Supplementary Material

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| **Supplementary Table 1: Papers excluded and the associated rationale to avoid double-counting** | | | | | | | | | |
| **Study No.** | **Authors** | **Year** | **Country of Study** | **Research Theme** | **Study Design** | **Duplicate Participants?** | **Included in Outcome Synthesis?** | **Why excluded?** | |
| 50 | Alexander, Crouch, Halstead & Piachaud | 2006 | UK | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Yes | Yes | Extends data collected in Halstead et al. (1999) from 6 years to 12yrs | |
| 51 | Alexander, Hiremath, Chester, Green, Gunaratna & Hoare | 2011 | UK | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Yes | Yes | Reports on entire sample from service used in Alexander et al. 2010 (the 2010 paper look at ID & PD diagnosis only) | |
| 58 | Allely | 2018 | UK | Studies of adults with ID in forensic/secure services | Systematic Review | Yes | No | All studies already included from our search findings | |
| 7 | Burge, Ouellette-Kuntz et al. | 2002 | Canada | Studies of adults with ID in GMH | Retrospective Casenote/ Chart Review | Yes | Yes | Compares the samples from Saeed et al. to a further sample | |
| 63 | Cervantes, Kuriakose, Donnelley et al. | 2019 | US | Studies of CYP with ID/autism in inpatient services | Retrospective Casenote/ Chart Review | Yes | Yes | Follows up an additional time period from Kuriakose, Filton, Marr et al. (2018) | |
| 13 | Chaplin | 2004 | UK | Studies of adults with ID in GMH | Literature Review | Yes | No | All studies already included from our search findings | |
| 14 | Chaplin | 2009 | UK | Studies of adults with ID in GMH | Literature Review | Yes | No | All studies already included from our search findings | |
| 97 | Chowdhury and Benson | 2011 | US | Studies of adult with ID in specialist ID units/services | Literature Review | Yes | Yes | Not all papers included in our search findings | |
| 61 | Esan, Chester, Gunaratna, Hoare & Alexander | 2014 | UK | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Yes | Yes | Although duplicates from Alexander et al. 2010 reports specifically on autistic patient outcomes | |
| 70 | Glover, Brown & Hatton | 2014 | UK | Studies of adult with ID in specialist ID units/services | Audit/Case Register/ Census Data | Not clear | Yes | Likely includes the ppts from UK studies during this census period but compares as entire inpatient sample across 2010 & 13 (most UK studies cross-sectional) | |
| 74 | Hatton | 2016 | UK | Studies of adult with ID in specialist ID units/services | Audit/Case Register/ Census Data | Not clear | Yes | Contains data from Glover et al. (2014) but adds further comparisons by data and location | |
| 92 | Huitema, Verstegen & de Vogel | 2021 | The Netherlands | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Not clear | Yes | Contains same sample from Verstegen et al (2020) but reports additional outcome measure | |
| 40 | Iversen, Horndalsveen, Matre, Henriksen, Fusche, Kildah & Bakken | 2019 | Norway | Studies of adult with ID in specialist ID units/services | Mixed Methods | Yes | Yes | Although duplicate ppts from Bakken & Hodden 2018 reports specifically on those a borderline PD diagnosis | |
| 79 | Kalb, Stuart & Vasa | 2018 | US | Studies of CYP with ID/autism in inpatient services | Audit/Case Register/ Census Data | Not clear | Yes | Likely includes the ppts from US studies during the study period but explored autism specific admission expenditure | |
| 72 | Keown, Mercer & Scott | 2008 | UK | Studies of adults with ID in GMH | Audit/Case Register/ Census Data | Not clear | Yes | Likely includes the ppts from UK studies during the study period but explored voluntary vs. involuntary admissions specifically | |
| 26 | Lunsky, Bradley, Durbin & Koegl | 2008 | Canada | Studies of adult with ID in specialist ID units/services | Cross-Sectional Study Design | Yes | Yes | Further explores sample in Lunsky et al. 2006 comparing specialist ID programme admissions to GMH programme admissions | |
| 59 | Lunsky, Gracey & Bradley | 2009 | Canada | Studies of adult with ID in specialist ID units/services | Retrospective Casenote/Chart Review | Yes | Yes | Although duplicate ppts from Lunsky et al. 2006 reports specifically on those with autism | |
| 4 | Lunsky, Gracey, Koegl, Bradley, Durbin & Raina | 2011 | Canada | Studies of adults with ID in GMH | Cross-Sectional Study Design | Yes | Yes | Although duplicate ppts from Lunsky et al. 2006 reports specifically on those with forensic involvement (and a non-forensic comparison sample) | |
| 17 | Perera, Simpson, Douds & Campbell | 2009 | Scotland | Studies of adult with ID in specialist ID units/services | Cross-Sectional Study Design | Not clear | Yes | Likely contains some ppts from Lyall et al. (2007) but a wider sample (all Scotland, not just Lothian) | |
| 73 | Prichard, Palucka, Reid & Lunsky | 2007 | Canada | Studies of adult with ID in specialist ID units/services | Retrospective Casenote/ Chart Review | Yes | Yes | Although duplicate ppts from Lunsky et al. 2006 + 2009 compares inpatient & outpatient outcomes for ppts with autism | |
| 102 | Senn, Bulten, Tomlin and Völlm | 2020 | UK & The Netherlands | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Yes | Yes | Contains sample from Chester et al. (2018) but also reports Dutch sample |
| 4 | Verstegen, de Vogel, Huitema, Didden and Nijman | 2020 | The Netherlands | Studies of adults with ID in forensic/secure services | Retrospective Casenote/ Chart Review | Yes | Yes | Contains some ppt from Senn et al. (2020) but reports larger Dutch sample | |
| 76 | Vollm, Edworthy, Huband, Talbot, Majid et al. | 2018 | UK | Studies of adults with ID in forensic/secure services | Mixed Methods | Yes | Yes | Same sample as Chester et al. (2018) but reports additional outcome measure (admissions) | |
| 106 | Lunsky & Balogh | 2010 | Canada | Studies of adults with ID in GMH | Retrospective Casenote/ Chart Review | Yes | Yes | Contains ppts from other Canadian papers but also includes wider (pan-Canada) data than previous Lunsky, White, Kokoski, Palucka, Pritchard, etc. papers | |

**Supplementary Table 2:** Studies that met eligibility criteria organised by sample recruited (children and adolescents or adults) and type of inpatient service.

| **Study & Country** | **Design** | **N** | **Sample** | **Domain Outcomes** | **Findings** |
| --- | --- | --- | --- | --- | --- |
| Adults with intellectual and developmental disabilities (including autism) in general inpatient mental health or specialist intellectual disability services | | | | | |
| Alexander, Piachaud & Singh (2001), UK. | Retrospective case note study | N=56   * Intellectual disability beds within a general psychiatric ward (32) * Purpose-built intellectual disability unit (24) | Admissions to all inpatient facilities in two London districts.  Intellectual disability beds within general ward  59% male  Mean age = 33yrs  16% borderline intellectual disability  53% mild intellectual disability  28% moderate intellectual disability  3% severe intellectual disability  19% detained under Mental Health Act  Purpose built unit  63% male  Mean age = 30yrs  8% borderline intellectual disability  63% mild intellectual disability  0% moderate intellectual disability  29% severe intellectual disability  25% detained under Mental Health Act | *Measure of effectiveness:*   * Length of stay * Readmission | * Median length of stay was longer for the purpose-built unit (194 days) than for patients admitted to intellectual disability beds within a general psychiatric ward (32 days). * 6 readmissions to the purpose build intellectual disability unit during the study period (accounted for by 4 individuals) * 7 readmissions to the general ward during the study period (accounted for by 5 people). |
| Ashaye, ~~Mathew~~ & Dhadphale (1997), UK~~.~~ | Cross sectional comparative study | N=89   * Longstay (>1yr) sample with intellectual disabilities (40) * Longstay elderly sample with intellectual disabilities (23) * Elderly psychiatric sample without intellectual disabilities (26) | Individuals within an intellectual disability hospital and a comparison group from a general psychiatric service.    Longstay patients with intellectual disabilities  Patients in intellectual disability hospital aged between 50-65yrs (*M* = 55yrs).  55% male  80% moderate to severe ID  Elderly longstay patients with intellectual disabilities  Patients aged >65+yrs in same intellectual disability hospital (*M* = 71yrs).  43.4% male  Elderly psychiatric patients without intellectual disabilities  Patients aged >65+yrs (*M* = 78yrs) in longstay wards of old age psychiatric service.  50% male | *Measures of effectiveness*   * Length of stay * Health of the Nation Outcome Scales (HoNOS) 105 | * Mean length of stay for longstay intellectual disability patients was 38.5yrs (range =12-58yrs) compared to 46.6yrs (range = 19-61) for elderly longstay intellectual disability patients and 27.3yrs (range = 1-69yrs) for elderly longstay psychiatric patients. * No significant difference found between the intellectual disability groups for depressed mood scale of HoNOS 105, however the elderly psychiatric group had significantly more problems than the elderly intellectual disability group with depressed mood. * Elderly psychiatric patients had significantly more problems with relationships than the elderly intellectual disability group, as measured by the HoNOS 105. * No differences found in problems with relationships between the two intellectual disability groups. * The elderly psychiatric group had significantly more problems with occupation and activities as measured by the HoNOS 105. |
| Axmon, Bjӧrne, Nylander & Ahlstrӧm (2016), Sweden. | Cross Section Cohort Study | N=7936 (entire intellectual disability cohort)   * Individuals with one registration (1558) * Individuals with at least one inpatient registration (573) | All psychiatric registrations on Swedish National Patient register between 2002-2012 for older (55yrs+) individuals with intellectual disabilities.  Age and sex matched comparison cohort from the general population.  Each cohort:  Mean age at start of study period=53yrs (range=45-85yrs)  Mean age at end of study period=64yrs (range=55-96yrs)  55% male | *Measures of effectiveness*   * Length of stay * Admissions | * People with intellectual disabilities had longer inpatient stays compared to the general population (median intellectual disability cohort length of inpatient stay = 12 days , range=1-66; median general population cohort length of inpatient stay = 8 , range=1-45; p=0.002) and spent more days as an inpatient during the study period than inpatients in the general population (median intellectual disability cohort no. of inpatient days = 23, range=2-302; median general population cohort no. of inpatient days = 21, range=1-167; p=0.062). * Individuals with intellectual disabilities living within ‘special housing’ had shorter inpatient stays. * 7.2% of the intellectual disability had at least one inpatient stay compared to 2.4% of the general population, however there was no significant different between the number of inpatient registrations between the two cohorts (median intellectual disability cohort no. of inpatient stays = 2, range=1-12; median general population cohort no. of inpatient stays = 2, range=1-13; p=0.71). * Individuals with intellectual disabilities were 3-4 times more likely to have one psychiatric registration compared to the general population (OR=3.59, 95% CI 3.23-4.00) |
| Bakken & Hoidat (2019), Norway~~.~~ | Retrospective case note review | N=133   * Inpatients (106) * Outpatients (27) | Discharges from specialist psychiatric unit (inpatient and outpatient) for adults with ID in Norway between 2010 and 2016.  Entire Sample:  Mean age = 30.8yrs (SD=11.3)  51.1% male  18% no ID, but ASD diagnosis  46.6% mild ID  17.3% moderate ID  9% severe ID  1.5% profound ID  7.5% unspecified  47.4% ASD  Inpatient Sample:  50.9% male  17% no ID  50% mild ID  17.9% moderate ID  11.3% severe ID  1.9% profound ID  7.5% unspecified  46.2% ASD  38.6% detained involuntarily at admission  Outpatient Sample:  51.8% male  25.9% no ID  33.3% mild ID  14.8% moderate ID  22.2% severe ID  0% profound ID  3.7% unspecified  51.9% ASD | *Measure of effectiveness*   * Length of stay   *Measure of patient safety*   * Use of seclusion * Use of physical intervention | * For inpatients average length of stay was 9.1 months (SD=8.3), with an additional average 11.2 months (SD=9.5) follow up, making an average service length of 20.3 months (SD=10.3), ranging from 2-67 months. * Of those admitted as inpatients, 50.9% utilised seclusion and 45.3% required physical intervention. * Outpatients had an average admission (service length contact) of 9.3 months (SD=6.5). |
| Beckman et al. (2020), USA. | Qualitative analysis of Newsletters. | N=37 issues | Newsletters produced by patients of the Dual Diagnosis Unit, a residential unit for people with diagnoses of developmental disability and serious mental illness in the Central State Hospital (Indiana, USA) between September 1988 and June 1992. | *Measures of Patient Experience*  Patients’ narratives of psychiatric hospitalization | * Common topics that appear in many newspaper stories include food served at the hospital, special events and outings, and relationships with other patients or hospital e.g. “*We appreciate the ones who are detailed and work overtime on our ward. We like our attendants too because they take care of us and treat us like people*” (Charles J. and John L. 1989), p). Patients had special appreciation for staff members who went “above and beyond” to create a festive atmosphere and provide tasty meals. * “Good behaviour” was a pervasive theme. Access to good food, increased freedoms, including the ability to leave the hospital for outings or family visits were all seen as rewards for good behaviour. “*When you go to all your activities, you get on step 4. I did and I got more money. I didn’t go to all my activities one day and I got back on step 3. I get more money on step 4. And I get to go home more days on step 4.*” (Jeffrey S. 1988). * Analysis of the articles illustrated what actions constituted poor behaviour, such as “*fighting, stealing, arguing, fussing and patients, bossing other patients*” (Sam C. 1988b). Some patients wrote about when they had engaged in “bad” behaviour, such as fighting with staff or striking another patient: “*I wasn’t good last night. I was acting real bad*” (Linda S. 1989). The newsletters provided patients with a forum to publicly take stock of their “bad behaviour” and commit to behavioural change: “*The first thing I’m going to do is make sure I take my medicine and my shower when it is due. I want to do good and I want people to know me for what I can do instead of what I used to be*” (Kenneth S. 1989) |
| Burge, Ouellette-Kuntz, Saeed, McCreary, Paquette & Sim (2002), Canada. | Retrospective chart review | N= 101   * admissions with intellectual disabilities (62 individuals) * Comparison group without intellectual disabilities. | Admissions of individuals with intellectual disabilities from two acute care psychiatric units over a four-year period.  50% male  59.7% mild intellectual disability  8.1% moderate intellectual disability  1.6% profound intellectual disability  30.6% unspecified | *Measures of effectiveness*   * Length of stay * Readmissions   *Measures of patient safety*   * Use of PRN medication | * Admissions with intellectual disabilities were generally younger and more likely to end with discharge to another service provider compared to admissions without intellectual disabilities. * Median length of stay did not differ significantly between those with intellectual disabilities and those without (8 days compared to 9 respectively). * Male patients with intellectual disabilities were significantly more likely to stay longer than females with intellectual disabilities. * 29% of individuals with intellectual disabilities were readmitted during the study period and a negative correlation was found between length of stay and number of admissions. * 39.6% of admissions with intellectual disabilities received PRN medication during admission. |
| Chaplin (2004), UK. | Literature review | N=27 studies | Database search in the areas of inpatient care, day-hospital care and home treatment and intellectual disability.  Studies meeting specific inclusion criteria were included in the review. | *Measures of effectiveness*   * Length of stay * Admissions | * Most studies found within the review reported shorter lengths of stay for those with intellectual disabilities in general rather than specialist beds. * Some evidence to suggest those with milder intellectual disabilities use general services and those with more severe intellectual disabilities use specialist services. * Suggested that new specialist services appear to give a better outcome than previous general services, but overall dearth of evidence in this area. * The studies found provide conflicting evidence regarding the outcomes of individuals with intellectual disabilities compared to those without intellectual disabilities using general services. |
| Chaplin (2009), UK. | Literature review | N=28 studies | Updated database search in the areas of inpatient care, day-hospital care and home treatment and intellectual disability.  Studies meeting specific inclusion criteria were included in the review. | *Measures of effectiveness*   * Length of stay * Admissions   *Measures of patient safety*   * Use of seclusions * Use of physical intervention * Observation levels * Incidents of aggression | * Three studies in the review showed individuals with intellectual disabilities stayed longer on specialised units than general psychiatric ones, and one study showed that they also stayed longer on specialised units than individuals without intellectual disabilities on general units. * Mixed findings were shown regarding length of stay comparisons for those with intellectual disabilities on general units compared to those without intellectual disabilities on general units. * Some of the studies in the review found individuals with intellectual disabilities in general psychiatric wards to be more likely to display aggression, be detained under the Mental Health Act, receive seclusion or restraint or require 1:1 nursing, however showed lower levels of substance misuse. * One study showed similar rates of detention under the Mental Health Act for individuals with intellectual disabilities in specialist units and those in general units. |
