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Title: Prevalence of vitamin D deficiency in people with learning disability: A systematic review.

Citation: British Journal of Learning Disabilities; Dec 2019; vol. 47 (no. 4); p. 279-288

Author(s): Walton, Catherine; Isaac, Andrew; Kerr, Mike

Accessible Summary: People with learning disability have more health problems in comparison to people without learning disability. Low levels of vitamin D in the body is called vitamin D deficiency. This can increase the chance of bone disease, falls and broken bones. This article has reviewed the research evidence from the last 16 years about vitamin D deficiency for people with learning disability. The research shows that people with learning disability have an equal, and possibly higher, chance of vitamin D deficiency. More research is needed to confirm these findings. In order to find out more about how many people with learning disability have vitamin D deficiency, a much larger study is needed. Background: Inequality and unmet needs. Vitamin D deficiency can increase the risk of bone disease, muscle weakness and fractures. The aim of this systematic review is to assess for the prevalence of vitamin D deficiency in people with learning disability.

Method: The “Preferred Reporting Items for Systematic Reviews and Meta-analyses” checklist was followed where possible.

Results: Eight studies were included in the qualitative synthesis. The quality of the studies was assessed utilising the “Appraisal of Cross-sectional Studies” tool. The prevalence of inpatients with learning disability and deficient vitamin D levels ranged from 41% to 92%. This is equal to, and likely higher than, the rate for institutionalised adults in the UK. 49%–77% of individuals with learning disability living in the community had inadequate vitamin D levels. In comparison to the general population, this is provisional evidence to suggest that people with learning disability could have an increased risk of inadequate vitamin D levels.

Conclusion: Due to the low number of studies, and the heterogeneous populations of the included studies, firm conclusions could not be drawn. However, the results show that people with learning disability have at least an equal risk of vitamin D deficiency in comparison to the general population. There is provisional evidence to suggest that the prevalence could be higher for people with learning disability, and therefore, there is a need for further population-based studies.

Title: The impact of an epilepsy nurse competency framework on the costs of supporting adults with epilepsy and intellectual disability: findings from the EpAID study.

Citation: Journal of Intellectual Disability Research; Dec 2019; vol. 63 (no. 12); p. 1391-1400


Background: The development of a nurse-led approach to managing epilepsy in adults with an intellectual disability (ID) offers the potential of improved outcomes and lower costs of care. We undertook a cluster randomised trial to assess the impact on costs and outcomes of the provision of ID nurses working to a designated epilepsy nurse competency framework. Here, we report the impact of the intervention on costs.

Method: Across the United Kingdom, eight sites randomly allocated to the intervention recruited 184 participants and nine sites allocated to treatment as usual recruited 128 participants. Cost and outcome data were collected mainly by telephone interview at baseline and after 6 months. Total costs at 6 months were compared from the perspective of health and social services and society, with adjustments for pre-specified participant and cluster characteristics at baseline including costs. Missing data were imputed using multiple imputation. Uncertainty was quantified by bootstrapping.

Results: The intervention was associated with lower per participant costs from a health and social services perspective of −£357 (2014/2015 GBP) (95% confidence interval −£986, £294) and from a societal perspective of −£631 (95% confidence interval −£1473, £181). Results were not sensitive to the exclusion of accommodation costs.
Conclusions: Our findings suggest that the competency framework is unlikely to increase the cost of caring for people with epilepsy and ID and may reduce costs.

Title: Staff understandings of abuse and poor practice in residential settings for adults with intellectual disabilities

Citation: Journal of Applied Research in Intellectual Disabilities; Oct 2019
Author(s): Fyson, Rachel; Patterson, Anne

Background: A common factor in the abuse of people with intellectual disabilities in residential settings has been the failure of care staff and frontline managers to recognise poor practice at an early stage and prevent its development into a culture of abuse. In this context, staff understandings of abuse and poor practice in residential services for people with intellectual disabilities were explored.

Method: Semi-structured interviews (n = 56) were undertaken with care staff and frontline managers working across England. Interviews included the use of vignettes, based on real-life experiences of people with intellectual disabilities, to prompt discussion.

Results: Staff struggled to define either “abuse” or “poor practice”, focussing more on individual acts or omissions than on institutional practices. When faced with vignettes, staff demonstrated a lack of agreement regarding what constitutes either abuse or poor practice.

Conclusions: The implications for practice in residential care settings and for safeguarding training are discussed. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

Title: Parents’ perceptions regarding couple relationships of their adult children with intellectual disabilities

Citation: Journal of Applied Research in Intellectual Disabilities; Oct 2019
Author(s): Neuman, Ran

Background: A particular challenge facing parents of children with intellectual disabilities occurs when their adult children with intellectual disabilities has an interest in pursuing couple relationships. This study explores parents’ perceptions regarding the nature of couple relationships, the right of their adult children with intellectual disabilities to pursue such relationships, the difficulties their children encounter and their own role in providing support.

Method: Interviews were conducted with 30 parents of adults with intellectual disabilities who had left home for independent and semi-independent living arrangements. A thematic content analysis was conducted.

