTION: What is the effectiveness of community-based rehabilitation for adults with developmental disorders (including intellectual disabilities and autism spectrum disorders)?

BACKGROUND

Developmental disorders, including intellectual disability and autism spectrum disorders (ASD), affect individuals worldwide and account for more than 0.4% of all disability-adjusted life years (DALYs) (Murray et al., 2012). Therefore, finding feasible and effective treatments to help individuals with developmental disorders and their families is a high priority. Although many treatment programs have been established and researched for children with developmental disorders, less is known about effective programming for adults with these conditions. Furthermore, many programs are resource-intensive and the scale-up of such programs is challenging, especially in low-resource settings, including lower- and middle-income countries (LAMICs), which is where the majority of individuals with developmental disorders reside and where the treatment gap has been estimated to be as high as 85% (Demyttenaere et al., 2004).

Moreover, as children with developmental disorders become ineligible for school-based services with age, additional needs arise, such as the need for independent living support, employment opportunities and adult life skills (World Health Organization [WHO], 2014). While some individuals may receive interventions and training in these areas in secondary school, it is unlikely that all adults with developmental disorders receive these interventions. WHO recommends that community-based rehabilitation (CBR) be offered to children with intellectual disabilities. This profile aims to examine the level of evidence of CBR services to support adults with developmental disorders, including intellectual disabilities and autism spectrum disorders.

PART 1: EVIDENCE REVIEW

Population/ Intervention / Comparison / Outcome (PICO)

- **Population:** Adults with developmental disorders (including intellectual disabilities and autism spectrum disorders)
- **Interventions:** Psychosocial rehabilitation enhancing independent living, occupational and social skills (including social skills life skills, vocational training and assisted- or independent living facilities)
- **Comparison:** Care as usual
- **Outcomes**
 - **Critical** – Functioning, participation, quality of life
 - **Important** – Users and caregivers' satisfaction with services

Search strategy

In order to identify relevant systematic reviews, the following databases were searched: MEDLINE, Embase, the Cochrane Library, Global Health and PsychINFO, up to November 2014. The following search strategy was used:

- (meta analysis OR review OR systematic review) AND adult AND (psychosocial OR social OR psychological OR therap*) AND (intellectual disability OR mental retard* OR developmental disabilit* OR autis*).

The electronic database search returned 1214 results, of which 1200 remained after results were checked for duplication. After screening titles and abstracts of the 1200 results, the full text of 12 articles was examined.

Included in GRADE tables or footnotes

There were no studies that were suitable for quality assessment using GRADE methodology. Please see narrative description for relevant findings.

Excluded from GRADE tables and footnotes

Bishop-Fitzpatrick L, Minshew NJ, Eack SM (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*.43(3):687-694. doi:10.1007/s10803-012-1615-8.

REASON FOR EXCLUSION: Only provided a narrative review.

Hamelin JP, Frijters J, Giffiths D, Condillac R, Owen F (2011). Meta-analysis of deinstitutionalization adaptive behaviour outcomes: Research and clinical implications. *Journal of Intellectual and Developmental Disability*.36:61-72.

REASON FOR EXCLUSION: Focused on statistical syntheses of between-group and within-group effect sizes.

Tobin MC, Drager KDR, Richardson LF (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders*.8:214-229.

REASON FOR EXCLUSION: Only provided a narrative review.

PICO Table

Intervention	Comparison	Outcome	Systematic reviews used for GRADE	Justification for systematic review used
Psychosocial rehabilitation	Care as usual	Functioning	N/A	N/A
		Participation	N/A	N/A
		Quality of life	N/A	N/A
		User satisfaction	N/A	N/A

Narrative description of evidence excluded from GRADE tables and footnotes

Hamelin et al. (2011) included 23 studies with 2083 participants (with an individual study sample size range 15 – 346) in examination of deinstitutionalization practices for adults with intellectual disabilities. The mean age of the samples was 37.7 years (SD = 9.14), with an average sample consisting of 57% males. Across studies, the level of intellectual functioning varied across the spectrum of intellectual disabilities, from studies including only participants with severe intellectual disabilities to studies involving mixed levels of intellectual disabilities. With respect to type of community living arrangement studied, 15 studies evaluated group home or small, supported housing; 4 studies examined intermediate care facilities; and 4 studies did not specify type of community placement. A majority of the studies (N=16) were conducted in the United States of America (USA), with the remaining studies conducted in the United Kingdom (UK) (N=4), Canada (N=2) and Australia (N=1). There were no studies conducted in LAMIC. The review showed that habilitative gains were found in 75% of adaptive behaviour domains, with a standardized mean difference (SMD) effect size estimate of 0.40 (SD = 0.36).

The systematic review by **Bishop-Fitzpatrick et al. (2013)** highlighted 3 randomized controlled trials (RCTs) of psychosocial interventions for adults with ASD. Three of the four studies examined social cognition training, with SMD effect size estimates ranging from 0.75 to 3.59; however, sample sizes for these RCTs were very small (n = 10 to 17), limiting the quality of the evidence.

Tobin et al.s (2014) systematic review investigated what is currently known about support for social participation for adults with ASD. A computerized database search followed by hand searching was conducted to locate empirical studies published after 1995 in peer-reviewed journals that described social participation or social support for adults with ASD. 14 studies were identified and were evaluated for strength of evidence and then organized into topical themes. These studies focused on support for social participation from two perspectives: social functioning and quality of life. Supporting social functioning and social participation is important, as this is one route through which individuals with ASD may be able to form relationships and establish natural support networks, which can in turn contribute to quality of life. In addition, working to improve social skills is of key importance as social functioning heavily impacts outcomes in a variety of areas. The review found that social participation, social functioning and quality of life for adults with ASD appear to be facilitated through informal social support from social networks, participation in social skills groups, and membership in support groups.