| Chinn, Hall, Ali et al. (2011), UK. | Qualitative Study – semi-structured interviews | N=17 | Service users originating from three  east London boroughs living in specialist intellectual disability psychiatric in-patient facilities outside their home boroughs (mean distance from home = 49 miles).  Mean Age = 34yrs (range=17-52yrs)  76.5% male  80% mild intellectual disability  35.3% forensic section  35.3% civil section  29.4% voluntary admission | *Measures of Patient Experience*   * Service user views/ evaluation of service | * Themes identified from the interview data included: Punitive versus therapeutic treatment; Discomforting environments; Demeaning versus supportive staff relationships; Power and hierarchies; Group versus individualised placements; Far from home and family and indicate that service users experience their time as in-patients marked by lack of control, periods of inactivity, limited access to information and opportunities to participate in decision making. * Findings supports the need for specialist services to be provided locally, highlighting how placement far from home can sever individuals from their families and support networks as well as their home environments which reinforce and support their cultural, religious and ethnic identities and practices. |
| Chowdhury and Benson, (2011), USA | Literature review | N=15 studies  1,238 participants | Literature search of studies 1980–2009 assessing Quality of Life (as an outcome measure) following deinstitutionalisation or relocation/discharge to the community from inpatient services for individuals with intellectual disabilities.  Studies meeting specific inclusion criteria were included in the review.  Age = 18 to 61 years[[1]](#footnote-2) | *Measures of Patient Experience*  Assessments of Quality of Life. | * Studies were largely consistent in finding positive changes in quality of life after relocation to homes in the community. * Compared with institutions, studies identified that participants had increased opportunities of choice, greater involvement in a variety of leisure activities, increased interaction with staff and other residents, increased participation in outings, improvements in material well-being, and increased levels of dignity. * Improvements were most prominent in the first 6 months to 1 year after relocation the plateaued or declined. * Studies identified in the review (n=5) reported no difference in levels of community participation and access between institution and community assessments. * The review reported some evidence suggesting that healthcare needs might not be met as satisfactorily in the community as in institutions. * Limitations of the review included lack of use of standardized measures of quality of life, with the majority of studies using proxy ratings of quality of life. |
| Davies, Josham & Francis (2020), UK. |  | N=27 | Admissions and discharges from specialist intellectual disability assessment and treatment unit between June 2018 and October 2019.  77.7% male  77.7% mild ID  11.1% moderate ID  11.1% severe ID | *Measures of Effectiveness*   * The Behaviour Problems Inventory (BPI) * Psychiatric Assessment Scale for Adults with Developmental Disabilities Checklist–Revised (PASSAD)   *Measures of Patient Experience*  Quality of Life Scale (WHO-QOL 8) adapted for people with intellectual disabilities. | * Significant improvements were noticed on all the measures after admission. * Significant increase in score on WHO-QOL following discharge (Admission mean score=25.35, median=25.5; discharge mean score=32.35, median=33.5; t=-4.6, p=<0.01), indicating improvements in quality of life. * Significant decreases on all scales of the BPI and the PASSAD, indicating improvements in behaviours that challenge and mental health difficulties following admission. |
| Di Lorenzo, Olmi, Riolo, Galeazzi & Ferri (2019), Italy. | Retrospective case note review | N=106   * inpatient stay <29 days (83) * inpatient stay >29 days (23) | All patients admitted to a 12-bedded Italian Psychiatric Intensive Treatment Facility (PITF) between 2016 and 2017.  48% male  Mean age (entire sample) = 46.35yrs (SD=14.98) | *Measures of effectiveness*   * Length of stay | * 2% (n=3) of all stays had diagnosis of ID on discharge (compared to 34% schizophrenia, 25% dysthymia, anxiety & attachment disorders, 14% bipolar disorders, 10% personality disorders, 2% substances misuse and 13% organic psychosis). * All of those with an ID diagnosis stayed less than 29 days, constituting 3% of all <29-day admissions (compared to 35% schizophrenia, 25% dysthymia, anxiety & attachment disorders, 13% bipolar disorders, 9% personality disorders, 3% substances misuse and 12% organic psychosis). * None of those with an intellectual disability at discharge stayed longer than 29 days (compared to 33% schizophrenia, 24% dysthymia, anxiety & attachment disorders, 8% bipolar disorders, 16% personality disorders, 0% substances misuse and 20% organic psychosis). |
| Gomez-Ramiro, Fico, Anmella, V´azquez , Sagu´e-Vilavella et al. (2021) Spain | Retrospective case register analysis | N=1,958   * 44 intellectual disability admissions18 autism spectrum disorder admissions | Adult emergency psychiatric admissions to a large Spanish hospital before (Dec 2019-March 2020) and during the first three of months of the COVID lockdown (March 2020-June 2020).  Mean Age = 41.31yrs (sd=16.44)  52.75% male  4.4% intellectual disability  2.2% autism spectrum disorder | *Measures of Effectiveness*  Admission figures | * A significant decrease in all psychiatric emergency admissions during the first three months of the COVID lockdown compared to the three months before (37.9% decrease, 95% CI=0.377–0.558; p<0.01). * Statistically significant increase in admissions for autism spectrum disorders (0.3%, N=4 before lockdown, 1.9%, N=14, during lockdown, χ2(1)=11.98, 95% CI 0.11-0.31, p<0.001), substance use disorders (12.3%, N=149 before lockdown, 15.5%, N=115, during lockdown, χ2(1)=3.88, 95% CI =0.126-0.181, p<0.001), and dementia (0.05%, N=6 before lockdown, 1.5%, N=11, during lockdown, χ2(1)=3.97, 95% CI 0.007-0.024, p<0.001). * No significant difference in intellectual disability admissions before (2.5%, N=30) or during (1.9%, N=14) the first three months of lockdown * Significant increase in the number of acute psychiatric hospitalisations for all diagnoses during the first three months of lockdown (23.5%, N=284, before lockdown, 34.4%, n=258, during lockdown χ2(1)=27.41, 95% CI 0.310-0.394, p<0.001). |
| Ganguly, Gore, Marston & Roy (2009), UK, England. | Retrospective analysis of admissions. |  | All admissions to large intellectual disability hospital (April 2003-March 2006) compared to data from 1975-7, 1985-7 and 1995-7 from the same hospital. | *Measure of effectiveness*   * Admissions | * Progressive increase in formal admissions and decrease in formal ones. * Increase in in admissions form hostels or group homes increased threefold and admissions from home decreased. * Longstay admissions decreased during second and fourth periods (reductions between 1975-7 and 1985-7 and between 1995-7 and 2003-6) and increases in the third period (between 1985-7 and 1995-7). * Percentage of first admissions gradually increased and percentage of re-admissions decreased over the four time periods. |
| Glover, Brown & Hatton (2014), UK, England. | Comparison of census data | * 3,250 inpatients (2013 census) * 5,001 inpatients (2010 census) | 2013 census covered all patients in in-patient psychiatric care in a bed designated for the care of individuals with ID/ASD spectrum disorders, or identified as having ID/ASD spectrum disorders, in England on Sept 30th.  2010 census covered all patients in inpatient psychiatric beds in England and Wales on March 31st. | *Measure of effectiveness*   * Admission and/or discharge figures | * 35% reduction in inpatients (2010 census = 5,001 vs. 2013 census = 3,250). * Greater reductions in seen in open wards (-48%) compared to secure beds (low: -23%, medium & high: -9%), for female patients than male patients (-46% vs. -30%), in NHS (-47%) rather than private sector beds (-11%) and for those with very short (<3months) (-38%) or very long (>5yrs) stays (-69%). * Data reflected a greater reduction in mental health wards compared to intellectual disability wards (60% vs 27%) but could be reflective of incomplete data (see Glover *et al*., 2014, p148 for discussion). |
| Gowda, Gopika, Kumar Manjunatha, Yadav, Srinivas, Dawn & Math (2017), India. | Retrospective chart review | N=78   * Admissions with intellectual disabilities (24) * Admissions without intellectual disabilities (55) | Patients admitted as Homeless Mentally Ill (HMI) from 1st January 2002 to 31st December 2015 to the Department of Psychiatry at National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore.  46.2% male  Mean age=34.6yrs (SD=12.21) | *Measures of effectiveness*   * Length of stay * Clinical Global Impression Scale (CGI) for Severity and Global Improvement 101 * Discharge Pathway   (Social re-integration characterised as discharge back to family) | * Mean duration of inpatient care for all admission was 15 weeks. * 24 (30.8%) admissions had intellectual disabilities. * Mean Clinical Global Impression severity at admission for all patients was 5.07 (SD=1.7). * Logistic regression showed that intellectual disability was negatively correlated with family reintegration (B=-2.204, P=0.002). |
| Gustafsson & Sonnander (2004), Sweden. | Review of mental health care register | N=172   * In-patient services (47) * Outpatients (125) | Patients with intellectual disabilities receiving in- and out-patient psychiatric care at general mental health clinics in a county in one medium-sized Swedish county.  Inpatient group  71% mild intellectual disability (2000)  76% mild intellectual disability (2001)  Outpatient group  89% mild intellectual disability (2000)  90% mild intellectual disability (2001) | *Measure of effectiveness*   * Admission (registration) and/or discharge figures | * 1.7% (27) of adults registered for inpatient psychiatric care in 2000 had intellectual disabilities and 1.2% (20) in 2001. * In both 2000 and 2001 approximately 1% of individuals of adults consulting a psychiatrist at an outpatient mental health clinic had an ICD-10 diagnosis of intellectual disability (61 and 64 respectively). * Among adults referred to the mental health services (both in- and outpatients) the majority had mild or moderate intellectual disability and suffered from psychotic or affective disorders. |
| Gustafsson (1997), Sweden. | Retrospective case note review from Health Register | N=52   * Inpatients (36) * Outpatients (16) | Adults with intellectual disabilities receiving specialist services and admitted to inpatient psychiatric care between 1985 and 1990.  Inpatients  61.1% male  Mean age = 39.1yrs (range = 22-79yrs)  63.9% mild intellectual disability  30.5% severe intellectual disability  5.5% unspecified | *Measures of effectiveness*   * Length of stay | * Average length of stay was 50.8 days (median: 11.5). * Individuals with mild intellectual disabilities were significantly more likely to have stays greater than 12 days compared to those with severe intellectual disabilities. * Individuals with intellectual disabilities living on their own prior to admission had significantly longer stays than those living in a group home or residential institution before admission (55.57 days compared to 21.25, and 10.91 days respectively). |
| Hall, Parkes, Samuels & Hassiotis (2006), UK. | Comparative evaluation study | N=37   * Intellectual disability beds within an acute mainstream psychiatric ward (19) * Enhanced community services (18) | Admissions to inpatient (10 male) and outreach (9 male) services for people with intellectual disabilities and mental health problems.  Inpatient:  Median age = 40yrs (range = 19-68yrs)  Mild intellectual disability (n=16)  Moderate intellectual disability = 15.7% (n=3)  Detained under Mental Health Act (n=4)  Outreach:  Median age = 41yrs (23-68yrs)  Mild intellectual disability (n=17)  Moderate intellectual disability (n=1)  Detained under Mental Health Act = 5.5% (n=1) | *Measures of effectiveness:*   * Length of stay * Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) 104 * Global Assessment of Functioning Scales (GAF) 102 * Mini-Psychiatric Assessment Scale for adults with a developmental disability (PAS-ADD) 138 * Threshold Assessment Grid (TAG) 139   *Measures of Patient experience*   * Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities short version (CANDID-S) 140   Outcome assessments were completed at admission, discharge and six month follow up (inpatient group), or point of crisis, after nine weeks (median admission time) and six months after crisis point (community group) | * Mean inpatient length of stay for inpatient group was eight weeks. * Both inpatient and community groups showed significant improvements on GAF 102, TAG 139 and HoNOS-LD scores 104. * The inpatient group had higher HoNOS-LD 104 scores compared to the community group at baseline. * The inpatient group had significantly higher TAG 139 scores that the community group and this difference persisted over time. * The inpatient group continued to improve on most outcome measures following discharge, however the community group experienced a slight deterioration between nine weeks and six month follow up. * Inpatients were found to have more unmet needs at baseline as measured by the CANDID-S 140 and reported by staff and users. Unmet needs decreased according to staff and user ratings and met needs increased according to staff. * User ratings for the community group showed significant decreases in unmet needs and significant increases in met needs as measured by the CANDID-S 140, but the staff ratings did not (ratings of unmet needs only correlated at nine weeks/discharge and six-month follow up). |
| Hatton (2016), UK. | National census data from England, Scotland, Wales and Northern Ireland |  | National statistical data collected on at least two occasions between 2011 and 2015 from the four parts of the UK on the number of people with learning disabilities in inpatient services. These included: the Learning Disability Inpatient Census (England), the Mental Health and Learning Disability Inpatient Census (Scotland), annual census data (Wales) and the Mental Illness and Learning Disability Census (Northern Ireland). | *Measure of effectiveness*   * Admission and/or discharge figures | * Census data reported a 7% drop in individuals with intellectual disabilities in inpatient services in England, from 3,250 to 3,000 between 2013 and 2015. * Scottish census data showed a 15% drop in individuals with intellectual disabilities in inpatient services in two years (from 272 to 230 between 2012 and 2014). * Northern Ireland data showed a 54% drop of individuals with intellectual disabilities in inpatient services between 2011 and 2015 (from 315 to 144) (Authors note that Northern Ireland is still completing de-institutional process and closure of some long-stay services). * Welsh NHS inpatient figures of individuals with intellectual disabilities increased by 10% over four years (from 118 people in 2011 to 130 in 2015) (Authors note that the overall Wales admission trend unable to be calculated due to placement of some individuals with intellectual disabilities in independent sector unites or outside Wales). * Most recent census data reported 5.5% of individuals with intellectual disabilities in inpatients services as under 18 years old in England (2015), 7.6% in Welsh NHS (2015) and 7.6% in Norther Ireland (2015). |
| Hellerud & Bakken (2019), Norway. | Mixed Methods literature view and semi-structure interviews with families and professionals | N=15   * families of patients with intellectual disabilities (3) * professional caregivers (12) | Families and caregivers of individuals with ID admitted to a specialised inpatient psychiatric unit in Norway. | *Measures of patient experience*   * Met/unmet needs * Family perspectives of care and treatment | * Families reported varying good and bad experiences of admission, with statements of relief over physical safe of their loved one (including risk they pose to others) and meeting of needs such as food and shelter. * However also identified concerns for safety regarding risk of abuse, lack of knowledge about medication, absence of control and the challenges of understanding the detention process and discussing mental health across cultures and languages. |
| Hemmings, O’Hara, McCarthy, Holt, Eoster, Costello, Hammon, Xenitidis & Bouras (2009), UK. | Questionnaire/case note review | N=154   * Admissions to specialist unit only (35) * Admissions to generic unit only (62) * Admissions to both (57) | Inpatient admissions of individuals with intellectual disabilities to dual diagnosis and generic mental health wards in South London area between 1999 and 2004.  Specialist unit  60% male  Mean admission age = 37.7yrs  80% Mild intellectual disability  20% Moderate intellectual disability  0% severe intellectual disability  25.7% formal admission  Generic unit  61.3% male  Mean admission age = 39yrs  83.9% Mild intellectual disability  16.1% Moderate intellectual disability  0% severe intellectual disability  37.1% formal admission  Both  54.4% male  Mean admission age = 35yrs  73.7% Mild intellectual disability  21.1% Moderate intellectual disability  3% severe intellectual disability  52.6% formal admission | *Measures of effectiveness*   * Length of stay * Discharge pathway | * Median length of stay was significantly longer for specialist admissions at 19.3 weeks (range = 2-159) compared to generic admissions (Median = 5.5 weeks, range =0.1-71). * Individuals admitted to both types of unit had shorter stays than those admitted to specialist units only but longer stays than those admitted to generic units only (Median = 9.5 weeks, range = 0.9-63) * 36% of those admitted to the specialist unit only discharged were discharged to their family home (compared 59% admitted from their family home), however this was still significantly higher than those admitted to generic units only (16.9%). * 45% of those admitted to the specialist unit only were discharged to supported accommodation (compared to 34% admitted from supported accommodation). |
| Hurst, Nadarajah & Cumella (1994), UK. | Retrospective case note review | N=157 | All first admissions to an inpatient unit for individuals with intellectual disabilities over an eight-year period.  61.7% male  Mean admission age = 30yrs (range = 15-63yrs)  4% borderline intellectual disability  66% mild intellectual disability  Moderate intellectual disability 30%  20% detained under the Mental Health Act | *Measures of effectiveness*   * Length of stay * Discharge pathway * Readmissions | * Median length of stay was 68 days in the 8-year study period. * Two individuals remained inpatient at the time of the survey. * 94% of those discharged were placed in the community. * Of those discharged, 63% were relieved of their presenting disorder, 25% improved, 11% not improved and 1% were considered to have worsened. * 37% of patients were re-admitted (38% multiple times). |