Results: Whereas parents used “mutual support” to characterize couple relationships in general, they viewed their children with intellectual disabilities as primarily focused on “physical intimacy” and the couple relationship as a “status symbol,” as well as expressed reservations about their becoming parents.

Conclusions: Parents should be helped to adopt a more consistent and positive attitude towards their intellectual disabilities children’s pursuit of couple relationships. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

Title: Self-determination and future goals in a sample of adults with intellectual disability

Citation: Journal of Intellectual Disability Research; Nov 2019
Author(s): Di Maggio, I.; Shogren, K. A.; Wehmeyer, M. L.; Nota, L.
**Background:** In recent years, increased attention has been directed towards the importance of identifying the future goals of people with intellectual disability (ID) and promoting their abilities to design their future. Consistent with these, the first aim of this study is to investigate the future goals of people with ID in terms of content and temporal distance. Moreover, the second aim of this study is to test the predictive role of self-determination on the number of future goals reported by people with ID.

**Methods:** In this study, 96 young adults with ID were involved and a mixed method design was chosen. Specifically, qualitative procedures (consensual qualitative analyses) and quantitative procedures (structural equation modelling) were carried out.

**Results:** The results showed that the future goals of people with ID are characterised by different factors related to autonomy, health/well-being, interpersonal relations and personal growth. Moreover, self-determination (assessed with Self-Determination Questionnaire—Version for Adults) predicts a higher number of future goals reported by people with ID.

**Conclusions:** These results suggest the importance of providing adequate support to the development of self-determination. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract).

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**Title:** Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities

**Citation:** Journal of Clinical Nursing; Oct 2019

**Author(s):** Brown, Michael; Higgins, Anna; MacArthur, Juliet

**Aims and objectives:** To explore the experiences of the families of young adults with intellectual disabilities at the point of transition from child to adult health services. Background: The population of people with intellectual disabilities is changing rapidly, with young people with increasingly complex needs surviving into adulthood and requiring transition from child to adult health services. Design: An interpretative qualitative design.

**Methods:** Semi-structured interviews were held with ten family carers of young adults with intellectual disabilities and complex care needs, who were in the process of or had recently completed a transition from child to adult health services in Scotland. Data were analysed using thematic analysis. The COREQ checklist was used.

**Results:** Transition emerged as a highly emotional and challenging period for family carers. Their experiences were captured in five main themes: “a deep sense of loss,” “an overwhelming process,” “parents making transitions happen,” “a shock to the adult healthcare system” and “the unbearable pressure.” Nurses were often seen as instrumental to counteracting some of these challenges.

**Conclusions:** There is an urgent need to respond to the challenges experienced by carers at the point of transition and beyond, by ensuring early and coordinated planning, effective information sharing and communication and clear transition processes and guidelines. A person-centred and family-centred approach is required to minimise negative impact on the health and well-being of the young adult with intellectual disabilities and their carers. Relevance to clinical practice: Registered nurses have a key role in providing information and support, along with coordinating care at the time of transition from child to adult health services for young adults with complex intellectual disabilities. It is vital that their input is person-centred and responds effectively to the expert knowledge of family carers, while at the same time ensuring their needs for information and support are also addressed. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

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**Title:** How is anxiety identified and diagnosed in individuals with autism spectrum disorder and intellectual disability? A scoping review

**Citation:** Journal of Mental Health Research in Intellectual Disabilities; Oct 2019

**Author(s):** Appleton, Helen; Roberts, Jacqueline; Simpson, Kate
**Introduction:** Individuals with Autism Spectrum Disorder display a pattern of social communication deficits and restricted and repetitive behaviors that leave them particularly vulnerable to developing anxiety. The presence of a co-occurring Intellectual Disability further complicates the situation, compromising traditional diagnostic techniques and processes. The dual diagnosis of ASD and ID appears to result in specific behavioral patterns that affect the way anxiety is identified in this population.

**Method:** A scoping review was undertaken to explore what is currently known about the way anxiety is identified and diagnosed in individuals with ASD and ID.

**Results:** In the limited research available consistent themes of difficulties with the diagnostic process, inconsistencies among measurement tools and the need to consider behavioral symptomology were found.

**Conclusion:** Further research needs to be conducted to enhance our understanding of how anxiety is identified in those with ASD and ID. This research could more accurately inform reliable diagnostic processes and lead to better treatment and outcomes for this population. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

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**Title:** Evaluation of agomelatine for the treatment of sleep problems in adults with autism spectrum disorder and co-morbid intellectual disability

**Citation:** Journal of Psychopharmacology; Nov 2019; vol. 33 (no. 11); p. 1395-1406

**Author(s):** Ballester, Pura; Martínez, María José; Inda, María-del-Mar; Javaloyes, Auxiliadora; Richdale, Amanda L.; Muriel, Javier; Belda, César; Toral, Natalia; Morales, Domingo; Fernández, Eduardo; Peiró, Ana M

**Purpose:** Intellectual disability (ID) and autism spectrum disorder (ASD) are common, co-occurring developmental disorders and are frequently associated with sleep problems. This study aimed to assess the effectiveness and tolerability of agomelatine as a pharmacotherapy for sleep problems in ASD adults with ID.