In **2012**, **NICE** published clinical guidelines for the recognition, diagnosis and management of adults on the autism spectrum (NICE Clinical Guideline 142, 2012). These guidelines recommend psychosocial interventions for social skills and broader life skills including, where appropriate, anger management, supported employment, anti-victimization and structured leisure programmes. The guidelines specify different types of interventions for individuals with and without intellectual disabilities, highlighting the need to individualize intervention programmes. See also **Pilling et al. (2012)** for additional information.

The **WHO and World Bank (2011) joint report, *World Report on Disability***, reported that CBR has been adopted in over 90 countries; however, the evidence on CBR programmes varies. Research and evaluation are increasingly conducted and information sharing is increasingly done through regional networks, such as the CBR Africa Network, the CBR Asia-Pacific Network and the CBR American and Caribbean Network.

PART 2: FROM EVIDENCE TO RECOMMENDATIONS

Summary of evidence table

	Intervention vs. control
Outcome	Psychosocial rehabilitation vs. no treatment control or standard care
Functioning	N/A
Participation	N/A
Quality of Life	N/A
Users and caregivers' satisfaction	N/A

Evidence to recommendation table

Benefits	<p>The evidence is inconclusive and so it is not possible to determine if psychosocial rehabilitation, such as CBR, is effective in adults with developmental disorders, including intellectual disabilities and autism spectrum disorders.</p> <p>Additional evidence suggests that social skills training and community interventions can be effective for adults with autism spectrum disorders in increasing social skills and adaptive behaviours (i.e., life skills).</p> <p>Based on low quality evidence from quasi-experimental parallel group controlled trials and an economic model, NICE recommends an individual supported employment programme for adults with autism spectrum disorders.</p>
Harms	There is no evidence of harm and some positive changes have been reported.
Summary of the quality of evidence	Evidence is very low quality and inconclusive.

Value and preferences

In favour	<p>Although developmental disorders emerge in childhood, they are lifelong conditions that affect both the individuals with the developmental disorders and their families, including parents and siblings.</p> <p>The UN Convention on the Rights of People with Disabilities emphasizes social inclusion of people with intellectual disabilities. Psychosocial rehabilitation, including CBR, is in line with the rights of people with disabilities because these interventions provide opportunities for these individuals to participate in social life and be considered equal members of society.</p>
Against	<p>It is possible that some individuals with developmental disorders, including intellectual disabilities and autism spectrum disorders, could experience increased stigma through participation in psychosocial rehabilitation programmes.</p>
Uncertainty or variability?	<p>There is some variability in values and preferences. However, the provision of psychosocial rehabilitation, including CBR, is in line with internationally endorsed principles on the rights of people with disabilities.</p>

Feasibility (including resource use considerations)	<p>Psychosocial rehabilitation, including CBR, seems to be a feasible and potentially cost-saving intervention. However more work is needed to show how best we can include adults with developmental disorders within the programmes.</p>
Uncertainty or variability?	<p>Feasibility of implementation will vary, depending on local financial and human resources.</p>

Recommendation and remarks

Recommendation

Non-specialized health care providers can offer supporting, collaborating and facilitating referral to and from community based rehabilitation (CBR) programmes, if available, for care of adults with developmental disorders, including intellectual disabilities and pervasive developmental disorders (including autism).

Rationale: Evidence supporting the efficacy of community-based rehabilitation for adults with developmental disorders is sparse and inconclusive. The provision of psychosocial rehabilitation is in line with internationally endorsed principles on the rights of people with disabilities.

Remarks

Intervention programmes should be developed and adapted taking into consideration the sociocultural context and with involvement of program users.

Judgements about the strength of a recommendation

Factor	Decision
Quality of the evidence	<input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low <input checked="" type="checkbox"/> Very low
Balance of benefits versus harms	<input checked="" type="checkbox"/> Benefits clearly outweigh harms <input type="checkbox"/> Benefits and harms are balanced <input type="checkbox"/> Potential harms clearly outweigh potential benefits
Values and preferences	<input type="checkbox"/> No major variability <input checked="" type="checkbox"/> Major variability
Resource use	<input checked="" type="checkbox"/> Less resource-intensive <input type="checkbox"/> More resource-intensive
Others (Acceptability/Feasibility/Equity/Accessibility)	The provision of CBR generally has high acceptability, promotes equity and is feasible. These are important considerations that contribute to the strength of the recommendation despite the very low quality of evidence.
Strength	CONDITIONAL

OTHER REFERENCES

Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. In: NICE Clinical Guidelines. London: National Institute for Clinical Excellence (NICE); 2012 (NICE Clinical Guideline 142; <http://guidance.nice.org.uk/cg142>, accessed 30 November 2014).

Demyttenaere K, Bruffaerts R, Posada-Villa J, Gasquet I, Kovess V, Lepine JP, et al (2004). Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. *Journal of the American Medical Association*.291(21):2581-2590.

Murray CJ, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 380(9859):2197-223.
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Pilling S, Baron-Cohen S, Megnin-Viggars O, Lee R, Taylor C (2012). Recognition, referral, diagnosis, and management of adults with autism: Summary of NICE Guidance. *British Medical Journal*.344:e4082. doi:<http://dx.doi.org/10.1136/bmj.e4082>.

World Health Organization and The World Bank. World Report on Disability. Geneva: World Health Organization; 2011 (http://www.who.int/disabilities/world_report/2011/en/, accessed 30 November 2014).