| Iversen, Horndalsveen, Matre, Henriksen, Fusche, Kildah & Bakken (2019), Norway. | Mixed methodology using retrospective case note file review and evaluation of inpatient treatment | N=6 | Admissions of adults with diagnosis of borderline personality disorder and ID to specialist psychiatric inpatient unit for adults with ID in Norway.  33% male  Age range = 30-50 years  83.3% Mild ID (n=5)  16.7% Moderate ID (n=1) | *Measure of effectiveness*   * Length of stay * Aberrant Behaviour Checklist (ABC) 103. * Symptom Checklist Revised (SCL-90-R) 141Aberrant Behaviour Checklist (ABC) 103. * Symptom Checklist Revised (SCL-90-R) 141 | * Length of stay ranged between four and eight months. * Significant differences (equating improvements) in mental health and behaviour problems on both measures following inpatient treatment. * ABC 103 subscale scores before and after inpatient stay - irritability: M=29.33, SD=9.14 *vs*. 17.00, SD=9.96, *p=0.027*; social withdrawal: M=7.33. SD=5.57 *vs*. M=2.17, SD=3.12, *p=0.041*; hyperactivity: M=22.17, SD=10.34 *vs*. M=7.67, SD=5.32, *p=0.043*) * SCL-90-R 141 subscale scores before and after inpatient stay – interpersonal sensitivity: M=19.5, SD=5.01 *vs*. 10.83, SD=3.82, *p=0.027*; depression: M=25.0. SD=9.58 *vs*. M=13.5, SD=9.27, *p=0.028*; anxiety: M=23.67, SD=7.37 *vs*. M=14.0, SD=7.54, *p=0.028;* hostility: M=16.83, SD=5.08 *vs*. M=9.50, SD=5.17, *p=0.027*). * Global Severity Index scores before and after inpatient stay – M=148.33, SD=48.33 *vs*. M=86.50, SD=41.44, *p=0.027.* |
| Keown, Mercer & Scott (2008), England. | Retrospective analysis of admissions. |  | Examined number of voluntary and involuntary admissions for mental disorders between 1996 and 2006. | *Measure of effectiveness*   * Admissions | * 11% yearly decrease in all admissions between 1996 and 2006 (including those without intellectual disabilities). * Decrease accounted for by 3 subpopulations (i) individuals with intellectual disabilities - 58% decrease (ii) individuals with depression – 33% decrease, (iii) individuals with dementia – 28% decrease. |
| Kokoski, White, Palucka & Lunsky (2009), Canada. | Case note review | N=18   * Individuals with autism spectrum disorders diagnosis (9) * Individuals without autism spectrum disorders diagnosis (9) | Individuals with autism spectrum disorders discharged from a specialised intellectual disability and mental health inpatient unit in Canada between 2006 and 2008.  Autism spectrum disorders group  Males (n=7)  Age range = 20-40yrs  Mild intellectual disability (n=2)  Moderate intellectual disability (n=5)  Severe intellectual disability (n=2)  Matched Group without autism spectrum disorders  Males (n=5)  Age range = 21-47yrs  Mild intellectual disability (n=5)  Moderate intellectual disability (n=4)  Severe intellectual disability (n=0) | *Measure of effectiveness:*   * Length of stay * Global Assessment of Functioning Scales (GAF) 102 * Aberrant Behaviour Checklist (ABC) 103 * Reiss Screen for Maladaptive Behaviour 142 | * Average length of stay for the autism spectrum disorder diagnosis group was 146 days (*SD* = 74) compared to 137 (*SD* = 80) days in the matched group. * Clinical assessment scores indicated higher impairment in the autism spectrum disorder group compared to the match group at admission and discharge. * Both groups showed improvement in GAF (Hall, 1995) scores. * Reiss Screen (Reiss, 1988) totals decreased (indicating improvement) in the autism spectrum disorder group. * Increases in ABC scores (indicating improvement) (Aman & Singh, 1985) were seen in the matched group. |
| Larue, Goulet, Prevost, Dumais & Bellavance (2018), Canada. | Descriptive retrospective mixed methods study (including file review and focus groups) | N=11   * Co-morbid autistic disorder (7) | Cohort of males admitted to a Canadian hospital intellectual disability Psychiatry Programme in June 2008 and followed until 2012.  100% male  Mean age at admission = 41 years. | *Measures of patient safety*   * Use of seclusion * Use of restraint | * Between 2008 and 2012 the average hours of seclusion fell for the majority of patients. * For four patients the average hours spent in seclusion fell by 3 to 12 hours per month. * For six of the patients the average time in seclusions decreased by 45 hours or more. * Use of restraint decreased by 1 to 3 hours per month for nine patients. * One patient had a significant increase in the number of hours of restraint during the study period. * The factors identified as contributing to the change in use of seclusion and restraint were: cohesion of the care providers, the involvement of families and efforts to determine the function of the behaviour. |
| Li, Srasuebkul, Reppermund & Trollor (2018), Australia. | Retrospective data-linkage study (four government datasets) | N=35,056   * individuals with intellectual disabilities (899) * individuals without intellectual disabilities (34,157) | Cohort of adults (>18yrs) study examining emergency department presentation and re-admission following ‘index’ (first) psychiatric admission, from July  2005 to June 2012 in New South Wales.  51% male  Mean age at index admission = 42yrs (IQR=32-54yrs)  3% with intellectual disabilities | *Measure of effectiveness*   * Admissions (Emergency department presentation following ‘index separation’ - release/discharge after first admission). * Readmission following index separation. | * Intellectual disability was a significant factor associated with emergency department presentation at 1 month (OR=3.03; CI95%=2.54 to 3.40; p=<0.001), 2-5 months (OR=3.00; CI95%=2.58 to 3.47; p=<0.001) and 6-26 months (OR=2.94; CI95%=2.54 to 3.40; p=<0.001) following the index admission. * Intellectual disability was a significant factor associated with psychiatric readmission at 1 month (OR=1.63; CI95%=1.37 to 1.94; p=<0.001), 2-5 months (OR=1.54; CI95%=1.28 to 1.85; p=<0.001) and 6-26 months (OR=1.75, CI95%=1.49 to 2.07; p=<0.001) following the index admission. |
| Lohrer, Greene, Browning & Lesser (2002), US. | Questionnaire | N=128   * 64 admissions with intellectual disabilities (62 individuals) * 64 admissions without intellectual disabilities (64 individuals) | Individuals with intellectual disabilities admitted to inpatient psychiatric services within ten general community hospitals during a three-month period.  Admissions with intellectual disabilities  57.8% males  Mean age = 33.6yrs (*SD* = 8.5)  55% mild intellectual disability  23.3% moderate intellectual disability  13.3% severe intellectual disability  8.3% profound intellectual disability  Admissions without intellectual disabilities  57.8% male  Mean age = 38.2yrs (*SD* = 9.6) | Measures of effectiveness   * Length of stay * Discharge pathway * Discharge requirements   *Measures of patient safety*   * Observation levels * Medication | * Length of stay analysis (n=115) showed that overall patients with intellectual disabilities had longer hospital stays (*M*= 29.4 days, *SD* = 29.7, range = 3-142) than those without (*M* = 22 days, *SD* = 21.6, range = 1-106). * Discharge planning did not show that those with intellectual disabilities presented greater difficulty in placement, nor any significant difference in remaining beyond target date when compared to patients without intellectual disabilities. * Individuals with intellectual disabilities were significantly less likely to require a discharge placement that differed from that on admission (9.1% compared to 26.7%). * Individuals with intellectual disabilities required significantly higher 1:1 staffing levels than those without (43.5% compared to 12.5%). * No significant differences found for changes in medication or dosage or use of 'special accommodation' between the those with intellectual disabilities and the comparison group. * Multivariate analysis did not show an intellectual disability diagnosis itself to be a predictor of length of stay. |
| Lunsky & Balogh (2010), Canada. | Retrospective case note review (identified via Canadian Institute for Health Information). | N=121,515   * admissions for psychiatric care with developmental disabilities (3,487) * admissions for psychiatric care without developmental disabilities (118,038) | Individuals with developmental disability across Canada (15-65yrs+) hospitalised for psychiatric reasons between April 2005 and March 2006. | *Measures of effectiveness*   * Admissions * Length of stay * Readmissions | * 41.5% of hospital admissions for those with developmental disabilities were for psychiatric conditions. * Younger adults (15-24yrs) with developmental disabilities were admitted to hospital at a higher rate (35.7%) than young adults without developmental disabilities (16.2%) * Older adults (65yrs+) with developmental disabilities were discharged from hospital at a lower rate (3.3%) than older adults without developmental disabilities (21.1%). * More males with developmental disabilities had psychiatric admissions (57.2%) compared to females with developmental disabilities (42.8%); whereas more females without developmental disabilities had psychiatric admissions (52.2%) compared to males without developmental disabilities (47.8%). * Males with developmental disabilities were admitted to hospital for psychiatric reasons at a significantly higher rate than male without developmental disabilities (OR = 1.22; 95% CI 1.12 to 1.33, χ2= 19.09, df = 1, P < 0.001). * Length of stay categories (1 day, 2-7 days, 8-30 days, 31-365 days and >365 days) did not different significantly between those with developmental disabilities and those without. * Those developmental disabilities were more likely to have been hospitalized multiple times (36.3% with more than one psychiatric admission) compared with people without developmental disability (20.5%) in the same 1-year period. |
| Lunsky, Bradley, Durbin & Koegl (2008), Canada. | Cross sectional study (secondary analysis of census data) | N=371   * Specialised intellectual disability programmes (102) * General mental health programmes (269) | Inpatients (16yrs+) with intellectual disabilities in one of Ontario’s nine psychiatric hospitals between 1998 and 2003.  59.4% male (specialised programmes)  68.3% male (general psychiatric services) | *Measures of effectiveness*   * Length of stay * Discharge pathway recommendations | * Specialised programmes did not differ significantly in terms of number of days spent in hospital compared to generalised programmes, with an average time over 5yrs for both groups. * Levels of recommended care were high for all inpatients in the study but slightly higher for those in the specialised programmes, however this did not reach significance (includes recommendations for level 5/tertiary care). |
| Lunsky, Bradley, Durbin, Koegl, Canrinus & Goering (2006), Canada. | Secondary analysis of census data | N=2,196   * Inpatient sample of individuals with intellectual disabilities (394) | Inpatients with and without intellectual disabilities (16yrs+) in one of Ontario’s nine psychiatric hospitals between 1998 and 2003. | *Measures of effectiveness*   * Length of stay | * Overall inpatient length of stay (n=2,196) was 3.65yrs. * Inpatients with intellectual disabilities (n=394) had significantly longer admissions than those without (an average of 6.6yrs compared to 3.0yrs). * 4% of those with intellectual disabilities required inpatient care compared to 2% of individuals without intellectual disabilities. * Inpatients were significantly more likely to have an intellectual disability and psychiatric diagnoses than outpatients. * Unable to extract inpatient with intellectual disabilities figures from all data but higher proportion of individuals with intellectual disabilities required higher levels of support as outpatients. |
| Lunsky, Grace & Bradley (2009), Canada. | Case note study | N=69   * Inpatients with autism spectrum disorders (19) * Autism spectrum disorder outreach patients (4) * Matched (inpatient/ outreach) patients with autism spectrum disorder alone (23) * Matched patients without autism spectrum disorders or intellectual disabilities (23) | Individuals with autism spectrum disorders identified through Ontario’s three psychiatric hospitals.  Sample with autism spectrum disorders  74% Male  Mean age = 35.43yrs (SD = 9.12)  69.6% (14 inpatients, 2 outpatients) enrolled in intellectual disability programmes. | *Measures of effectiveness*   * Length of stay * Discharge pathway recommendations | * Individuals with autism spectrum disorders and intellectual disabilities represented 12% of all inpatients with intellectual disabilities in the three hospitals included in the study. * Longer average length of stay for individuals with autism spectrum disorders (*M* = 6.3 years; *SD* = 6.95) compared to individuals with intellectual disabilities alone and individuals without intellectual disabilities or autism spectrum disorders, * Significantly more days spent in hospital by those with autism spectrum disorders and intellectual disabilities (*M* = 2300.89; *SD* = 2537.18) compared to those with intellectual disabilities alone (*M* = 774.42; *SD* = 997.13), and those without autism spectrum disorders or intellectual disabilities (*M* = 981.56; *SD* = 1134.40). * Individuals with autism spectrum disorders (83%) had higher recommended levels of care (levels 4 and 5\*) than those with intellectual disabilities (52.1%) alone or those without autism spectrum disorders or intellectual disabilities (30.4%). * Fewer individuals with autism spectrum disorders and intellectual disabilities (17.4%) were recommended lower levels of care (levels 2 and 3) compared to those with intellectual disabilities alone (47.8%) and those without autism spectrum disorders or intellectual disabilities (56.5%). |
| Lunsky, Gracey, Koegl, Bradley, Durbin & Raina (2011), Canada. | Cross-sectional case note review | N=2218 (entire inpatient sample)   * individuals with intellectual disabilities + forensic involvement (74) * individuals with intellectual disabilities + no forensic involvement (282) * individuals with forensic involvement without intellectual disabilities (506) | Individuals with intellectual disabilities with forensic involvement identified from inpatient facilities in Ontario’s nine psychiatric hospitals.  ID forensic group  81% males (n=60)  Mean age=38.07yrs  26 residing in forensic inpatient units  11 residing in specialised intellectual disability units  37 residing in other hospital programmes | *Measure of effectiveness*   * Length of stay * Discharge pathway recommendations | * Inpatients with intellectual disabilities and forensic issues were younger (mean age=38.7yrs), had a shorter period of stay (2.6 years compared to 7.8 years) and more likely to be male compared to individuals with intellectual disabilities without forensic issues (mean age=48.71yrs) but not compared to forensic patients with intellectual disabilities. * The mean length of stay for the entire inpatient cohort was 3.65 years (Lunsky et al., 2006). Higher prevalence of personality disorders and lower rates of mood disorders in inpatients with intellectual disabilities with forensic issues compared to inpatient with intellectual disabilities without forensic issues. * Lower rates of substance abuse and psychotic disorders seen in inpatients with intellectual disabilities with forensic issues compared to inpatients with forensic issues without intellectual disabilities. * Inpatients with intellectual disabilities and forensic issues had higher levels of recommended care than inpatients with forensic issues without intellectual disabilities and had the largest number of inpatients recommended for the highest level of care (17.8%) out of the three groups (non-ID forensic = 10.0%; ID-non-forensic=10.9%). |
| Lunsky, White, Palucka, Weiss, Bockus & Gofine (2010), Canada. | Retrospective chart review | N=33   * Individuals with mild intellectual disability (17) * Individuals with moderate to severe intellectual disability (16) | Discharged patients from an inpatient unit for individuals with intellectual disabilities over a 3-year study period.  42.5% male  Mean age = 35.19yrs (*SD* = 9.15)  51.5% mild intellectual disability  42.4% moderate intellectual disability  6.1% severe intellectual disability  Compared treatment outcomes of mild intellectual disability patients to those with moderate/severe intellectual disability. | *Measures of effectiveness*   * Length of stay * Global Assessment of Functioning Scales (GAF) 102 * Reiss Screen for Maladaptive Behaviour 142 * Aberrant Behaviour Checklist (ABC) 103 * Discharge placement * Readmissions | * Mean length of stay for all patients was 119 days with no significant difference found between the mild and moderate/severe intellectual disability groups. * Significant interaction between GAF 102 score and IQ functioning was found, with those with mild intellectual disability showing a significant improvement compared to minimal improvement for individuals with moderate to severe intellectual disability. * Reiss scores 142 showed a significant improvement from admission to discharge but no difference between the mild and moderate/severe intellectual disability groups. * ABC 103 scores demonstrated significant improvement on hyperactivity subscale from admission to discharge but again, no difference between the two groups. * 11 patients required more supportive environments than at admission upon discharge (6 with mild intellectual disability, 5 with moderate/severe intellectual disability). * 7 patients re-admitted during the study period (5 with mild intellectual disability, 2 with moderate/severe intellectual disability). |
| Lyall & Kelly (2007), UK, Scotland. | Case note review | N=348 intellectual disabilities admissions   * accounted for by 213 individuals | All admissions (348) to specialist psychiatric beds for individuals with intellectual disabilities with additional mental illness, severe challenging behaviour or forensic problems between 1995 and 2003.  Specialist admissions:  63% mild intellectual disability  30% moderate intellectual disability  7% severe intellectual disability  Comparison group of adults with intellectual disabilities in general adult psychiatric beds also identified. | *Measures of effectiveness:*   * Admissions | * 16.9% of admissions to the specialist beds were previously residents in a long-stay intellectual disability hospital who had been re-settled following closure of the hospital. * 41 of the 213 individuals admitted had two or more admissions. * The admission trends for the specialist beds and admissions of individuals with intellectual disabilities to general psychiatric beds showed a reduction in the rate of admissions to specialist beds, as maximum occupancy was reached, and an associated increase in admissions of adults with intellectual disabilities to general psychiatric wards. |
| MacKenzie-Davies & Mansell (2007), UK. | Questionnaire based survey of all assessment and treatment units in England | N=333 | Individuals with intellectual disabilities living in the 38 units that responded to the survey.  69% male  Mean age = 36yrs (*SD* = 12.8,range = 14-74yrs)  7% borderline or no intellectual disability  73% Mild or moderate intellectual disability  20% severe or profound intellectual disability  40% detained under the Mental Health Act | *Measures of effectiveness*   * Length of stay * Discharge plans | * Average length of stay for units not described as long-stay, was 21 months (range = 0-285 months). * Average length of stay for units described as permanent accommodation was 9.3 years (range = 3 months – 27 years7months). * Views of unit managers included knowledge and experience of staff, unit philosophy and professional links and multi-disciplinary working commonly identified as strengths. Sufficient staff and small- scale environment and ability to achieve good standards of care were also identified. * Problems identified by managers included inappropriate admissions, bed-blocking, relationships with other services, staff recruitment and retention, unit local and environment and mix of patients. |