**Method:** A randomised, crossover, triple-blind, placebo-controlled clinical trial, with two three-month periods of treatment starting with either agomelatine or placebo and a washout period of two weeks. Ambulatory circadian monitoring (24 hours/7 days) evaluated total sleep time (TST) as the primary outcome variable.

**Results:** Participants (N=23; 35±12 years old; 83% male) had a median of three (interquartile range (IQR) 1–4) co-morbidities and were taking a median of five (IQR 2–7) prescribed drugs. Before agomelatine or placebo treatment, all subjects presented with insomnia symptoms, including sleep latency (100% abnormal, 55±23 minutes) or TST (55% abnormal, 449±177 minutes), and 66% had circadian rhythm sleep–wake abnormalities with rhythm phase advancements according to the M5 sleep phase marker values. During the three-month agomelatine treatment, night TST significantly increased by a mean of 83 minutes (16% abnormal, 532±121 minutes), together with a phase correction (M5 1:45±2:28 hours vs. 3:15±2:20 hours), improving sleep stability in wrist temperature rhythm (0.43±0.29 vs. 0.52±0.18 AU). Adverse events were mild and transient.

**Conclusions:** Agomelatine was effective and well tolerated for treating insomnia and circadian rhythm sleep problems present in adults with ASD and ID. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

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**Title:** Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort

**Citation:** Journal of Child Psychology and Psychiatry; Nov 2019; vol. 60 (no. 11); p. 1210-1218

**Author(s):** Bailey, Tom; Totsika, Vasiliki; Hastings, Richard P.; Hatton, Chris; Emerson, Eric
Background: The study examined developmental trajectories of prosocial behaviours, internalising and externalising behaviour problems in children with intellectual disabilities (ID) between pre-school and middle childhood.

Method: Growth models examined the best-fitting trajectories for internalising and externalising behaviour problems, as well as prosocial behaviours, in 555 children with ID between the ages of three and 11 years from the UK Millennium Cohort Study. Models were also fitted to examine the association of child outcomes with time-varying maternal psychological distress and life satisfaction. Finally, models were extended to compare trajectories with typically developing children.

Results: Externalising behaviour problems and prosocial behaviours generally improved, whereas internalising problems did not change systematically over time. A cubic trend indicated a slowing down of improvement between ages 5 and 7 for prosocial behaviours and externalising problems. Maternal psychological distress positively co-varied with internalising and externalising behaviour problems over time. Life satisfaction was not related to changes in child behaviours over time. Compared to behavioural trajectories in typical development, intercepts were worse and trajectories also differed in the ID group.

Conclusions: Over an 8-year period, externalising behaviour problems and prosocial behaviours of children with ID tended to improve. These behavioural improvements slowed between five and seven years, possibly coinciding with school-related environmental changes. Children with ID significantly differ from children with typical development in both the initial level of difficulties (exhibiting higher externalising and internalising behaviours, and lower prosocial behaviours) and subsequent development as they age, showing comparatively lower decreases in both externalising and internalising behaviours, and lower increases in prosocial behaviours. Findings also highlight the significant role of maternal mental health problems in the trajectory of child behaviour problems. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

Title: Factors associated with increases over time in the quality of active support in supported accommodation services for people with intellectual disabilities: A multi-level model

Citation: Research in Developmental Disabilities; Nov 2019; vol. 94

Author(s): Bould, Emma; Bigby, Christine; Iacono, Teresa; Beadle-Brown, Julie

Background: Disability support organisations have embraced Active Support, but it has proved difficult to embed in services.

Aims: This study aimed to identify the factors associated with increases over time in the quality of Active Support.

Method: Data were collected on the predicted variable of the quality of Active Support, and predictor variables of service user, staff and service characteristics, including practice leadership, and composition and size of services from 51 services in 8 organisations over 2–7 time points. Data were analysed using multi-level modelling.

Results: There was significant linear change in Active Support scores (group mean centered at the organisational level) over time. Individuals with lower support needs received better Active Support and those with higher support needs experienced greater increases over time. Stronger practice leadership and more staff with training in Active Support were significant predictors of the quality of Active Support. Larger services with seven or more individuals and where there was a very heterogeneous mix of individuals were associated with lower quality of support.

Conclusions: Ensuring strong practice leadership, and staff training in Active Support that emphasises the principle of adapting support to each individual’s level of ability and preferences are key to delivering high levels of Active Support. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)
Title: Gender differences in physical activity and sedentary behaviour in adults with intellectual disabilities: A systematic review and meta-analysis.

Citation: Journal of applied research in intellectual disabilities : JARID; Nov 2019; vol. 32 (no. 6); p. 1359-1374

Author(s): Westrop, Sophie C; Melville, Craig A; Muirhead, Fiona; McGarty, Arlene M

Background: Adults with intellectual disabilities are reported to be highly inactive, with research required to understand contributory factors. This systematic review aimed to investigate gender differences in physical activity (PA) and sedentary behaviour (SB) in adults with intellectual disabilities.

Methods: This systematic review was reported in accordance with PRISMA guidelines. Seven databases were searched up to, and including, January 2018. Screening identified papers that assessed gender-specific PA and/or SB outcomes in adults with intellectual disabilities. Data were synthesized using a narrative synthesis and random effects model meta-analyses.