| Mansell, Ritchie & Dyer (2010), UK. | Single occasion survey (analysis of national audit data) | N=217 (out of 239) services returned questionnaires   * 179 NHS * 38 Independent sector | NHS and Independent sector health settings providing specialist inpatient services for people with intellectual disabilities registered with the Healthcare Commission.  119 assessment and treatment units  73 low secure services  25 medium secure services  These services provided 1,891 places with just over 70% male on average and aged between 25 and 54yrs.  37 units had 0% of individuals detained under the Mental Health Act.  The remaining services had on average, 66% of individuals detained under the Mental Health Act (range 9-100%) | *Measure of effectiveness*   * Discharge pathway   *Measures of patient safety*   * Use of seclusion * Use of physical restraint   *Measures of patient experience*   * Service user or relative complaints. * Family visits | * NHS units had more patients who had finished active treatment but did not have any plans to leave the unit in the next month (19% compared to 6% in independent sector units). * 25% of these patients were in assessment and treatment units, 10% in low secure services and 3% in medium secure. * NHS units were found to use less seclusion and physical restraint and have fewer locked areas than independent sector units. * No difference was found between NHS and independent sector units in the number of incidents where a patient was hurt by another patient or staff member. * Independent sector units also received more complaints from users (for assessment and treatment units, low secure and medium secure services) and received more complaints from relatives in assessment and treatment units and low secure services than NHS units. * NHS units showed higher numbers of visitors (family, friends or professionals) than independent sector units. |
| O’Brien & Beasley (2007), US. | Analysis of US healthcare insurance costs report (billing data) | * Billing data from a specialist intellectual and developmental disabilities inpatient psychiatric service. * Comparison billing data from general psychiatric services in the same medical centre. | Examination of cost-related data for specialist inpatient psychiatric services for individuals with intellectual and developmental disabilities in a large US medical Centre in 2006. | *Measures of effectiveness*   * Length of stay * Discharges | * Length of stay on the specialist unit was 17.9 days and 8.6 days on the general units. * Average length of stay for out-of-state patients is longer than that for in-state patients. * 74% of individuals were discharged within 10 days on the general psychiatric units compared to 44.5% on the specialist unit. * In the specialist unit 2.3% of individuals were discharged on day and two (compared to 15.6% on the general units) and 9% were discharged by day 6 (compared to 58.7%). * For longer stays, 26% of the specialist patients were discharged after the twentieth day (compared to 8%), and 9.1% were discharged after the fortieth day (compared to 2.7% in the general psychiatric services). |
| Oxley, Sathanandan, Gazizova, Fitzgerald & Puri (2013), UK. | Retrospective case note review | N=101 admissions   * 1999-2001 cohort (60) * 2009-2011 cohort (40) | Admissions to a twelve-bed inpatient unit for individuals with intellectual disabilities with acute mental illness and/or challenging behaviour over two time periods.  1999-2001 cohort  Male to female ratio – 1.4:1  Mean age = 29.58yrs (range = 14-63yrs)  2009-2011 cohort  Male to female ratio – 3.1:1  Mean age = 36.16yrs (range = 19-72yrs) | *Measure of effectiveness*   * Length of stay * Discharge pathway * Readmissions | * Results showed an overall reduction in the number of admissions between the two time periods (from 60 to 41). * Average length of stay increased between the two time periods from 198.6 days in the 1999-2001 cohort to 244.6 days in the 2009-2011 cohort. * Changes in residence following discharge were higher in the later cohort with more individuals being discharged to a different residential home or to supported living, compared to going the back to the same residential placement or family home in the earlier cohort. * A significant reduction in readmissions was also seen (16 between 1999 and 2001 compared to 1 from 2009 to 2011). |
| Palucka, Raina, Liu & Lunsky (2012), Canada. | Retrospective case note review | N=20 | Individuals with intellectual disabilities discharged from a specialised unit between 2003 and 2011 identified as having past or current involvement with the criminal justice system.  65% male  Mean age=30.15yrs (SD=7.55)  60% mild intellectual disability  30% mild-to-moderate intellectual disability  5% moderate intellectual disability  5% moderate-to-severe intellectual disability | *Measure of effectiveness*   * Length of stay | * Median length of stay was 570 days (SD=1190, range=62-4670) * Identification of subgroups based on psychiatric diagnosis (severe mental illness, impulse control disorders, autism spectrum disorders and intellectual disability with no major psychiatric diagnosis) highlighting trends in challenges in treatment and discharge. |
| Perera, Simpson, Douds & Campbell (2009), Scotland. | Single occasion survey on inpatient services for adults with intellectual disabilities in Scotland | N=388 | Adults with intellectual disabilities identified across 15 health boards in Scotland.  78% male  Age range = 16-75+yrs  Comparisons made with general psychiatric patients from analysis of findings on national database (ISD/NHSS, 2008). | *Measures of effectiveness*   * Length of stay | * Median length of stay for general psychiatric patients was identified as 5 months whereas it was 5 years for those with intellectual disabilities. * Nearly half of the sample with intellectual disabilities (47.9%) had been inpatients for more than 5 years (compared to only 15% of general psychiatric patients). * 21% of individuals with intellectual disabilities had been in hospital for less than a year (compared to 63% for general psychiatric patients) and 16.8% had been in hospital for less than 6 months. * 17.52% of individuals with intellectual disabilities were identified as delayed discharges. |
| Prichard, Palucka, Reid & Lunsky (2007), Canada. | Case note review | N=89   * inpatients (20) * Outpatient group (in-depth consultation) (20) * Outpatient facilitation services (brief consultation and not included in analysis) (49) | Patients with an autism spectrum disorder identified in specialist programmes for individuals with ID/ASD spectrum disorders at Ontario’s Centre for Addiction and Mental Health between Oct 1999 and January 2005.  Inpatient group  Male to female ratio = 2:1  Mean age = 31yrs (range = 17-52yrs)  Outpatient group  Male to female ratio = 3:1  Mean age = 25.7yrs (range = 15-56yrs) | *Measure of effectiveness:*   * Admissions and/or discharge figures * Discharge pathway | * Individuals with autism spectrum disorders comprised approximately 27% of all clients admitted to the dual diagnosis unit in the study period. * At discharge, outpatients were more likely to have a less severe form of autism spectrum disorders (e.g. pervasive developmental disorder-not otherwise specified, autism spectrum disorder, autistic features/traits, etc.) than in comparison to the inpatient group. * Challenging behaviour was the primary referral reason for both inpatient and outpatient groups, however more individuals from the in-patient group were referred due to forensic involvement (20%) compared to the outpatient group (5%). * Eight inpatients did not return to their original place of residence (compared to two from the outpatient group). |
| Raitasuo, Taiminen & Salokangas (1999), Finland. | Cross sectional cohort case review study | N=40 | 40 consecutive admissions to a specialist psychiatric inpatient unit for individuals with intellectual disabilities.  70% male (n=28)  Median age = 28yrs (range = 15-52)  78% borderline or mild intellectual disability  5% severe or profound intellectual disability | *Measures of effectiveness*   * Length of stay * Brief Psychiatric Rating Scale 143 * Diagnostic Assessment for Severely Handicapped (DASH) Scale 144 * Visual Analogue Scale (VAS) * Discharge placement | * Mean length of stay was 2.91 months (*SD* = 3.35, range = 0.16-12.3). * Clinical measures showed significant improvements in psychiatric symptoms between admission and discharge, and some at follow up. * 33 individuals returned to original living placement following discharge; 3 to less restrictive environments, and 4 to more supportive placements. * 21 individuals required inpatient aftercare over 34 instances (14 urgent and 20 scheduled). |
| Richings, Cook & Roy (2011), UK. | Service evaluation data | N=102 | All referrals (61% male) to a new community assessment and treatment service in its first two years of a new model, incorporating inpatient, day assessment and outreach facilities.  53% mild intellectual disability  35% moderate intellectual disability  11% severe intellectual disability  42.8% detained under Mental Health Act | *Measures of effectiveness*   * Length of stay * Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) 104 * Discharge pathway   *Measure of patient safety*   * Incidents of aggression and physical violence | * 50% of referrals spent time as an inpatient. * Average time spent as inpatient was 103 days (range = 16-553). * Mean length of inpatient stay in new service model was significantly shorter than previous service model (198 days). * 35% of referrals treated as inpatients under new service model compared 91% in previous model. * Mean HoNOS-LD 104 score on admission (all referrals was 25 (range = 6-42), mean final score was 19 (range = 3-52). * For all referrals to the service 73% were able to remain in or return to their previous placement * For those who spent time on as an inpatient, 51% were able to remain in or return to their previous placement. * New service model reported lower frequency of aggressive incidents and incidents of physical violence amongst inpatients compared to previous service model. |
| Saeed, Ouellette-Kuntz, Stuart & Burge (2003), Canada. | Retrospective cohort design, chart review | N=581   * admissions with intellectual disabilities (294) * Comparison group without intellectual disabilities (287) (stratified sample across acute and chronic hospitals) | All psychiatric patients with intellectual disabilities (56% male) admitted over a five-year period from two acute care general hospitals and one chronic psychiatric hospital in Ontario.  Admissions with intellectual disabilities  56% male  Mean age = 35.8yrs (*SD* = 15.0)  48% involuntary admission  Comparison group  46% male  Mean age = 39.1yrs (*SD* = 17.8)  36% involuntary admission | *Measures of effectiveness*   * Length of stay | * Significantly longer median length of stay for individuals with intellectual disabilities (21 days) compared to the general psychiatric population (16 days) * Individuals with intellectual disabilities also found to be 30% less likely to be discharged on any given day. |
| Sandhu & Tomlins (2017), UK. | Retrospective case note review | N=36 referrals   * admissions to assessment and treatment unit (10) | Individuals with intellectual disabilities referred to a local assessment and treatment unit or outreach programme between January 2013 and April 2014.  Inpatients  Age range= 21-55yrs  80% male  90% mild intellectual disability  10% severe intellectual disability.  Outreach  Age range= 21-60yrs  87.5% male  52.2% mild intellectual disability  8.3% mild-to-moderate intellectual disability  20.8% moderate intellectual disability  8.3% moderate-to-severe intellectual disability  8.3% severe intellectual disability | *Measures of effectiveness*   * Length of stay * Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) 104 * Discharge pathway   *Measures of patient safety*   * Incidents of aggression or challenging behaviour (including self-harm) | * Mean length of inpatient stay was 129 days (18.5 weeks). * 50% of clients stayed longer than 4 months and 50% stayed less, with 20% staying less than 2 weeks. * Mean HoNOS-LD 104 score (n=7) on admission was 34.4 (SD=16.37, range=21-63) and at discharge was 20 (SD=8.54, range 4-30). * 70% of clients referred to the inpatient had ‘challenging behaviour’ compared to 54.2% of those using the outreach service, and 60% were referred for mental health compared to 33.3%. Referral rates for ‘harm to self’ was similar between those admitted as an inpatient and those using outreach services (40% compared to 37.5%). * Fewer clients were discharged to their family home (30%) than were admitted (60%), with clients moving on to other inpatient care (20%) or respite care (30%). |
| Schmitz-Buhl, Gairing, Rietz, Haussermann et al. (2019), Germany. | Retrospective case note review. | N=5764   * 1,773 inpatients detained involuntarily * 3,991 inpatients detained voluntarily. | Analysis of inpatient admissions to four psychiatric hospitals in Cologne in 2011.  *Entire sample:*  Mean age = 45.4yrs (SD=16.8)  55.1% male  3.2% intellectual disability  *Involuntarily detained sample:*  Mean age = 48yrs (SD=20.0)  55.7% male  1.3% intellectual disability  *Voluntarily detained sample:*  Mean age = 44yrs (SD=15.1)  56.6% male  1.2% intellectual disability | *Measure of effectiveness*   * Length of stay | * Involuntarily detention (included non-ID) was associated with longer length of stay (M=27.9 days, SD=36.8) compared to voluntary detention (M=20.7, SD=25.5). * Highest risk of involuntary treatment was associated with organic mental disorders, non-organic psychotic disorders and intellectual disability. |
| Seager, Bell & O'Brien (2000), UK. | Case note review (and semi-structured interviews) | N=154 | Discharged patients (67% male) from two learning disability hospitals (1981-1999).  Mean age = 50yrs (range = 24-83yrs)  73% severe or profound intellectual disability. | *Measures of effectiveness*   * Readmission | * Readmission rate of 8.4% (13 individuals, 15 re-admissions). * A non-significant trend highlighted higher rates of readmission amongst individuals with borderline to moderate intellectual disability compared to severe or profound. |
| Sheehan, Mutch, Marston, Osborn & Hassiotis (2021), UK. | Clinical Record database from a large NHS Trust serving mentally ill individuals  with mild-to-moderate intellectual disability. | N=654   * 339 with ID with/without autism   315 with autism only (no ID) | Adults (≥18 years) with ICD-10 diagnostic codes F70–F79  and/or F84 who accessed secondary mental healthcare during January 2009 and November 2018.  All  63% male  33.2yrs (14.4) mean ages at cohort entry  57.5% white  ID+/-ASD  52.2% male  35.8yrs (14.9) mean age (sd) at cohort entry  60.5% white  N=114 Mild ID  N=16 Moderate ID  N=209 Missing/Not recorded  ASD only  74.6% male  30.5yrs (13.27) mean age (sd) at cohort entry  54.3% white | *Measures of Effectiveness*   * Admissions * Discharge Placement * Readmissions | * 33.3% of entire cohort (n=216) admitted to inpatient care during study period, with 45.7% of ID+/-ASD admitted and 33% of ASD only admitted. * Median length of stay for first admission was 34 days (interquartile range, 11–95 days) in the ID+/-ASD group, and 27 days (interquartile range, 14–58 days) in the autism-only group (P = 0.211). * Likelihood of psychiatric admission was higher for the ID+/-ASD group (adjusted odds ratio (aOR), 4.00; 95% CI 2.41–6.63), for males (aOR, 2.28; 95% CI 1.39–3.75), those of younger age (aOR, 0.98; 95%CI 0.97–1.00) and those with a diagnosis of schizophrenia spectrum disorder (aOR, 5.08; 95% CI 3.00–8.61), affective disorder (aOR, 2.23; 95% CI 1.29–3.83) or personality disorder (aOR, 1.94; 95% CI 1.02–3.68), and record of a previous admission (aOR, 2.18; 95% CI 1.17–4.05). * Discharge destination after first admission was usual residence for 57.4% for ID +/-ASD and 78.7% for the autism-only group. * Discharge to a place other than usual residence was associated with longer duration of admission (aOR, 1.01; 95% CI 1.00–1.01), and having externalising or internalising challenging behaviours (aOR, 3.34; 95% CI 0.65–17.13 and aOR, 9.87; 95% CI 1.75–55.70, respectively). * Living in a more deprived area was associated with discharge to usual residence (aOR, 0.90; 95% CI 0.83–0.97). * 40% of those admitted during the study period were re-admitted or had need of crisis intervention services within the first 12 months of discharge. * Those with ASD only had a greater risk of readmission but this difference was not statistically significant (aOR, 1.43; 95% CI 0.66–3.05). * Comorbid diagnoses of affective disorder or personality disorder were significantly associated with readmission (aOR, 3.11; 95% CI 1.34–7.23 and aOR, 8.28; 95% CI 2.85–24.04, respectively). |
| Singh, Khalid & Dickinson (1994), UK. | Case note review | N=13 admissions   * accounted for by 11 individuals | Adults admitted to beds for individuals with intellectual disabilities within a general psychiatric ward during the first eighteen months of service.  45.4% male  Mean age =38yrs  100% borderline or mild intellectual disability  23% (n=3) individuals admitted under the Mental Health Act. | *Measures of effectiveness*   * Length of stay * Discharge pathway | * Average length of stay was 8 weeks. * Six individuals returned to their original residence prior to admission (5 community and 1 non-community). * Five individuals were transferred to hospital and the remaining one returned to a different community residence. |
| Slevin, McConkey, Truesdale-Kennedy & Taggart (2008), UK. | Total service population comparison survey (cross-sectional within-subjects design) | N=48 | All admissions to an assessment and treatment for individuals with intellectual disabilities during a fifteen-month period.  56% male  Age range = 15-50+yrs  Ratio of 18:1,000 people with moderate to severe intellectual disability | *Measures of effectiveness:*   * Length of stay * Aberrant Behaviour Checklist (ABC) 103 * Mini-Psychiatric Assessment Scale for adults with a developmental disability (PAS-ADD) 138 * Readmission   *Measures of patient safety*   * Observation levels | * 76% of admissions lasted from less than a week to 12 weeks. * 24% of admissions lasted between 16 and 42 weeks. * Significant differences in level of challenging behaviour between those who were medium-long stay on the unit and those who were short stay. * The ABC 103 results showed significant reductions across a number of subscales between admission, discharge and one at follow up. * Significant reductions on all subscale scores of the PAS-ADD 138 between admission and follow up. * 10 individuals were readmitted to the unit on one or more occasions. * 29% required special observations (23% requiring 1:1 and 6% needing close but not constant supervision). * 10% of individuals remained in unit following completion of study and reported as delayed discharges. |
| Tajuddin, Nadkarni, Biswas, Watson & Bhaumik (2004), UK. | Retrospective case note review | N=95 admissions   * accounted for by 72 individuals | All admissions to specialist inpatient unit for individuals with intellectual disabilities over two-year period.  68% male  Mean age on admission = 34.0yrs (range = 18-63yrs)  63.8% mild intellectual disability (n=46)  30.5% moderate intellectual disability (n=22)  5.5% severe intellectual disability (n=4)  16.8% formal admissions under Mental Health Act (n=16) | *Measures of effectiveness*   * Length of stay * Reiss Screen for Maladaptive Behaviour 142 * Discharge pathway * Readmissions | * Mean length of stay for 90 completed discharges was 70.8 days (range = 2-215) compared to 46.6 days in the Trower, Treadwell & Bhaumik (1998) study (range = 2-194). * Diagnosis of depression more likely to be associated with a shorter stay and schizophrenia with a longer one. * An autism spectrum disorder diagnosis associated with longer than average stay. * Reiss Screen 142 administered to 58 of the 72 patients on admission and shortly before discharge with significant improvement shown prior to discharge. * 68 of the 90 discharged individuals returned to their original place of residence. * 22% of individuals admitted on more than one occasion. |
| Trower, Treadwell & Bhaumik (1998), UK. | Retrospective case note review | N=113 admissions   * accounted for by 80 individuals. | All admissions to a specialist inpatient unit for individuals with intellectual disabilities over a two-year period.  65% male  Mean admission age = 33.5yrs (range = 18-66)  49% mild intellectual disability  32% moderate intellectual disability  19% severe intellectual disability  17.6% (n=20) admissions under Mental Health Act (85% mild intellectual disabilities). | *Measures of effectiveness*   * Length of stay * Discharge pathway * Readmissions | * Mean duration of stay for 102 completed admissions was 46.6 days (range = 2-194). * 89 individuals returned to the residence they were admitted from. * 22 individuals were admitted more than once to the unit during the study period (4 of these individuals were admitted between 3 and 7 times). |
| Turner and Mooney, (2016), UK |  | N=710 seclusion events | Patients (ID and non-ID) from 11 hospitals from an independent sector provider in the UK (ID service patients were typically of mild to moderate ID). | *Measures of Patient Safety*  Use of seclusion (incidents and duration) | * Patients in the ID group service spent significantly less time in seclusion than patients in the non-ID service (U = 40,165.5, p < .001, r = −.31), with the median time spent in seclusion (one seclusion event) lasting an average of 120mins (2hrs) in the ID service, compared to an average of 363mins (6hrs 3mins) for one seclusion event in the non-ID service. * Male patients spent significantly more time in seclusion compared to the female patients (*U* = 46,060, *p* < .001, *r* = −.22) with the median time spent in seclusion (one seclusion event) lasting an average of 270mins (4hrs 30mins) for males compared to an average of 135mins (2hrs 15mins) for females. * A significant interaction was found between gender and ID diagnosis *H*(3)=141.41, *p* < .001. * Median duration of seclusion showed male ID patients (*M*=5hr 5mins, *U*=8144.5, *r* = −.38), male non-ID patients (*M*=4hrs 30mins, *U*=8972.5, *r*=-.45) and female non-ID patients (*M*=7 h, 30 min, *U*=76,650, *r*=−.54) to spend significantly longer in seclusion compared to female ID patients (*M*=1hr 45mins). * Patients in the non-ID service were more likely to be secluded for actual assaults (*z* = 2.7), whereas patients in the ID service were more likely to be secluded for attempted assaults (*z* = 3.9). |
| Van Melle, Noorthoorn, Widdershoven, Mulder and Voskes (2020), The Netherlands. |  | N=6068  1068 secluded patients | Patients within 32 closed acute admission wards for adult patients of 18 mental healthcare institutions providing the High and Intensive Care (HIC) inpatient care model across the Netherlands in 2014.  56.1% male  41.1yrs mean age | *Measures of effectiveness*   * Admissions   *Measures of patient safety.*   * Seclusion | * 4% of all admitted patients had autism or a developmental disability, and 2% of all admitted patients had an intellectual disability. * 3.9% of the secluded population had autism or a developmental disability, and 2.3% of the secluded population had an intellectual disability. * Young age, male gender, having no final diagnosis, bipolar disorder, psychosis, schizophrenia and organic disorder were associated with increased seclusion * use; intellectual or developmental disability was not. * Wards that scored high on the HIC monitor, displaying higher HIC model fidelity and implementation of the HIC model, showed lower seclusion rates than wards that scored low on the HIC monitor. |
| van Minnen, Hoogduin & Broekman (1997), Netherlands. | Controlled Trial | N=60   * Inpatient treatment (30) * Outreach treatment (30) | Male and female adult referrals to a hospital specialising in inpatient treatment for those with intellectual disabilities and psychiatric disorders.  Referrals randomly assigned to inpatient or outreach treatment.  Hospital group  80% male  Mean age = 31.4yrs (SD = 12.6)  Outreach group  72% male  Mean age = 31.0yrs (SD = 10.8) | *Measures of effectiveness*   * Psychopathology Inventory for Mentally Retarded Adults (PIRMA) (Dutch Version) 145 * Reiss Screen for Maladaptive Behaviour 142 * Global Rating Scale for Improvement (GSI) * Scale for Aggressive Behaviour for People with Mental Retardation (SAB) 146   *Measures of patient experience*   * Nijmegan Child-Rearing Situation Questionnaire (NCSQ) 147 | * No significant differences found between groups for psychiatric symptoms using the PRIMA, Reiss Screen and GSI 145 142 (administered on admission and at 7, 14, 21 and 28 weeks after admission). * Severity of psychiatric symptoms at baseline did not appear to predict treatment outcome. * 84% of hospital admissions prevented for the outreach treatment group (4 of the 24 individuals treated through the outreach programme required admission to hospital). * No significant increase in carer burden (measured by NCSQ) 148 during outreach treatment and at endpoint, a slight decrease was noted. |
| White, Lunsky & Grieve (2010), Canada. | Retrospective case review | N=181   * Specialist intellectual disability unit (41) * Generic units (140) | Adults with intellectual disabilities discharged from specialist and generic inpatient units in a psychiatric hospital in Ontario between 2006 and mid-2009.  Specialist unit  46.3% male  Mean age = 34.1yrs (*SD* = 10.28)  17.1% forensic admission  Generic units  67.1% male  Mean age = 38.7yrs (*SD* = 12.80)  12.9% forensic admission | *Measures of effectiveness:*   * Length of stay * Global Assessment of Functioning Scales (GAF) 102 * Resident assessment instrument-mental health (RAI-MH) 149 * Medication (not PRN) | * Significant difference in length of stay between specialist and generic units with the former staying longer (specialist median = 119 days, range = 8-4628 days; generic median = 26 days, range = 4-3696 days). * Individuals discharged from generic hospitals were significantly more likely to have a stay of 3 months of less (77.1% vs. 31.7 %) * Both specialist and generic units showed a significant increase in GAF 102 score indicating increased functioning on discharge. * Patients in the generic unit showed significantly higher mean GAF 102 scores at admission and discharge compared to the specialist unit. * At time of discharge individuals from the specialist unit were prescribed significantly fewer medications compared to those on generic wards (similar numbers on admission). |
| Xenitidis, Gratsa, Bouras, Hammond, Ditchfield, Holt, Martin & Brooks (2004), UK. | Prospective cohort study: | N=84   * Specialist intellectual disability inpatient service (39) * Generic inpatient Unit (45) | All inpatients admitted to a specialist intellectual disability psychiatric unit and comparison group of individuals with intellectual disabilities admitted to a general psychiatric unit.  50.7% males  Mean age = 34.55yrs (*SD* = 13.11yrs)  81.7% mild intellectual disability  14.1% moderate intellectual disability  4.2% severe intellectual disability  41% of specialist unit detained under Mental Health Act  42.2% of generic inpatient unit detained under Mental Health Act | *Measure of effectiveness*   * Length of stay * Discharge pathway * The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist) 150 * Global Assessment of Functioning Scales 102 * Disability Assessment Scale (DAS) 151 * Threshold Assessment Grid (TAG) 139 * Readmissions | * Significantly longer length of stay in specialist placements (*M*: 23.2 weeks; *SD* = 14.1) compared to generic (*M* = 11.1 weeks, *SD* = 13.6). * Discharge pathway not significantly different to admission residence between specialist and generic units but discharge from specialist unit was significantly less likely to be to an out of area placement. * Statistically significant improvements found on all four clinical measures (33 participants from specialist unit included in analysis) between admission and discharge on specialist unit. * Readmission rates similar between units: five patients in specialists group readmitted twice compared to three in the generic group. The generic group also had one individual with three admissions and one with four. |
| Xenitidis, Henry, Russell, Ward & Murphy (1999), UK. | Case note review within-subjects design | N=64 | All admissions (males n = 46; females n=18) to an inpatient assessment and treatment unit for individuals with mild to moderate intellectual disability and severe challenging behaviour  Mean age = 28year (range = 17-46)  Mean IQ = 64 (*SD* = 8.96, range = 46-84).  Informal admissions = 42.2% | *Measures of effectiveness*   * Length of Stay * Discharge pathway (improvements in acc. status - admission from non-community setting e.g. Tier 4/prison, discharge to community setting).   *Measure of patient safety*   * Reduction of frequency of aggression (no. of incidents of aggression). * Reduction of severity of aggression (use of seclusion). | * Mean length of stay 12.84 months (range = 0-29) * 84.2% of all admissions from the community were returned to the community. * 47 admitted from non-community settings with 38 discharged to community (n=57 included in discharge analysis). * Only significant difference between those discharged to community compared to those discharged to non-community setting was presence of fire-setting. * Significant reduction in incidents of aggression following the intervention (58 cases included in comparison ), with 0.75 incidents per person per week before intervention compared to 0.33 after. * Significant reduction in the use of seclusion (from 0.15 episodes per person per week to 0.04) |

| **Study & Country** | **Design** | **N** | **Sample** | **Domain Outcomes** | **Findings** |
| --- | --- | --- | --- | --- | --- |
| Adults with intellectual disabilities and/or autism within forensic inpatient services. | | | | | |
| Alexander, Chester, Gray & Snowdon (2012), UK. | Retrospective case note review | N=362   * Intellectual disability and personality disorder group (48) * Intellectual disability without personality disorder group (97) * Personality disorder only group (217) | Discharged patients from four independent sector medium secure units between 1992 and 2001.  Intellectual disability and personality disorder group  67% male  Mean age on discharge = 32yrs (range = 26-37)  Intellectual disability without personality disorder group  89% male  Mean age on discharge = 28yrs (range = 24-35)  Personality disorder only group  65% male  Mean age on discharge = 27yrs (range = 24-33) | *Measures of effectiveness:*   * Length of stay * Post-release convictions * Re-offending at follow up * Psychopathy Checklist: Screening Version 131 * Historical, Clinical, Risk Management (HCR-20) 130 | * Individuals with intellectual disabilities and personality disorder had a longer length of stay (median = 853 days, interquartile range = 433, 1228) than both those with intellectual disabilities alone (median = 571 days, interquartile range = 224, 944) and those with personality disorder only (median = 240 days, interquartile range = 100, 683). * The personality disorder only group had a significantly shorter length of stay than both the intellectual disabilities and personality disorder, and intellectual disability alone groups. * Those with personality disorder only had significantly more convictions post-treatment than those with intellectual disabilities only and higher rates of re-offending at all follow up points. * There were no significant differences in the number of post-release convictions or re-offending at follow up points between the those with intellectual disabilities and personality disorder and those with intellectual disabilities alone, or between those with intellectual disabilities and personality disorder and personality disorder only. * The intellectual disabilities and personality disorder group and personality disorder only both scored significantly higher than those with intellectual disabilities alone on the PCL:SV 131. * On the HCR-20 130 those with intellectual disabilities and personality disorder scored significantly higher than both other groups. |
| Alexander, Crouch, Halstead & Pichaud (2006), UK. | Retrospective Case note review cohort study | N=74   * Cohort 1 (34): discharged between 1987 + 1993 * Cohort 2 (40): discharged between 1994 + 2000 | Two cohorts of discharged patients from a medium secure unit over a 12year period.  Cohort 1:  81% male  Median admission age = 27yrs (range = 15-55yrs)  4% no intellectual disability  41% borderline intellectual disability  41% mild intellectual disability  15 % Moderate intellectual disability  Cohort 2:  73% male  Median admission age = 26yrs (range = 19-56yrs)  16% borderline intellectual disability  65% mild intellectual disability  20% moderate intellectual disability | *Measures of effectiveness*   * Readmission * Discharge pathway * Relapse * Re-offending behaviours | * 30% of entire sample had contact with police at discharge and 11% received reconvictions. * 58% displayed ‘offending-like behaviour’ (behaviour that could be classed as an offence but did not lead to police contact) during the 12 year follow up period. * Rate of readmission was 30% (across both cohorts) during the follow up period and associated with ‘offending like behaviours’ rather than a specific diagnosis. * Following discharge 53% remained under the power of the Mental Health Act with 28% detained in hospital, special hospital, or nursing home. * 59% underwent a change of residence during the follow up period and this group had a higher likelihood of being re-admitted (four times more likely). * A higher percentage of cohort 1 (70%) was discharged to their own homes compared to cohort 2 (48%). * Significantly more individuals from cohort 1 suffered relapse in the first 5 years of follow up than cohort 2. * No significant difference found in rates of re-offending or -re-offending-like behaviours between the two cohorts. |
| Alexander, Green, O’Mahony, Gunaratna & Gangadharan (2010), UK. | Retrospective case review cohort analysis | N=138   * Intellectual disability and personality disorder group (diagnosed with dissocial or emotionally unstable personality disorder) (77) * Intellectual disability without personality disorder group (61) | Cohort of subpopulation within an inpatient unit for offenders with intellectual disabilities (79% male) over a six-year period.  Mean age for individuals with intellectual disability and personality disorder = 29.62yrs (SD = 9.4)  Mean age for individuals with intellectual disabilities and no personality disorder = 31.46yrs (SD = 9) | *Measures of effectiveness*   * Length of stay * Discharge pathway   *Measures of patient safety*   * Use of physical intervention * Observations levels * Use of seclusion | * No significant differences in median length of stay between individuals with intellectual disability and personality disorder discharged patients (n=77, M = 1183 days; SD = 849) and discharged patients with intellectual disability and no personality disorder (M = 1007 days; SD = 1159). * No significant differences were found between patients with personality disorder and those without in discharge pathway and ‘good outcomes’ (patients who could have moved to a lower level of therapeutic security at discharge), with 83% compared to 90%, respectively. * No significant differences found between use of physical intervention, seclusion and observation levels between inpatients with personality disorder and those without. |
| Alexander, Hiremath, Chester, Green, Gunaratna & Hoare (2011), UK. | Retrospective case review cohort analysis | N=138   * Discharged patients with intellectual disabilities (77) * Current inpatients with intellectual disabilities (61) * Difficult to discharge long stay participants (36) | Two cohorts of current inpatients and previously discharged patients from a 64-bedded medium secure inpatient unit for offenders with intellectual disabilities over a six-year period.  78.9% male  Mean age on admission = 30.43 (SD=9.27)  39.1% on forensic section | *Measures of effectiveness*   * Length of stay * Discharge pathway   *Measures of patient safety*   * Use of physical intervention * Observations levels * Use of seclusion | * The median length of stay for the discharged cohort was 1,025 days (2.8 years). * Almost 90% of discharged patients went to lower levels security with a third going directly to community placements (n=24) and the remainder to low secure hospitals (n=43). * Two thirds of the current patients were classed as ‘difficult to discharge long stay’. * The difficult to discharge long stay group differed significantly from the discharged cohort in relation to higher levels of forensic sections, histories of abuse, histories of fire setting and substance misuse and diagnoses of personality disorder. * However, section type (civil or forensic), history of abuse, co-morbid diagnosis of personality disorder, history of substance misuse or firesetting were not predictors of length of stay in discharged patients. * Mean incidents of physical intervention measures for participants displaying institutional aggression (n=113) was: enhanced observation level M=3.98 (SD=5.88), use of physical intervention/rapid tranquilisation M=2.47 (SD=5.75) and use of seclusion M=0.91 (SD=1.99). |