Results: Twenty-six papers were included; 25 measured PA, and eight assessed SB. Women with intellectual disabilities were least active with a significant overall effect of gender identified. For SB, no consistent gender differences were found.

Conclusions: Reflecting the general population, men with intellectual disabilities were most active. Intellectual disability research should consider the role of gender to inform future interventions targeting inactivity.

Title: Oral health of adults with intellectual disabilities: a systematic review.

Citation: Journal of intellectual disability research : JIDR; Nov 2019; vol. 63 (no. 11); p. 1359-1378

Author(s): Ward, L M; Cooper, S A; Hughes-McCormack, L; Macpherson, L; Kinnear, D

Background: There have been several past reports that adults with intellectual disabilities experience poor oral health (tooth loss, periodontal health and untreated dental caries). Loss of a functional dentition has serious consequences, including problems with chewing, swallowing, nutrition, speech, temporomandibular joint osteoarthritis and pain and systemic health conditions. Poor oral health is largely preventable through proactive oral care support. In recent years, social care provision for adults has changed, with deinstitutionalisation and home-based personalised care now being the typical provision in high income countries. Hence, oral health inequalities might be reducing. However, there is limited recent evidence-synthesis on the topic. We aimed to address this.

Method: PROSPERO registration number: CRD42018089880. We conducted a preferred reporting items for systematic reviews and meta-analyses systematic review of publications since 2008. Four databases were searched with a clear search strategy, strict inclusion criteria for selection of papers, double scoring (two raters), systematic data extraction and quality appraisal of included papers.

Results: A total of 33/3958 retrieved articles were included, of which 14 were drawn from dental service users and 10 from Special Olympic athletes, therefore not necessarily being representative of the wider population with intellectual disabilities. Despite this limitation, adults with intellectual disabilities were still shown to experience poor oral health. High levels of poor oral hygiene and gingivitis were found, with many also affected by periodontitis and untreated dental decay. There is clear unmet need relating to both periodontal (gum) and tooth health, leading to tooth loss.

Conclusions: Despite reports in the past of poor oral health amongst adults with intellectual disabilities, and despite it being preventable, there remains a high burden of poor oral health. This highlights the need to raise awareness, and for polices on effective daily oral care, and appropriate service provision. The importance of oral health and its possible negative sequelae needs to be elevated amongst carers and professionals.
Clinical characteristics of individuals with intellectual disability who have experienced sexual abuse. An overview of the literature.

Citation: Research in developmental disabilities; Oct 2019; vol. 95 ; p. 103513

Author(s): Smit, Manon J; Scheffers, Mia; Emck, Claudia; van Busschbach, Jooske T; Beek, Peter J

Background: Sexual abuse in individuals with average IQ or above is associated with a wide range of behavioural, psychological and body-related characteristics. It is unknown whether individuals with intellectual disability (ID) and a history of sexual abuse suffer from similar clinical characteristics.

Objective: The aim of the review is to provide an overview of the literature on the clinical characteristics of individuals with ID who have experienced sexual abuse. PubMed, Embase, PsycInfo, CINAHL, Cochrane Library and Web of Sciences were searched for relevant publications using terms related to concepts of "intellectual disability" and "sexual abuse". Two independent reviewers screened and selected articles for inclusion in the study, resulting in seven studies.

Results: The studies mostly reported behavioural and psychological characteristics such as aggression, self-injury, or post-traumatic stress, anxiety or depressive symptoms associated with sexual abuse in individuals with ID. None mentioned body-related characteristics.

Conclusions: Similar to individuals with average IQ or above, sexual abuse in individuals with ID is associated with a broad range of behavioural and psychological characteristics. Conduct disorders, self-injury, inappropriate sexualised talk and poor feelings of personal safety seem to be more indicative for the ID population. Anxiety, depression and PTSD are prevalent in individuals with and without ID who both have experienced sexual abuse. Whether individuals with ID experience body-related characteristics is unclear.

Enhancing social inclusion of young adults with intellectual disabilities: A systematic review of original empirical studies.

Citation: Journal of applied research in intellectual disabilities : JARID; Oct 2019

Author(s): Louw, Julia S; Kirkpatrick, Bernadette; Leader, Geraldine

Background: Social inclusion is regarded as an important determinant of health, particularly for young adults with intellectual disabilities. However, only a limited number of reviews report on the findings of original empirical studies on social inclusion of young adults with intellectual disabilities. This review provides a succinct synopsis of original empirical studies on social inclusion among young adults with intellectual disabilities for the period between January 2013 and January 2019.

Methods: Studies were drawn from three electronic databases: ScienceDirect, PubMed and PsycINFO. In addition, hand searches were carried out in several international journals focusing on intellectual disability research. The review included both qualitative and quantitative studies. In all, 24 key studies met the inclusion criteria for this review. The Methodological Quality Checklist developed by Downs and Black (Journal of Epidemiology Community Health, 1998, 52, 377) was used to independently assess study quality, and the Cochrane Collaboration Intervention Clinical Appraisal Form was used to extract data and outcome measures for each study.