| Allely (2018), UK. | Systematic Literature Review | N=12 studies | Internet database search for studies relating to autism spectrum disorder in secure psychiatric care. | *Measures of patient experience*   * Studies identifying quality of life and inpatient experiences | * Only one study in twelve explored the experiences or quality of life of patients with an autism spectrum condition. * Of the twelve studies identified, three examined effectiveness of interventions or treatment for individuals with autism spectrum disorders in secure psychiatric hospitals. |
| Butwell, Jamieson, Leese & Taylor (2000), UK. | Retrospective cohort case note review (cohort analysis of data from Special Hospitals Case Register) | N=3,263   * accounting for 3822 episodes | All admissions (82% male) over a 10-year period to a high secure hospital (1986-1995). | *Measure of effectiveness*   * Length of stay | * Median length of stay for all (including those without intellectual disabilities) discharged patients was 6.6 years (range = 0.01-52.3). * Individuals detained under the Mental Health Act classification of ‘mental impairment’ had a median length of stay of 8 years (range = 0.2-40.6) and those with a ‘(severe) mental impairment’ a median of 19.9 years (range = 0.7-51.5) * Individuals detained under the Mental Health Act classification of mental illness and psychopathic disorder had a median length of stays of 6.1 years (range = 0.03-44.7) and 5.3 years (range = 0.2-40.6). |
| Cheshire, McCarthy, Devapriam, Chester, Graham, Grace & Alexander (2015), UK. | Retrospective case file audit | N=63 | Patients within a specialist forensic intellectual disability service consisting of medium secure, low secure and rehabilitation wards[[2]](#footnote-3) during a 12-month study period (2011-2012).  63.4% male  48.07% civil section  53.8% forensic section | *Measures of Patient Experience*   * Family contact * Home visits | * 81% of patients (N=51) maintained some degree of contact with their relatives (i.e. by letter, telephone, visits to home or family visits to the service). * 12 patients (19 per cent) were not in any contact with any member of their family. * 28 (44%) of all patients were visited by their family at the service during the year covered by the study and 28 (44%) did not receive any visits. * 111 home visits were carried out during the study period, an average of 1.8 home visits per patient. * 54% of patients had at least one visit during the 12-month study period while 46% (n=29) had no home visits. * No significant difference found in number of home visits between men and women (U=442.5, p=0.79). * There was a significant difference between patients within different levels of security and the number of home visits, with patients within rehabilitation wards having significantly more home visits than those in higher levels of security (χ2(2) =7.8, p=0.02). * No difference between patients under a civil or criminal section (U=442.5, p=0.49). * There were no significant differences in the number of home visits between patients treated “within area” or “out of area” (U=459.5, p=0.82). |
| Chester, Völlm, Tromas, Kapugama & Alexander (2018), UK. | Mixed methods (including file review, questionnaire & cross-sectional survey) | N=401   * long-stay patients with intellectual disabilities (66) * long-stay patients without intellectual disabilities (335) | Patients from all 3 high secure units in England and a stratified cluster sample of 23 (out of 57) medium secure units in England.  85.8% male  78.1% white  11.2% black  5.5% mixed race  3.5% Asian  1.7% unspecified/other  ID mean age = 40yrs  No ID mean age = 45yrs | *Measures of effectiveness*   * Length of stay * Discharge pathway * Risk and offending behaviours * Historical Clinical Risk Management Assessment (HCR-20) 130 | * The intellectual disability group had a significantly lower continuous length of stay (median=132.2months) than the non-intellectual disability group, (median=162.5 months). * For categorical care length of stay, no significant differences were found two groups. However, of those with intellectual disabilities, 43.9% had stayed between 5 and 10 years, 43.9% staying >10–20 years and 6.1% had stayed >20–30 years, with a further 6.1% having spent over 30 years in continuous care. * Intellectual disability patients were more likely have been admitted to continuous care under a civil section (37.9%) than those without (16.5%). * The intellectual disability group had higher scores on subscales and total scores of the HCR-20 130 structured clinical judgement tool, reaching statistical significance on the total (M=30.56, SD=4.38 vs M=27.38; SD=5.39), history (M=16.70; SD=2.15 vs M=15.23; SD=3.09) and clinical (M=7.07; SD=2.02 vs M=6.09; SD=2.68) subscales. |
| Devapriam, Fosker, Chester, Gangadharan, Hiremath and Alexander (2020), UK | Retrospective case note file | N=21 | Patients admitted to a 16-bedded specialist ID inpatient service consisting of an eight-bedded acute assessment unit  and an eight-bedded locked rehabilitation unit between 2008 and 2016.  71% male  43% autism spectrum disorder  Mean age 35.4 years (range=21-52yrs)  61.9% admitted on civil section  33.3% admitted on forensic section | *Measures of Effectiveness*   * Length of Stay * Discharges   Discharge placement | * Median length of stay in the service was 536 days (1.5years), with a range of 69-171 days (0.19-4.5years). * 20 of 21 patients discharged during the study period, with 81% (n=14) going to a lower level of security. * 14.3% (n=3) went to a higher security placement (e.g. moving from rehab to low secure or low secure to medium secure) and 1 patient (4.8%) remained within the rehabilitation unit. * 90.5% of patients (n=19) discharged on a civil section and 2.5% (n=2) discharged on a forensic section. |
| Esan, Chester, Gunaratna, Hoare & Alexander (2014), UK. | Retrospective case note review | N=138   * Individuals with autism spectrum disorder (42) * Individuals without autism spectrum disorder (96) | Individuals with an autism spectrum disorder in a specialist inpatient forensic service for individuals with intellectual disabilities. Reports treatment outcomes following a 6-year period.  Autism spectrum disorder group  86% Male  Mean age = 30.14yrs (SD = 9.14)  31% detained under Mental Health Act | *Measure of effectiveness:*   * Length of stay * Discharge pathway   *Measure of patient safety:*   * Use of physical intervention * Use of seclusion * Use of PRN * Observation levels | * No significant difference found between the length of stay of those with an autism spectrum disorder compared to those without, for either discharged (autism group median = 925 days, SD = 1101.8; comparison group median = 1080 days, SD = 1570) or current inpatients (autism group median = 1052.0 days, SD = 1570; comparison group median = 1323, SD = 1505 days). * Individuals with autism spectrum disorder were found to have significantly higher incidents of physical interventions and higher observations levels compared to inpatients without an autism spectrum disorder. |
| Griffiths, Roychowdhury & Girardi (2018), UK. | Retrospective case file review | N=347   * 96 with at least 1 episode of seclusion (ASD n=15) * 251 with no episodes of seclusion (ASD n=34) | Patients admitted to a UK-based private provider of low and medium secure inpatient services, between 2007 and 2015.  Secluded Asperger’s Sample:  100% male  Mean age = 27.9yrs (SD=7.9)  Entire Secluded cohort:  59% Male  Mean age = 30.8yrs (SD=10.7)  Non-secluded Asperger’s Sample:  88% male  Mean age = 32.5yrs (SD=13.0)  Entire non-secluded cohort:  67% Male  Mean age = 32.5yrs (SD=12.7) | *Measures of effectiveness*   * Length of stay * Health of the Nation Outcome Scales for people with in Secure Services (HoNOS-Secure) 152   *Measures of patient safety*   * Use of seclusion. | * Length of stay did not differ between secluded and non-secluded patients for the whole cohort (Non-secluded M=933.3 days; SD=604.4 vs secluded M=1018.3 days; SD=693.2), nor between those with Asperger’s Syndrome (Non-secluded M=867.3 days; SD=543.4 vs secluded M=938.4 days; SD=461.9) or other subgroups with mental health diagnosis. * The entire cohort and the ASD subgroup show improvement on HoNOS-secure scores between admission and discharge. * Secluded patients scored significantly higher on the HoNOS-secure (at both admission and discharge) compared to those who were not secluded in the whole cohort and the ASD subgroup. * 15 patients with Asperger’s syndrome were secluded (31%), compared to the entire cohort of 96 (27.6%). |
| Huitema, Verstegen & de Vogel (2021), The Netherlands. | Case file review | N= 614 | Patients at a Dutch forensic psychiatric hospital sentenced by court to mandatory inpatient treatment admitted between January 2014 and December 2019.  85% male | *Measure of Patient Safety*  Modified Observed Aggression Scale+ | * 60% of admitted patients displayed violence (n=369), with 21.5% (n=132) displaying physical violence. * There was no significant difference in the percentage of those diagnosed with an ID who displayed physical violence to those who did not (17.1% and 17.6% respectively; χ2=0.015, p=.901) * The presence of an intellectual disability, nor schizophrenia spectrum disorder, antisocial and borderline personality disorder or psychopathy, as measured with PCL-R score, was not associated with physical violence. |
| Halstead, Cahill, Fernando & Isweran (1999), UK. | Retrospective Case Review - Follow up survey | N=35 | Discharged patients from a medium secure unit who received at least one year’s treatment between 1987 and 1994.  83% male  Mean IQ score: 68 (SD = 11.4)  89% borderline or mild IQ  9% moderate intellectual disability  97% detained under the Mental Health Act | *Measures of effectiveness*   * Length of stay * Discharge pathway * Progress (determined by response to treatment, reduction in risk and considered safe for discharge or transfer) * Re-admission * Re-offending and re-conviction | * Mean length of stay in the unit was 30 months (SD = 13.2, range = 4-76). * 46% of the sample achieved ‘good progress’ by discharge. * 31% had made ‘some progress’ by discharge. * No change was detectable in 11% and 11% were thought to have deteriorated since discharge. * At discharge 9% of individuals went home, 49% to a hostel, 37% went to another hospital and 6% to a special hospital, * At follow up 12 individuals (34%) were hospitalised, 21 (60%) were living in the community and 2 (6%) patients had died. * Those who improved during inpatient treatment had significantly lower IQ (mean IQ: 68.4) than those who did not (mean IQ: 77.5). * 8 episodes of readmission were recorded during the follow up. * 34% displayed behaviour that could have been construed as offending during the follow up period. * 1 individual was reconvicted following discharge. |
| Lin, Barbaree, Selick, Ham, Wilton & Lunsky (2017), Canada. | Cohort Analysis | N=5,057   * forensic IDD patients (617) * Non-IDD forensic patients (4458) | Population-based cohort of  Ontario adults with IDD in forensic inpatient beds during 2005–2015.  Forensic IDD sample:  81.5% male  Non-IDD forensic sample:  83.7% male | *Measures of effectiveness*   * Length of stay * Admissions * Forensic admissions | * Over the study period forensic ID patients averaged 220.6 days more than forensic non-ID forensic admissions (d = 0.28, 95% CI: 0.20–0.37). * Admissions for individuals with IDD constituted 12.2% of the forensic inpatient population but only 0.8% of the general population (d = 1.57; 95% CI: 1.52–1.62). * No significant differences were found between the IDD and non-IDD groups in percentage of longer-stay admissions (33.4% vs. 29.3% respectively, d = 0.11). * No significant difference was found between the groups in relation to multiple admissions during the 10 years (IDD=36.0% vs. Non-IDD=33.3%, d = 0.07) |
| Morrissey, Hobson, Faulkner & James (2015), UK. | Retrospective case note review | N=68   * sub cohort admitted with 3yrs of data available (24) | All admissions (100% male) to the National High Secure Learning Disability Service 2008-2013.  Mean age = 34.2yrs  Mean IQ = 62.9 | *Measure of effectiveness*   * Length of stay * Emotional Problems Scale – Behaviour Rating Scale (EPS-BRS) 132 * Emotional Problems Scale – Self-Report Inventory (EPS-SRI) 132 * Readmissions   *Measures of patient safety*   * Incidents of violence | * Median length of stay for those discharged from the entire cohort was 9.92 years (range = 1.25-24.08). * For those still in treatment, the median length of stay was 5.92 years (range = 2.17-35.25). * Nine individuals (25%) from the entire cohort and four (44%) from the sub cohort were re-admitted during the study period. * For the sub cohort, a significant difference was found in scores on the EPS behaviour rating externalising subscale 132following treatment, suggesting a deterioration in problem behaviours (increase in mean score from 36.3 to 53.5) * Significant reduction in 'total pathology' from baseline to follow up found on the EPS-Self Report Inventory 132 with a mean score decrease from 75.9 to 60. * Significantly lower total pathology scores for those discharged compared to those still in treatment at two- and three-years post admission. * No significant reduction in mean violent incidents per year per person throughout years one to three years following admission but a significant reduction seen when compared to a fourth year (mean incidence in first year 6.05 compared to 2.8 in fourth) |
| Morrissey, Langdon, Geach, Chester, Ferriter et al. (2017),  UK. | Systematic Literature Review | N=60 studies | Systematic review of literature and consultation exercise focusing on outcomes of forensic services for people with intellectual disabilities. | *Measures of effectiveness*   * Length of Stay   *Measures of patient experience*   * Consultation groups with patients and carers | * A range of 1-9 years was reported for the 22 studies that included data on length of stay. * Patients and carers reported on areas they felt important when considering outcomes of forensic services for people with intellectual disabilities within the domains of effectiveness, patient safety and patient experience. Comments included length of stay, appropriate placement and treatment, improvements in clinical symptoms and behaviour, staffing provision, use of seclusion, quality of life and engagement in meaningful activity. |
| Murphy & Mullens (2017), UK. | Mixed-methods design (including semi-structured interviews) | N=7 | Seven male patients with an autism spectrum disorder admitted to a high secure psychiatric hospital.  Age range = 22-49yrs | *Measures of patient experience*   * Lancashire quality of life profile (LQOLP) 153 * Semi-structured interview | * Patients with an ASD reported comparable or slightly above satisfaction levels in all domains of the LQOLP 153 compared to non-forensic general psychiatric inpatients, medium secure and high secure psychiatric inpatients. * For the domains of global well-being, finance and religion in the LQOLP 153, patients with an ASD had significantly higher satisfaction (>1) than other patient groups. * Patients reported the loss of freedom and restrictions on personal possessions was extremely difficult for them, particularly if they had specific interests. * Stress and discomfort were frequently related to the presence of other patients e.g. noise levels, isolation, bullying and unpredictability. * There was variation in personal attitudes towards being detained however a positive experience of the hospital was given by the participants and that it had made a positive difference to them. * Relationships with clinical staff and opportunities to attend a wide range of activities and therapies were valued by the patients and viewed as having made a positive difference on their lives, along with access to an independent advocate and regular progress meetings. |
| Murphy, Bush, and Puzzo, (2017), UK. | Audit of case files | N=198   * 8 ASD | Patients in a UK high-secure hospital case files studied within a 12-month time frame.  100% male  100% detained under forensic section of MHA | *Measures of Effectiveness*   * Length of Stay * Prevalence   *Measures of Patient Safety*   * Use of Seclusion (frequency and hours, short term and long-term seclusion). * Patient ‘incompatibilities’[[3]](#footnote-4) (including violent or aggressive behaviour) | * Approximately 4% cent of the total patient population had diagnosis of ASD. * No patients met the formal criteria for an intellectual disability. * The length of detainment for the patient group (ASD and non-ASD) varied between 2 and 15 years, with a mean of 4.8 years. * Mean length of stay for those with ASD who experienced at least 1 seclusion was 4.83 years, SD=5.18, range=1.42yrs-14.92yrs (ASD excluded mean age=24.57yrs, SD=12.45, range=22yrs-37yrs) compared to those without ASD with a mean length of stay of 5.26 years, SD=5.70, range=0.5yrs-31.91yrs (non-ASD secluded mean age=36.54yrs, SD=9.51, range=19yrs-59yrs) * 103 of 198 patients (52.2%) in the hospital had at least one formal incompatibility with another patient. * 7 of 8 patients with ASD (87.5%) had at least one incompatibility compared to 96 of 190 patients without ASD (50.5%). * 16.7% of incompatibilities involved at least one patient with ASD. * The difference in proportions between patients with an ASD in the total hospital population (4.04%) and patients with an ASD on the incompatibilities list (6.8%) was significant χ2(1, n=198) = 4.405, *p*=0.40. * 127of 198 (64.1%) patients in the hospital were secluded on the grounds of behaviour and risk. * 6 of 8 patients with ASD (75%) were secluded compared to 121 of 190 patients without ASD (63.7%). * The total number of seclusions was 877 (355 short term seclusions and 522 long term seclusions) and the total hours spent in seclusion was 193,330.18hours (25,625.94hrs short term and 167,704.24hrs long term). * Mean number of seclusions suggests patients with an ASD experienced a higher number of, and more hours in, long term seclusions compared to patients without an ASD. * ASD mean no of LT seclusions = 7 (SD=5.38), mean hours in LT seclusions= 2,268.27 (SD=1,992.33); non-ASD mean no. of LT seclusions=4 (SD=4.39), mean hours in LT seclusion = 1,273.51 (SD=1,645.79). |
| Ray, Simpson, Jones, Shatokhina, Thakur & Mulsant (2019), Canada | Casenote review | N=510  9.2% (n=47) intellectual disability | Forensic patients with and without ID in one large Canadian hospital-based forensic mental health  Program.  ID  87.2% male  Non-ID  82.2% male | *Measures of Patient Safety*   * Use of physical intervention * Use of Seclusion * Incidents of aggression | * The ID group did not present with significantly more or less aggressive behaviours, conflicts with peers or be significantly more or less likely to become involved in episodes of physical restraint or locked seclusion than those without ID. * Those with ID were more likely to be detained in a higher level of security than those without ID, particularly more likely to be in a secure unit (OR, 0.74; 95% CI, 0.58–0.93). |