Results: Among the key findings, structured and organized social inclusion interventions were reported to create better opportunities to engage in social interactions and improve social skills. Moreover, evaluating outcomes on the two core quality-of-life domains, that of interpersonal relationships and community participation, were reported to facilitate positive outcomes for social inclusion of young adults with intellectual disabilities.

Conclusion: There is a need to do an in-depth exploration of the potential impact of facilitators that promote social inclusion of young adults with intellectual disabilities, by conducting rigorous empirical investigations.
Title: The Effectiveness of Web-Based Interventions Delivered to Children and Young People With Neurodevelopmental Disorders: Systematic Review and Meta-Analysis.

Citation: Journal of medical Internet research; Nov 2019; vol. 21 (no. 11); p. e13478

Author(s): Khan, Kareem; Hall, Charlotte L; Davies, E Bethan; Hollis, Chris; Glazebrook, Cris

Background: The prevalence of certain neurodevelopmental disorders, specifically autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD), has been increasing over the last four decades. Nonpharmacological interventions are available that can improve outcomes and reduce associated symptoms such as anxiety, but these are often difficult to access. Children and young people are using the internet and digital technology at higher rates than any other demographic, but although Web-based interventions have the potential to improve health outcomes in those with long-term conditions, no previous reviews have investigated the effectiveness of Web-based interventions delivered to children and young people with neurodevelopmental disorders.

Objective: This study aimed to review the effectiveness of randomized controlled trials (RCTs) of Web-based interventions delivered to children and young people with neurodevelopmental disorders.

Methods: Six databases and one trial register were searched in August and September 2018. RCTs were included if they were published in a peer-reviewed journal. Interventions were included if they (1) aimed to improve the diagnostic symptomology of the targeted neurodevelopmental disorder or associated psychological symptoms as measured by a valid and reliable outcome measure; (2) were delivered on the Web; (3) targeted a youth population (aged ≤18 years or reported a mean age of ≤18 years) with a diagnosis or suspected diagnosis of a neurodevelopmental disorder. Methodological quality was rated using the Joanna Briggs Institute Critical Appraisal Checklist for RCTs.

Results: Of 5140 studies retrieved, 10 fulfilled the inclusion criteria. Half of the interventions were delivered to children and young people with ASDs with the other five targeting ADHD, tic disorder, dyscalculia, and specific learning disorder. In total, 6 of the 10 trials found that a Web-based intervention was effective in improving condition-specific outcomes or reducing comorbid psychological symptoms in children and young people. The 4 trials that failed to find an effect were all delivered by apps. The meta-analysis was conducted on five of the trials and did not show a significant effect, with a high level of heterogeneity detected (n=182 [33.4%, 182/545], 5 RCTs; pooled standardized mean difference=-0.39; 95% CI -0.98 to 0.20; Z=-1.29; P=.19 [I²=72%; P=.006]).

Conclusions: Web-based interventions can be effective in reducing symptoms in children and young people with neurodevelopmental disorders; however, caution should be taken when interpreting these findings owing to methodological limitations, the minimal number of papers retrieved, and small samples of included studies. Overall, the number of studies was small and mainly limited to ASD, thus restricting the generalizability of the findings.TRIAL REGISTRATION PROSPERO International Prospective Register of Systematic Reviews: CRD42018108824; http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018108824.

Title: The experiences of adults with intellectual disability in the involvement of nursing care planning in health services.

Citation: British Journal of Learning Disabilities; Dec 2019; vol. 47 (no. 4); p. 233-240

Author(s): Doody, Owen; Lyons, Rosemary; Ryan, Ruth

Accessible summary: Adults with intellectual disabilities and their families receiving services have plans for their care, education and social support. This occurs through meetings and results in a "care plan" or "plan of support." There are differences in nursing, educational and social care plans. At present, adults with intellectual disability have little involvement in nursing care planning. Involving adults with intellectual disability in nursing care planning is important, and there is a need to share and publish this involvement.

Background: Adults with intellectual disability should be involved in decision-making about their care. However, little is known regarding their experience of engaging in care planning within health
services. In a rapidly changing healthcare environment, the relevance and necessity of demonstrating care delivered and care outcomes is essential for all professionals and this review highlights the need for intellectual/learning disability nurses to prioritise disseminating this evidence beyond the practice environment.

Materials and Methods: Integrative literature review informed by the approach of Whittemore and Knaff (2005). CINAHL, Scopus, Web of Science, PsycArticles, PsycInfo, MEDLINE, Cochrane Library, Embase and Academic Search Complete were searched for papers published between 01 January 2005 and 01 June 2017.

Results: No study met the inclusion criteria for nursing care planning. However, through examining the literature that made it to the full-text review stage, two key aspects were identified: exploring the relevance and categories of plans, and disseminating evidence of practice.

Conclusion: This integrative review provides evidence that the experiences of adults with intellectual disability involvement in care planning within health services are absent within the literature. While guidance exists regarding involving adults with intellectual disability in planning their care, there is confusion, ambiguity and an interchangeable use of terms that makes it difficult to distinguish between nursing care plans, person-centred plans, individual programme plan, individualised support plan, health action plans, personalised support plans and personalised plans.

Title: The Effectiveness of Rehabilitation Interventions on the Employment and Functioning of People with Intellectual Disabilities: A Systematic Review.

Citation: Journal of Occupational Rehabilitation; Dec 2019; vol. 29 (no. 4); p. 773-802

Author(s): Nevala, Nina; Pehkonen, Irmeli; Teittinen, Antti; Vesala, Hannu T.; Pörtfors, Pia; Anttila, Heidi

Purpose: This systematic review analyzed the effectiveness of rehabilitation interventions on the employment and functioning of people with intellectual disabilities (ID), as well as barriers and facilitators of employment.

Methods: This was a systematic review of quantitative, qualitative, and mixed methods studies. The outcomes were employment, transition to the open labor market and functioning. The review included qualitative studies of employment barriers and facilitators. The population comprised people with ID aged 16–68 years. Peer-reviewed articles published in English between January 1990 and February 2019 were obtained from the databases Cinhahl, the Cochrane Library, Embase, Eric, Medic, Medline, OTseeker, Pedro, PsycInfo, PubMed, Socindex, and the Web of Science. We also searched Google Scholar and Base. The modified selection instrument (PIOS: participants, intervention, outcome, and study design) used in the selection of the articles depended on the selection criteria.

Results: Ten quantitative (one randomized controlled, one concurrently controlled, and eight cohort studies), six qualitative studies, one multimethod study, and 21 case studies met the inclusion criteria. The quantitative studies showed that secondary education increases employment among people with ID when it includes work experience and personal support services. Supported employment also increased employment in the open labor market, which sheltered work did not. The barriers to employment were the use of sheltered work, discrimination in vocational experience, the use of class teaching, and deficient work experience while still at school. The facilitators of employment were one's own activity, the support of one's family, job coaching, a well-designed work environment, appreciation of one's work, support form one's employer and work organization, knowledge and experience of employment during secondary education, and for entrepreneurs, the use of a support person.

Conclusions: The employment of people with ID can be improved through secondary education including proper teaching methods and personal support services, the use of supported work, workplace accommodations and support from one's family and employer. These results can be utilized in the development of rehabilitation, education, and the employment of people with ID, to allow them the opportunity to work in the open labor market and participate in society.
Title: The home environments and occupational engagement of people with intellectual disabilities in supported living.

Citation: British Journal of Occupational Therapy; Nov 2019; vol. 82 (no. 11); p. 698-709
Author(s): Ashley, Danielle; Fossey, Ellie; Bigby, Christine

Introduction: Social inclusion for people with intellectual disabilities includes engagement in the occupations of daily life. Given the focus on people with intellectual disabilities living independently with support, identifying the qualities of their home environments is integral to understanding the possibilities for engagement in occupations of daily life and better quality of life outcomes. In turn, this can inform the types of person-centred supports, such as active support, necessary to enable increased engagement for people with intellectual disabilities.

Method: A case study methodology and mixed methods were utilised to develop an in-depth understanding of the home environments of six people with intellectual disabilities in supported living, and their experience of how these environments impacted their occupational engagement both at home and in their community. Semi-structured interviews and observation of participants' home environments, using the Residential Environment Impact Survey – Short Form, were completed.

Findings: Participants valued the opportunity to be self-reliant and live in their own homes. They had adequate means to engage in basic daily activities; however, their homes lacked expression of their occupational identity, and they had minimal occupational opportunities and demands, resulting in limited occupational engagement.

Conclusion: For people with intellectual disabilities, it is important to increase opportunities for participation in valued occupations that foster social identities, and to provide adequate environmental supports and demands, to enable sustained occupational engagement and social inclusion.

Title: Do people with intellectual disabilities understand their prescription medication? A scoping review.

Citation: Journal of applied research in intellectual disabilities : JARID; Nov 2019; vol. 32 (no. 6); p. 1375-1388
Author(s): Smith, Megan V A; Adams, Danielle; Carr, Claudia; Mengoni, Silvana E

Background: People with intellectual disabilities are more likely to experience poor health than the general population and are frequently prescribed multiple medications. Therefore, it is important that people with intellectual disabilities understand their medication and potential adverse effects.

Method: A scoping review explored people with intellectual disabilities' knowledge of prescription medications, their risks and how medication understanding can be improved.

Results: Ten journal articles were included. People with intellectual disabilities often lacked understanding of their medication, including its name, purpose and when and how to take it. Participants were often confused or unaware of adverse effects associated with their medication. Information was sometimes explained to carers rather than people with intellectual disabilities. Some interventions and accessible information helped to improve knowledge in people with intellectual disabilities.

Conclusion: There is a need for accessible and tailored information about medication to be discussed with people with intellectual disabilities in order to meet legal and best practice standards.

Title: Therapeutic effects of methylphenidate for attention-deficit/hyperactivity disorder in children with borderline intellectual functioning or intellectual disability: A systematic review and meta-analysis.