| Reed, Russell, Xenitidis & Murphy (2004), UK. | Retrospective case note review/clinical record review | N=86   * Offenders (Receiving care under a ‘forensic’ order e.g. Sections 35,37, 37/41 or 38 of Mental Health Act, or a probation order) (45) * Non-Offenders (informal patients or those detained under Sections 2 or 3 of the Mental Health Act) (41) | Individuals with intellectual disabilities and challenging behaviour admitted to a low secure inpatient unit.  Offenders group  75.6% male  Mean age = 29yrs (range = 16-44)  FSIQ: 66 (range = 47-79)  Non-offenders group  68.3% male  Mean age = 27yrs (range = 17-46)  Mean full Scale IQ = 65 (range = 46-84) | *Measures of effectiveness:*   * Length of stay * Discharge placement * Challenging behaviour (severity and frequency of incidents)   *Measure of patient safety*   * Use of physical restraint * Use of seclusion | * No significant difference between mean length of stay for offenders compared to non-offenders (71 weeks; range = 12-185 compared to 67 weeks; range = 28-148). * Offenders statistically more likely to be discharged to non-community settings. * Offenders more likely to be discharged to a less restrictive setting that original placement (71% compared to 59%) but difference not statistically significant. * No significant difference found in total rates of challenging behaviour between offenders and non-offenders however the non-offender group were significantly more assaultive to staff and to other patients, and used weapons more significantly. * Non-significant trend showed greater reduction in incidents of challenging behaviour between baseline and end for offenders than non-offenders (0.79 to 0.36 incidents per person week compared to 0.23 to 0.11). * Significantly higher rates of restraint and relocation required for non-offenders than non-offenders (mean restraint incidents per month for offenders = 0.52, SD = 0.55; mean incidents for non-offenders = 2.51, SD = 6.36; mean relocation incidents per month for offenders = 0.36, SD = 0.52; mean for non-offenders = 1.34, SD = 2.09) * No significantly difference found between offenders and non-offenders in rate of seclusion or any change in rate following treatment. |
| Senn, Bulten, Tomlin and Völlm (2020), UK and Netherlands | Cross-sectional study | N = 503   * 401 long-stay patients in England * 102 long stay patients in the Netherlands. | Patients detained in England for 5 years in medium secure care,  or 10 years in high secure care, or 15 years in continuous secure  care if patients had stayed in a combination of high and medium  secure settings. Patients in the Netherlands admitted to one of two participating TBS (forensic) long-stay  hospitals, admission characterised as unsuccessful treatment at a  minimum of two TBS (forensic) facilities for a total of at least 6 years, where treatment success is defined in terms of a significant reduction in  risk of re-offending.  English Sample  Mean age = 44.5yrs (SD=11.3)  85.8% male  Dutch Sample  Mean age = 51.7yrs (SD=8.9)  98% male | *Measures of Effectiveness*   * Length of stay | * The Dutch long-stay patients had, on average, a longer length of stay (18.3 years vs. 14.6 years; d = 0.45; 95% CI (0.23, 0.67), p <0.001). * A diagnosis of ASD was less common in the English sample (2.5%, n=10) compared to the Dutch (21.6%, n=22), χ2 (1) =49.67, p=<0.001. |
| Verstegen, de Vogel, Huitema, Didden and Nijmen (2020), The Netherlands. |  | N=614 | Patients in a Dutch forensic psychiatric hospital mandatory for inpatient treatment admitted between  January 2014 and December 2019  85% male  61.5% admitted under criminal commitment (section) | *Measures of effectiveness*   * Length of stay   *Measures of patient safety*   * Violent incidents | * The mean number of years that the patients were hospitalized was 2.26 (SD = 1.98). * Patients who were physically violent exhibited their first violent incident after a median number of 261 days after admittance into the hospital. * 60% of all admitted patients (369 out of 615) exhibited any form of violent behaviour and 21.5% (132 out of 615 patients) exhibited physically violent behaviour. * The median number of physically violent incidents per physically violent patient was 2, with a maximum of 65 incidents per patient. * Of those inpatients not displaying physical violence, 17% had intellectual disability; Of those inpatients displaying physical violence, 17.7% had intellectual disability (χ2=0.015,p>.5) * 18% of individuals with intellectual disability display one incident of physical violence, 17.1% displayed 2+ incidents of physical violence and 15.8% displayed more than 5 incidents of physical violence. * The presence of a schizophrenia spectrum disorder, an antisocial and borderline personality disorder, psychopathy as measured with PCL-R score, and an intellectual disability was not associated with physical violence. |
| Völlm, Edworthy, Husband, Talbot, Majid et al. (2018), UK. | Mixed methods (including file review, questionnaire & cross-sectional survey) | N=401   * long-stay patients with intellectual disabilities (66) * long-stay patients without intellectual disabilities (335) | Patients from all 3 high secure units in England and a stratified cluster sample of 23 (out of 57) medium secure units in England.  85.8% male  Mean age = 44.46yrs (SD=11.26)  16% with intellectual disability | *Measures of effectiveness*   * Admissions | * Intellectual disability was found to be higher in high secure care than medium (24.1 vs. 13.3%; 27.00, p0.008) which the authors suggest may reflect bed availability in medium and high secure care for these individuals. |
| Williams, Thrift & Rose (2018), UK. | Qualitative design utilising semi-structured interviews | N=7 | Seven female patients who display offending behaviours from a single low secure women’s unit for those with intellectual disabilities.  Age range = 27-56yrs | *Measures of patient experience*   * Themes identified from Interpretive Phenomenological Analysis | * A superordinate theme from the interpretive phenomenological analysis was ‘Hospital as helpful AND undesirable’. * In the subtheme ‘Hospital as Helpful’ the participants identified the specialist inpatient treatment and staff support as helpful. * Narratives alluded to aspects of self-harm and the hospital was viewed as being able to meet such complex needs. * Hospital was seen as the ‘best alternative’ to other environments such as prison. * The subtheme ‘Hospital as undesirable’ included aspects of missing things or people, the hospital itself being a difficult environment to live in and desiring the freedom to live in the community. |
| Wooster, McCarthy & Chaplin (2018), UK. | Retrospective case note study | N=40   * admissions to medium secure (29) * admissions to low secure (11) | Patients with ID admitted to and discharged from medium and low secure service wards in an NHS specialist forensic ID service between 2009 and 2016.  100% male  Mean age at admission = 31.7yrs (low secure mean = 34.2yrs; medium secure mean = 30.8yrs)  85% mild ID  5% borderline ID  5% moderate ID | *Measures of effectiveness*   * Length of stay * Discharge pathway * Readmission * Reoffending on discharge | * The average length of stay for all patients was 692.2 days. For the low secure patients, the average was 594.8 days and for the medium secure, 724.2 days. * 67.5% of patients were discharged to the community, including 81.5%% to supported living, 3.7% to a probation hostel and 14.8% to their family home. * 7.5% of patients were transferred to the UK High Secure Learning Disability Service (all from the medium secure unit). * 7.5% were transferred to ‘open’ ID wards or stepdown facilities (two patients from medium secure and one from low secure). * Three medium secure patients undertook a horizontal transfer to another medium secure unit in the UK. * 7.5% of patients were transferred to prisons (two patients from medium secure and one from low). * Of the 30 patients eligible for readmission, 20% (n=8) were readmitted during the study period, all of whom were discharged to the community (seven patients discharged from medium secure and one from low secure). * The mean length of time to readmission was 871 days (1002.9 days for medium secure readmissions and 15 days for the low secure readmission). * Nine patients from medium secure re-offended following discharge as did one from low secure. * The mean length of time to offence following discharge was 904.4 days (997 days for medium secure discharged patients and 72 days for the low secure patient). |

| **Study & Country** | **Design** | **N** | **Sample** | **Domain Outcomes** | **Findings** |
| --- | --- | --- | --- | --- | --- |
| **Children and adolescents with intellectual disabilities and/or autism within inpatient psychiatric services** | | | | | |
| Cervantes, Kuriakose, Donnelley et al. (2019), US. | Retrospective case note review | N=52   * ASD:CP follow-up admissions (20) * ASD:CP initial admissions (20) * Pre-ASD:CP admissions (17) | First time ASD inpatient admissions following an ASD specific care pathway (ASD:CP) in a follow-up period from January 2017 to December 2018 compared to the initial ASD:CP admission period and previous non-ASD:CP in Kuriakose et al. (2018).  Follow-up ASD:CP admissions  100% male  Age range = 4-17 years | *Measures of effectiveness*   * Length of stay   *Measures of patient safety*   * Use of physical intervention * Use of PRN medication | * No significant differences reported in length of stay between the three groups (all p>0.05), or in the number of physical interventions used. * Significant differences were reported in the use of PRN medication, with fewer administrations of intramuscular injections in the follow up ASD:CP compared to the non-ASD:CP (Mean rank 20.0 vs. 33.21; U=63.50,p=0.004,r=-.51). The initial ASD:CP admissions received less administrations of PRN than the non-ASD care pathway group and more than the ASD:CP follow up group (Mean rank = 25.68), however this difference did not reached significance for either group (all p>0.05). |
| Chaplin, Roach, Johnson & Thompson (2015), UK. | Analysis Data collected as part of national audit | N=151   * admissions with intellectual disabilities (38) * admissions without intellectual disabilities (113) | Admissions from 14 CAMHS inpatient units (specialist intellectual disabilities and general adolescent mental health units).  Intellectual disabilities admissions  63% males  Mean age = 14.2yrs (*SD* = 2.06).  21% compulsory admission.  Mild intellectual disability (n=14)  Moderate intellectual disability (n=10)  Severe intellectual disability (n=13)  Admissions without intellectual disabilities  40% males  Mean age = 14.4yrs (*SD* = 2.51).  16% compulsory admission | *Measure of effectiveness*   * Length of Stay * Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) 154 | * Significantly longer length of stay for individuals with intellectual disabilities (*M =* 109.9 days, *SD* = 68.3) compared to individuals without (*M* = 78.2 days, *SD* = 117). * No significant difference in length of stay for individuals with intellectual disabilities admitted to a specialist intellectual disabilities unit compared to those admitted to a general mental health unit. * Individuals with intellectual disabilities had significantly higher HoNOSCA scores 154 on admission and discharge but no significant difference was found in the degree of improvements when compared to individuals without intellectual disabilities. * Individuals with intellectual disabilities admitted to a general mental health unit showed significant improvements in HoNOSCA scores 154 between admission and discharge and improved to a greater extent than those with intellectual disabilities. * General mental health units admit more individuals with mild intellectual disabilities. |
| Croteau Mottron, Dorais,  Tarride and Perreault (2019), Canada | Analysis of public health services databases | N=1,227   * Years 1-5 (550) * Years 6-12 (338) * Years 13-17 (140)   Years 18-25 (179) | Cohort of newly diagnosed autism spectrum individuals  identified from the Régie de l'assurance maladie du Québec administrative database between January 1998 and December 2010.  Age 1-5yrs  80.9% Male  3.5% Intellectual disability  Age 6-12yrs  80.5% Male  4.9% Intellectual disability  Age 13-17yrs  80.0% Male  7.2% Intellectual disability  Age 18-25yrs  78.2% Male  20.7% Intellectual disability | *Measures of Effectiveness*   * Length of stay   Admissions | * Psychiatric hospitalizations decreased by at least half after 5 years of follow-up for all groups. * Psychiatric hospitalizations were more common in individuals diagnosed at an older age and represent the greatest cost. * Psychiatric hospitalizations and visits to specialists and other neuropsychiatric diagnoses were more frequent in those previously exposed to psychoactive drugs in the year preceding cohort entry * Hospitalizations represented over 80% of overall expenditures for adolescents and young adults. * Psychiatric hospitalization costs were mainly driven by lengthy stays in adolescents and young adults. * For 1-5yr olds 17.3% had at least one hospital admission before cohort entry with M=0.2 (SD=0.6) hospital admissions before cohort entry and a median length of stay of 1.0 (IQR=1.0-3.0) days before cohort entry. * For 6-12yr olds 12.6% had at least one hospital admission before cohort entry, with M=0.2 (SD=0.4) hospital admissions before cohort entry and median length of stay of 1.0 (IQR=1.0-7.5) (days) before cohort entry. * For 13-27yrs olds 15% had at least one hospital admission before cohort entry with M=0.3 (SD=0.8) admissions before cohort entry and a median length of stay of 9.0 (IQR=1.0-24.8) days before cohort entry. * For 18-25yrs olds 20.1% had at least one hospital admission before cohort entry with M= 0.3 (SD=0.7) hospital admissions before cohort entry and a median length of stay of =12.0 (IQR-2.3-27.0) days before cohort entry. |
| de Neira, Blasco-Fontecilla, Murillo,  Pérez-Balaguer et al. (2021), Spain. | Retrospective case file review | N=89  5 ASD admissions (4 to ER, 1 to AIU) | Adolescents admissions (<17yrs) to the Emergency Room (ER) or  hospitalized at the ten-bedded Acute Inpatient Unit (AIU) at a large Spanish hospital between March 2020 and April 2020 (first month of COVID lockdown) and compared to 2019 figures.  Mean age = 14.78yrs (SD=2.08)  32.75% male  0.06% autism spectrum disorder | *Measures of Effectiveness*   * Length of Stay * Admission figures | * Decrease in adolescents admitted to ER for psychiatric care between 2019 and the first month of COVID lockdown in 2020 – 64 compared to 25. * Adolescent psychiatric admissions AIU decreased from 31 in 2019 to 18 during the first month of COVID lockdown. * Significant Increase in adolescents admitted to AIU from ER in the first month of COVID lockdown in 2020 compared to 2019 (60% vs. 28.1%, p=<0.05). * The average hospital stay during the first month of COVID lockdown in 2020 was shorter in comparison to 2019 (8.94 days +4.87 vs. 14.32 days ± 10.23, p=0.08). * A decrease in admissions to both the ER and the AIU for those diagnosed with autism spectrum disorder was seen during the first month of COVID lockdown in 2020 compared to 2019 (ER: 0% vs. 6.3%; AIU: 5.6% vs 16.1%). * Self-injurious thoughts and behaviours were the most predominant reasons for consultation at both ER and AIU for all diagnostic categories. |
| Donnelly, Cervantes, Oparaeke, Stein, Filton et al. (2020), USA. | Repeated Measures within-subjects comparative design | N=58   * Staff implementing the ASD-CP (30) * Youth with ASD admitted to the ASD-CP | First time patients to an ASD care pathway diagnosed with an ASD, with low to no-verbal skills and hospitalized on a child/adolescent inpatient unit for 7+ days in a public hospital in a metropolitan city from July 2015 to June 2018.  Staff providing services to the above.  ASD Youth  100% male  11.21 (3.54) years mean age (SD). | *Measures of Effect*   * Length of Stay * Fidelity to pathway tools and strategies   *Measures of Patient Safety*   * ‘Crisis Interventions’ | * No significant findings were found between documented fidelity (high or low fidelity to ASD-CP) and patient length of stay (short=<14days, or long stay, >14 days). * Reward identification (part of the ASD-CP) early in the inpatient stay was significantly associated with fewer crisis interventions later in a patient’s stay (U=14.50, p=0.007, r= − 0.50). * Utility of the ASD-CP tools received an average rating of 4.17 (SD = 0.75) out of 5 on a Likert scale. * Scores for ASD-CP strategies had average rating of 4.33 (SD = 0.66). * No staff provided negative appraisals of tool or strategy utility overall and ratings for both ranged from 3 (somewhat useful) to 5 (very useful). |
| Gabriels, Agnew, Beresford, Morrow, Mesibov & Wamboldt (2012), US. | Retrospective case review of Specialist unit and general psychiatric inpatient programme | N=117   * General psychiatric inpatient unit (12) * Specialist inpatient programme (26) * Intensive day programme (79) | ID/ASD spectrum disorder admissions (79.4% male) aged 3-19 years, to a new intellectual disability service model offering a specialist short-term inpatient unit and intensive day treatment (partial hospitalisation) programme.  New service compared to sample of inpatient data from previous general psychiatric inpatient model (8.5% male). | *Measure of effectiveness*   * Length of stay * Readmission | * Mean length of stay for the pre-specialist (general psychiatric) programme was 45 days (range = 13-180) compared to 26.1 days (range = 10-56) for the specialist inpatient programme, and 12.6 days (range = 1-41) for the intensive day programme. * Readmission rates in the study periods were 33.3% in the psychiatric inpatient group, 11.5% in the specialist inpatient programme and 10.3% in the intensive day programme. |
| Imran, Bodla, Asif, Shoukat and Azeem (2020), Pakistan | Retrospective case note review | N=634 | Youth admitted to Pakistan’s first dedicated child & adolescent psychiatry inpatient unit in Lahore over a period of seven years.  56% female  12.3yrs (2.3) mean age (sd). | *Measures of Effectiveness*   * Length of stay * Clinical Global Impression Scale (CGI). | * Mean (sd) duration of admission was 15.60 (6.3) days. * 25% (n=159) of admissions had comorbid diagnosis of intellectual disability. * Significant change in mean CGI severity score (Z=- 9.97; P=0.000) following admission, with a mean (SD) improvement of 1.7 (0.7). |