Citation: Scientific reports; Nov 2019; vol. 9 (no. 1); p. 15908
**Author(s):** Sun, Cheuk-Kwan; Tseng, Ping-Tao; Wu, Ching-Kuan; Li, Dian-Jeng; Chen, Tien-Yu; Stubbs, Brendon; Carvalho, Andre F; Chen, Yen-Wen; Lin, Pao-Yen; Cheng, Yu-Shian; Wu, Ming-Kung

**Abstract:** Attention-deficit/hyperactivity disorder (ADHD) frequently co-occurs with intellectual disability in children, and may further compromise learning. Methylphenidate is a first-line treatment for ADHD, however no previous meta-analysis has evaluated its overall efficacy for ADHD in children with comorbid intellectual disability (ID) or borderline intellectual functioning. The PubMed/MEDLINE, Cochrane CENTRAL and ScienceDirect databases were systematically searched from inception through 2018/7/15 for clinical studies that investigated the effects of methylphenidate in children with ADHD and ID. A random-effects model meta-analysis was used for data synthesis. Eight studies (average Jadad score = 2.5) enrolling 242 participants receiving methylphenidate and 181 participants receiving placebo were included. The meta-analysis showed that methylphenidate led to a significant improvement in ADHD symptoms relative to placebo (Hedges’ g = 0.878, p < 0.001). Meta-regression analysis pointed to an association between the dose of methylphenidate and overall improvement in ADHD severity (slope = 1.334, p < 0.001). Finally, there was no significant difference in drop-out rate (odds ratio (OR) = 1.679, p = 0.260) or rate of treatment discontinuation due to adverse events (OR = 4.815, p = 0.053) between subjects receiving methylphenidate and those taking placebos. Our study suggests that methylphenidate retains its efficacy in children with ADHD and borderline intellectual functioning or ID.

**Title:** Impairment of cognitive memory inhibition in individuals with intellectual disability: A meta-analysis.

**Citation:** Psicothema; Nov 2019; vol. 31 (no. 4); p. 384-392

**Author(s):** Palomino, Elena; López-Frutos, José M; Botella, Juan; Sotillo, María

**Background:** Cognitive inhibition impairment is intimately related to the forgetfulness of relevant information. This meta-analysis aims to synthesise the evidence of impaired function of cognitive inhibition processes over memory in individuals with intellectual disability (ID).

**Method:** Eleven studies were selected and analysed and included a total of 683 participants. The studies were categorised according to variables such as the task used, the processes involved, the sensory modalities and the method.

**Results:** Despite the small sample of studies, the results revealed significant difficulties with cognitive memory inhibition (CMI) tasks in individuals with ID compared with typical development (TD) individuals (d = 0.62). CMI problems were found in all life stages except the 19-45-year-old stage. In this stage, there was a smaller amount of evidence even though it included the 31-40-year-old range, during which premature aging has been observed in ID.

**Conclusions:** An impairment of CMI in people with ID was observed. More studies are needed to more reliably assess the potential moderating role of age and other factors.

**Title:** Prescription of pain medication among older cancer patients with and without an intellectual disability: a national register study.

**Citation:** BMC cancer; Nov 2019; vol. 19 (no. 1); p. 1040

**Author(s):** Segerlantz, Mikael; Axmon, Anna; Gagnemo Persson, Rebecca; Brun, Eva; Ahlström, Gerd

**Background:** The longevity for people with intellectual disability (ID) has significantly increased in developed countries during the past decades. Consequently, the incidence of cancer is expected to increase in this group. The aim of the present study was to investigate the prescription of pain medication in older cancer patients with intellectual disability (ID) compared to older patients in the general population, surviving or living with a cancer diagnosis.
Methods: This Swedish national registry-based study, included people with ID aged 55 years or older in 2012, and alive at the end of that year (ID cohort, n = 7936). For comparisons, we used a referent cohort, one-to-one matched with the general population by year of birth and sex (gPop cohort, n = 7936). People with at least one diagnosis of cancer during 2002-2012 were identified using the Swedish National Patient Register, resulting in 555 cancer patients with ID and 877 cancer patients from the general population. These two cohorts of cancer patients were compared with respect to prescription of pain medication for the period 2006-2012. Outcome data were aggregated so that each patient was categorized as either having or not having at least one prescription of each investigated drug group during the study period, and relative risks (RRs) for prescription were estimated for prescription in the ID cohort vs the gPop cohort.

RESULTS: Cancer patients with ID were less likely than cancer patients in the gPop cohort to have at least one prescription of COX inhibitors (RR 0.61) and weak opioids (RR 0.63). They were, however, more likely to be prescribed paracetamol (RR 1.16), antidepressants (RR 2.09), anxiolytics (RR 2.84), and "other hypnotics, sedatives, and neuroleptics" (RR 1.39). No statistically significant differences between the two cohorts were found for strong opioids, antiepileptics, tricyclic antidepressants, or hypnotics and sedatives.

Conclusion: In the studied cohort of older people surviving or living with cancer, prescriptions for pain-treatment was less common in patients with ID compared to the general population. These results may suggest that pain is not sufficiently treated among cancer patients with ID, a situation that most likely would compromise the quality of life in this group.

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Title: "Horrific" treatment of children with learning disabilities must be ended, say MPs and peers

Citation: BMJ : British Medical Journal (Online); Nov 2019; vol. 367

Author(s): Adrian O'Dowd

Abstract: Treatment of young people with learning disabilities or autism in mental health hospitals is so bad that their human rights are being breached, claim MPs and peers. A highly critical inquiry report by the parliamentary Joint Committee on Human Rights published on 1 November condemned the "horrific reality" of the conditions under which many young people were detained in mental health hospitals. Evidence to the inquiry had been so "stark" and consistent that the committee said it had lost confidence that the system was doing what it claimed to and feared that the regulator the Care Quality Commission was failing in its methods of checking. The creation of legal duties on clinical commissioning groups and local authorities to ensure that the right services are available A narrowing of the Mental Health Act criteria to avoid inappropriate detention, and Substantial reform of the CQC's approach and processes, including unannounced inspections at weekends and late evenings and possible use of covert surveillance methods.

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Title: Mental health services: CQC warns of "perfect storm"

Citation: BMJ : British Medical Journal (Online); Oct 2019; vol. 367

Author(s): Iacobucci, Gareth

Abstract: A shortage of skilled staff, coupled with rising demand, has created a "perfect storm" for patients using mental health and learning disability services, England's healthcare regulator has warned. In its annual State of Care report for 2018-19, the Care Quality Commission said that although quality ratings across health and social care—including community mental health services—had been maintained overall, this masked "a real deterioration" in some specialist inpatient services over the past 12 months. As at 30 September 2019 the CQC reported that: 10% of inpatient services for people with learning disabilities or autism were rated inadequate, up from 1% in 2018 7% of child and adolescent inpatient mental health services were inadequate (3% in 2018), and 8% of acute care wards for adults of working age and psychiatric intensive care units were inadequate (2% in 2018). The report said that the "shocking abuse" uncovered by the BBC at Whorlton Hall in County Durham
had put the issue of inpatient care in secure facilities into sharp focus.2 The CQC said that since October 2018 it had rated 14 independent mental health hospitals that admit people with a learning disability or autism as inadequate and put them into special measures.

Title: Impact of mentoring on socio-emotional and mental health outcomes of youth with learning disabilities and attention-deficit hyperactivity disorder.

Citation: Child & Adolescent Mental Health; Nov 2019; vol. 24 (no. 4); p. 318-328
Author(s): Haft, Stephanie L.; Chen, Tiffany; LeBlanc, Chloë; Tencza, Francesca; Hoeft, Fumiko

Background: Learning disabilities (LD) and attention-deficit hyperactivity disorder (ADHD) are often accompanied by significant socio-emotional impairments and mental health challenges. However, there is a lack of controlled, quantitative research on potential interventions to address this issue. The current study evaluated the impact of a near-peer mentoring program for youth with LD/ADHD designed to promote socio-emotional well-being.

Methods: Youth with LD/ADHD who participated in the mentoring program (Mentored; n = 99) were compared to both nonmentored youth with LD/ADHD (Control-NM; n = 51) and typically developing youth without LD/ADHD (Control-TD; n = 81) prementoring in the fall and postmentoring in the spring. Participants were assessed using self-report measures of anxiety, depression, interpersonal relations, and self-esteem.

Results: Youth with LD/ADHD showed significantly higher scores of depression and significantly lower scores of interpersonal relations compared to the Control-TD group at fall baseline. The depression and self-esteem scores of the Mentored group significantly decreased and increased, respectively, after mentoring. These changes were associated with mentee-perceived mentorship quality. The Control-NM group showed significant decreases in both self-esteem and interpersonal relations, as well as increases in depression over time, while the Control-TD group remained stable across all measures.

Conclusions: Results suggest that mentoring shows promise as a potential intervention for youth with LD/ADHD who experience co-occurring socio-emotional and mental health difficulties. The study is the first, to our knowledge, to quantify the effect of a near-peer mentoring program on youth with LD/ADHD in a design with two control groups. Implications for research and practice involving LD, ADHD, and mental health disorders are discussed. Key Practitioner Message LD and ADHD are associated with increased anxiety, depression, and impaired self-esteem and interpersonal relationships. There is a lack of research on interventions that could address the mental health problems and socio-emotional difficulties that co-occur with learning disabilities and ADHD. Near-peer mentoring is a promising intervention that can improve socio-emotional well-being and mental health in youth with learning disabilities and ADHD, and highlights the importance of strong interpersonal relationships as a protective factor.

Title: Learning disabilities: making reasonable adjustments in hospital.

Citation: Nursing Times; Oct 2019; vol. 115 (no. 10); p. 38-42
Author(s): Phillips, Linda

Abstract: Being in hospital can be difficult for anybody, but it is particularly challenging for people who have a learning disability. Compared with the general population, this patient group is more likely to need and use health services, and is also more likely to have a poorer experience of care and poorer health outcomes (including avoidable death). Reasonable adjustments (which do not need to be costly) to the hospital care of people with learning disabilities are not only feasible and a statutory duty under the Equality Act 2010, but are also beneficial for all involved - and, first and foremost, for the person who has the learning disability. This article gives tried-and-tested examples of reasonable adjustments that can be made in hospital and features two case studies that clearly demonstrate the benefits of reasonable adjustments.
Sources Used:

The following databases are used in the creation of this bulletin: BNI, CINAHL, Medline & PsycINFO.

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