| Kalb, Stuart & Vasa (2018), US. | Secondary analysis of large US healthcare insurance database | N= 2,784,741   * admissions with autism spectrum disorders (46,343) * admissions with ADHD diagnosis (408, 066) * admissions with neither diagnosis (2,330,332) | Adolescents with autism spectrum disorder, with attention deficit hyperactivity disorder and those with neither diagnosis who presented with psychiatric-related emergency department visits.  ASD group:  80% male  Mean age = 13.9yrs (SD=1.6)  ADHD group:  68% male  Mean age = 14.1yrs (SD=1.6)  Without ASD/ADHD group:  49% male  Mean age = 14.6yrs (SD=1.6) | *Measures of effectiveness*   * Admissions (Emergency Department visits) | * A larger proportion of visits among adolescents with ASD (15%) and adolescents with ADHD (14%) resulted in a psychiatric hospitalization compared to adolescents without either diagnosis (7%). * Adolescents with ASD had an increased rate of psychiatric emergency department visits (M = 5.7 visits per 100 adolescents per year) compared to the other two groups (ADHD: IRR = 2.0, 95% CI: 1.9, 2.1; neither diagnosis: IRR = 9.6, 95% CI: 9.1, 10.0, both p < 0.001). * Between 2010 and 2013, there was no change in psychiatric emergency department visits among adolescents with ASD (IRR = 0.96, 95% CI = 0.92, 1.0, p = 0.07 for linear time trend). * Adolescents with ASD were more likely to have a repeat visit compared to adolescents with ADHD (30 days, OR = 1.3, 95% CI: 1.1, 1.5; 90 days, OR = 1.5, 95% CI: 1.3, 1.5) and those without either diagnosis (30 days, OR = 1.6, 95% CI: 1.4, 1.8; 90 days, OR = 2.2, 95% CI: 1.9, 2.4). * Adolescents with ASD had more outpatient mental health visits 30 days prior to their first psychiatric ED visit than adolescents with ADHD (IRR = 1.2, 95% CI: 1.1, 1.3) and adolescents without either diagnosis (IRR = 2.1, 95% CI: 1.9, 2.2) |
| Kerkela, Gyllenberg, Gissler, Sillanmaki, Keski-Santti et al. (2020), Finland. | Cohort analysis of Case Register data | N = 145,405 subjects, | Incidences of childhood and early adulthood hospital-treated psychiatric disorders in five large Finnish birth cohorts of individuals born between 1966 and 1997.  71,209 males  65,190 females  Aged 0 to 28  Childhood and Adolescents aged 0-18yrs  Young adulthood 18-18yrs | *Measures of Effectiveness*  Admissions | * Cumulative incidence of hospital-treated psychiatric disorders increased over the decades in Finland. * Total incidences of psychiatric disorders in childhood and adolescence among males increased in the birth cohorts over decades (Incidence Rate Ratio, IRR = 1.04 (1.04–1.05); p < 0.001) and females (IRR = 1.04 (1.03–1.04); p < 0.001). * Significant increase among females in early adulthood (IRR = 1.04 (1.03–1.05); p < 0.001), however the increase amongst males was not significant (IRR = 0.99 (0.99–1.00), p = 0.051). * Between 0.9 and 2.1% of males from the five birth cohorts had a diagnosis of intellectual disability. * Between 0.2 and 0.8% of females from the five birth cohorts had a diagnosis of intellectual disability |
| Kuriakose, Filton, Marr et al. (2018), US. | Retrospective case note review | N=37   * ASD:CP admissions (20) * Pre-ASD:CP admissions (17) | First time ASD inpatient admissions following an ASD specific care pathway (ASD:CP) between July 2015 and December 2016, compared to first time ASD admissions prior to the implementation of the ASD:CP from January 2014 to June 2015.  ASD:CP admissions  95% male  Age range = 4-17 years  Non-ASD:CP admissions  76.5% male  Age range = 4-17 years | *Measures of effectiveness*   * Length of stay   *Measures of patient safety*   * Use of physical intervention * Use of PRN medication | * Differences between the ASD care pathway and previous care pathway in the inpatient length of stay, number of holds/restraints during the inpatient stay, or the number of intramuscular medication administrations delivered were not significant. * A notable difference in the absolute number of days spent in the hospital was reported between the pre ASD care pathway (22.4 days) and ASD care pathway (13.4 days), approaching significance (unpaired t-test = 1.88, p=0.07). * A statistically significantly smaller number of admissions experienced physical intervention in the ASD-CP compared to those in the non-ASD care pathway (38.8% vs. 26.3%; Fisher’s Exact = 0.050, p=0.039). |
| Livanou, Singh, Liapi and Furtado (2020), UK. | Case note review | N=34 | Young offenders transitioning from national adolescent forensic medium secure units to adult services in the UK between May 2016 and November 2016.  70.59% males  17.65% 17.5yrs  73.53 18yrs  8.82% 19yrs  27% intellectual disability.  9% autism  64.71% White British  14.71% Black  5.88% Mixed  8.82% White other  5.88% South Asian  73.53% Civil section  26.47% Forensic section | *Measures of Effectiveness*  Discharge placement | * 35.29% (n=12) discharged to community, 2.9% (n=1) discharged to adult psychiatric hospital, 52.94% (n=18) to adult secure unit and 8.8% (n=3) to open units. * 84% of male patients with neurodevelopmental problems and/or learning disabilities were transferred to adult secure hospitals that were high, medium or low security. * 20% of male sample had an intellectual/developmental disability compared to 6% of females. |
| Lokhandwala, Khanna & West-Strum (2012), USA. | Cross sectional analysis of national inpatient care survey | N=25,930   * autism discharges (5,186) * matched comparison discharges without autism (20,744) | 2007 discharge records from largest all-payer national survey of in-patient care in the US. Extracted case records of individuals with a primary or secondary diagnosis of autism, plus a matched discharge control group without an autism diagnosis.  Each discharge group (approx.)  79% male  26% <10yrs  42% 10-20yrs  32% > 21yrs  Authors excluded all discharges where length of stay was greater than 365 days or total chargers were more than $1million. | *Measures of effectiveness*   * Length of stay * Admissions * Discharges | * Individuals with autism had 1.5 times longer length of stay than those without autism (6.5 days compared to 4.2). * A higher percentage of individuals with autism transferred to another health facility (9.6%) compared to those without autism (3.7%). * Factors predicting length of stay among individuals with autism were age, hospital location, size of hospital, admission route (e.g., emergency vs. routine) and discharge (routine vs. transfer to other health facility) * Overall admission rate of 65.6/100,000 for individuals with autism in 2007. * Admissions rates were highest amongst individuals with autism aged 10-20yrs, for males and for those with an income of >$63k, with private health insurance. * Total hospital charges were higher for those with autism compared to those without ($24,862.00 vs. $23,225.00). |
| Medel-Herrero & Gomez-Beneyto (2019), Spain. | Interrupted time series analysis of Hospital Morbidity survey data | N=1,152,880 | All psychiatric hospital discharges from Spanish Hospitals from 2002 to 2013 (69 months either side of the April 2008 economic crisis). | *Measures of effectiveness*   * Admissions | * Psychiatric hospitalisation rates for those aged 15-34 years stopped declining following the April 2008 economic crisis and remained steady for the next years, whereas all other ages groups appeared to continue to decline between 2002 and 2013. * Hospitalisation rates for organic psychosis and intellectual disability remained stable whereas monthly increases in depression (51.6%, CI95% 24.2-85.1, p=0.039), emotional and conduct disorders (46.1%, CI95% 24.7-71.2, p=0.018), neurotic and personality disorders (26.6%, CI95% 14.2-40.3, p=0.024) and alcohol/drug disorders (26.6%, CI95% 13.6-40.3, p=0.029) were seen following the onset of the economic crisis for 15-34-year olds. |
| Nayfack, Huffman, Feldman, Chan, Saynina & Wise (2014), USA. | Retrospective analysis | N=2,174,030   * autism spectrum disorder discharges (16,659) * cerebral palsy discharges (53,274) * Downs syndrome discharges (23,487) * all other discharges (2,083,082) | Analysis of paediatric hospitalisations between 1999-2009. Discharge data from non-federal acute care hospitals for children (aged 1-18yrs) with autism compared to children with cerebral palsy, Downs Syndrome and General Comparison.  Autism spectrum disorders discharge group  12.9% (n=2,145) with co-morbid intellectual disability  Entire discharge group  1.6% (n=34,784) discharges associated with intellectual disability. | *Measures of effectiveness*   * Admissions (hospitalisations) * Discharges | * Significant increase in the number of discharges associated with a diagnosis of autism between 1999 and 2009 (from 770 to 2,400). * Hospitalisations for those with autism spectrum disorders without intellectual disabilities increased steadily over the study period but hospitalisations for autism with intellectual disabilities did not change. * No significant change in the annual number of discharges for the cerebral palsy or Downs syndrome groups. * Largest increase in hospitalisations for individuals with autism were in the 10- to 14-year-old age group and 15- to 18-year-old group, showing increases of 328% and 243%, respectively between 1999 and 2009. * For all but the 1- to 4-year-old age group, the leading diagnosis category associated with hospitalisation of children with autism was Mental Health Disorder (proportion range = 25-60%). * Odds ratio of hospitalisation associated mental health disorder is greater for autism group than the general population. |
| Ozbaran, Kose, IBarankoglu & Dogan (2020), Turkey | Case file review | N=19   * 1 intellectual disability only * 1 co-morbid intellectual disability and autism spectrum disorder * 2 autism spectrum disorder only | Patients at a child and adolescent psychiatry inpatient service in a ‘[COVID]6’ Pandemic Hospital’ in Turkey operating during the 2019/2020 COVID outbreak.  Mean age = 14.63yrs (SD=2.76)  36.84% male  21.01% intellectual disability +/- autism | *Measures of Effectiveness*   * *Length of Stay* * *Clinical Global Impression Scale (CGIS) (Forkmann et al., 2011)* * *Discharge recommendations* | * Length of stay for all patients discharged after the first COVID case appeared in Turkey (but admitted before) was 26.4 days. * Length of stay for the patients who were hospitalized after the outbreak occurred was shorter at 10.3 days. * Significant negative correlation between the duration of inpatient admission and CGI-S scores on discharge (r=-6.22), suggesting patients benefit from inpatient admission. * Discharged patient with ASD only, admitted before COVID pandemic, had shorter length of stay at 8 days. * Two discharged patients with ID and ASD+ ID, admitted before COVID pandemic, had longer lengths of stay at 22 and 41 days respectively (admitted as inpatient for 15 and 8 days respectively, and remainder of ‘length of stay’ supported via telepsychiatry before absolute discharge). * Decrease in CGI-S scores (indicating improvement in mental health symptoms) between admission and absolute discharge for all patients (N=19 admissions M=6.0, SD=0.88; N=14 discharges M=3.35, SD=0.63). * Significant decrease in CGI-S scores of 12 absolute discharges regularly supported by telepsychiatry between inpatient hospitalisation and absolute discharge and 1st Month Telemedicine CGI-S (p < 0.001). * No significant difference found between inpatient discharge CGI-S scores and CGI-S scores following first month of telepsychiatry support (p=1.79). * No significant difference between the CGI-S scores of the patients who were hospitalised after the first COVID case in Turkey and those hospitalised before (p=0.179). * All patients with ASD, ID and ASD and ID showed decreases in CGS-I scores following admission. * 14 of 19 (73.6%) patients hospitalised during the study period were discharged (some against psychiatric advice). * One individual with ASD admitted after the pandemic remains an inpatient. |
| Robinson, Menezes, Mullin & Lê Cook (2020), USA | Analysis of healthcare insurance database | N=6,781   * 102 children with ASD * 1,105 children with Asthma * 28 children with ASD + Asthma   5,546 children with neither diagnosis | Health care expenditures of children (<18yrs) insured by a Medicaid managed care organization in the USA between 1st July 2015 to 30th June 2017. | *Measures of Effectiveness*  Admissions (measured by cost per patient per month) | * Children with ASD were significantly more likely to be male than children with asthma or neither diagnosis, and children with an asthma diagnosis were slightly older than children with an ASD diagnosis. * Children with ASD, compared to children with asthma and neither diagnosis, had significantly higher rates of comorbid intellectual disability, other developmental disorders, attention-deficit/hyperactivity disorder (ADHD), conduct disorder, and other mental health diagnoses. * Compared to children without asthma or ASD, children with ASD also had higher rates of comorbid depressive disorders, other mood disorders, and post-traumatic stress disorder. * Children with ASD had 1.7 times higher total medical expenditure ($515.72 vs. $308.55) compared to children with asthma or no ASD diagnosis, and 1.1 times higher physical health costs ($239.25 vs. $212.92), and 4.4 times higher mental health care costs than($240.60 vs. $54.50) compared to children with asthma. * Children with neither an ASD nor asthma diagnosis had proportionally similar costs to children with asthma, with markedly less mental health care than physical health care (6.5:1 physical health:mental health care for children with neither diagnosis vs. 3.8:1 for children with asthma), and 30% of physical health care provided in acute care settings. * Health service costs for children with ASD were split almost evenly between physical ($236.50) and mental health care ($240.60), and acute care comprised small fractions of each of these cost categories (inpatient/ emergency department admission was 11% of physical health service costs and 6% of mental health service costs). * Total inpatient cost per patient per month for mental health was $13.63 for children with ASD, $15.56 for children with asthma, $123.98 for children with ASD & asthma and $5.39 for children with no diagnosis (compared to cost per patient per month for physical health of $239.25 for children with ASD, $212.92 for children with asthma, $258.33 for children with ASD & asthma and $169.22 for children with no diagnosis). |
| Siegel & Gabriels (2014), US. | Literature Review and Case Vignettes |  | Examines the evidence for inpatient treatment of autism spectrum disorders in general and specialist child psychiatry units. | *Measures of effectiveness*   * Admissions | * Identified that children with autism spectrum disorders are hospitalised at disproportionate rates, and higher than the general population (1.3-7.0% compared to 0.23%). * Adult and child studies identified suggested that specialised inpatient treatment programmes deliver positive behavioural outcomes that endure two months after discharge. |
| Siegal, Doyle, Chlemelski, Payne, Ellsworth, et al. (2011), US. | Cross sectional survey of services | N=9   * Estimated to serve approximately 1,001 children with IDD per year. * 686 with autism spectrum disorders per year. | Patient information on children admitted to one of nine specialized inpatient psychiatry units located in eight hospitals.  Mean age = 12.72yrs (range=4-21yrs) | *Measures of effectiveness*   * Length of stay | * Across all units, the average length of stay was 42.3 days (mode 30 days, range 12–135 days). After removal of an outlier of 135 days, the average length of stay across the remaining units was 30.75 days. |
| Siegel, Milligan, Chemelski, Payne, Ellsworth, Harmon, Teer & Smith (2014), USA. | Prospective evaluation study of specialist inpatient psychiatric programme | N=38   * autism spectrum disorder admissions (19) * Admissions without autism spectrum disorder (19) | First time admissions of children with autism spectrum disorder and/or intellectual disabilities to a specialist inpatient psychiatric programme.  Autism spectrum disorder group  84.2% male  Mean age = 13.3yrs (SD = 3.2)  42.1% with intellectual disabilities  Comparison group  84.2% male  Mean age = 11.8yrs (SD = 2.5)  68% with intellectual disabilities | *Measures of effectiveness*   * Length of stay * Aberrant Behaviour Scale – Irritability subscale (ABC-I) 103 * Clinical Global Impression Scale (CGI) | * No significant difference in the length of stay between those with autism spectrum disorders (M = 44.9 days; SD = 17.4) and those without (M = 45 days, SD = 11.4). * Significant reductions in challenging behaviour between admission and discharge (as measured by ABC-I,103) and sustained with a slight increase for both groups at follow up. * Both groups showed significant improvements, as rated by the CGI scale at discharge. |
| Smith & Berney (2006), UK. | Retrospective case note study and staff interview regarding reason for admission, appropriateness of admission and outcome of admission | N=96   * ‘local’ cases from catchment area (51) * ‘national’ cases outside of catchment area (45) | Admissions (lasting longer than 72 hours) to inpatient services for young people with intellectual disabilities between 2002 and 2004.  Services consist of two open units (one for more dependent individuals and one for those with mild to borderline intellectual disability) and a low secure unit.  65.6% male (n=63)  Mean age = 14.10yrs (SD = 2.62)  5.2% borderline intellectual disability  31.2% mild intellectual disability  27.1% moderate intellectual disability  26.1% severe intellectual disability | *Measure of effectiveness*   * Length of stay * Discharge pathway | * Length of stay of on the secure unit was longer with a mean of 263 days (*SD* = 101), compared to the open units (*M* = 88 days, *SD* = 43, on the higher dependency unit; and *M* = 259 days, *SD* = 190, on the mild to borderline unit). * 82% of those on the secure unit were discharged to out of home specialist placements, including highly staffed, sometimes adult, forensic services, compared to 57% on the open units. * On the higher dependency open unit, 78% of individuals returned to their home. * ‘National’ cases were more likely to be sent to a specialist setting. * 78% of admissions considered appropriate and unavoidable. * 18% of avoidable admissions considered the results of inadequate community resources. |
| Theodoratos, McPherson, Franklin, Tonge, Einfield, Lennox & Ware (2017), Australia. | Questionnaire/ Case note review | N=98 | Cohort of adolescents with intellectual disability who presented to general hospital services in South East Queensland between January 2006 and June 2010.  55.1% male  Age range = 11-17yrs | *Measures of effectiveness*   * Admissions | * 12.1% of hospital admissions were mental health admissions (5 cases involving 3 individuals). |

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1. Where identified by studies. [↑](#footnote-ref-2)
2. Categories 1, 4 and 5 beds in the classification used by the Royal College of Psychiatrists’ Faculty of Psychiatry of Intellectual Disability (2013) [↑](#footnote-ref-3)
3. “incompatibility can be defined as a formal record of a significant breakdown in dynamics between two or more patients resulting in a risk of interpersonal conflict Reasons for inclusion on the formal register of incompatibilities include: threats of violence to another patient, actual violence, evidence of having collaborated to subvert

   safety or security, or information that suggests collaboration, information that suggests others are at risk, bullying, predatory behaviour and inappropriate sexual activity” (page 191). [↑](#footnote-ref-4)