



An 8-year study of admissions and discharges to a specialist intellectual disability inpatient unit

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Abstract

Background: In the United Kingdom, policy change has led to specialist intellectual disability inpatient bed reduction. Little evidence exists assessing the results for patients admitted to such units. This study evaluates the outcomes of a specialist intellectual disability inpatient unit.

Method: Gender/age/ethnicity/intellectual disability severity/co-morbid psychiatric/developmental disorders, treatment length and stay data were collected. The health of the nation outcome scales for people with learning disabilities (HoNOS-LD) scores at admission, treatment completion and discharge were recorded. Analysis of these multiple variables and correlations within different patient groups was investigated using various statistical tests.

Results: Of 169/176 patients (2010–2018), admission to discharge, HoNOS-LD global and all individual items score decreased significantly, for all patient categories. Treatment completion to discharge duration was significant for the whole cohort.

Conclusions: This is the largest study of intellectual disability inpatient outcomes. Discharge from the hospital appears not associated with duration of treatment. Using HoNOS-LD to demonstrate treatment effectiveness is recommended.

KEYWORDS

autism, developmental disability, inpatients, intellectual disability, mental health

1 | BACKGROUND

Intellectual disability is defined as impaired intelligence and social functioning that develops before adulthood and has a lasting effect on development (Department of Health, 2001). Mental health and behavioural issues are common co-morbidities for those with intellectual disability and are also more prevalent in this population (Cooper et al., 2007; Hughes-McCormack et al., 2017). The associated co-morbidities and general poorer health in the intellectually disabled population often results in complex clinical presentations (Hughes-McCormack et al., 2017). These are accentuated by the varying difficulties in communication and vulnerability and, importantly, also the

different severities of disability that individuals may present with (Purandare & Gravestock, 2019). The complex presentation of intellectual disability means that individuals may require specialist services equipped with qualified and experienced staff that can provide the appropriate and effective assessment and care (Devapriam et al., 2015; Purandare & Gravestock, 2019).

Over the past few decades, the United Kingdom, particularly England, has undergone significant transformation to the way that mental healthcare is provided to this population. The public scrutiny of specialist inpatient psychiatric units that occurred after the 'Winterbourne View Scandal' in 2011 was a catalyst for major review of intellectual disability services leading to the Transforming Care

report (Department of Health, 2012). The report focused on enabling people with intellectual disability admitted to inpatient psychiatric settings to move back out into the community, whilst also endeavouring to raise the quality standards for new inpatient admissions (Cooper et al., 2007; Department of Health, 2012). Following the launch of Transforming Care, the number of specialist mental health beds commissioned by Clinical Commissioning Groups reduced by 4.5% by the end of 2015—overall causing an almost 90% reduction in intellectual disability psychiatric beds in the NHS since 1987 (Devapriam et al., 2015; Public Health England, 2016). Most of the care given to those in this demographic is now through community services, but whilst most adults with intellectual disability live fairly independently, 21% still require contact with specialist services (Devapriam et al., 2015). In a survey of consultant intellectual disability psychiatrists in England ($n = 65$), 82% reported utilising specialist inpatient services on occasion for the better management of mental health and/or behavioural needs of some of their patients (Guinn et al., 2016). This underlines the limited but important role of effective specialist inpatient care in the management for those with intellectual disability.

There is a lack of evidence of longitudinal data of the specific patient characteristics and treatment outcomes of those accessing specialist inpatient settings particularly post-Transforming Care. This study looks to address this evidence gap. The health of the nation outcome scales for people with learning disabilities (HoNOS-LD), an outcome scale used to measure and record changes in clinical severity of people with mental health needs and intellectual disability, was used for this purpose (Guinn et al., 2016; Hillier et al., 2010; Te Pou, 2014).

2 | AIMS

To evaluate the outcomes of patients' progress during admission using the HoNOS-LD scale and if these outcomes vary in different clinical subgroups.

To examine if specific patient or clinical characteristics (i.e., level of intellectual disability, comorbid neurodevelopmental conditions, mental illness, physical health concerns) influence the length of stay (LoS) in an inpatient unit.

To examine differences in the length of treatment (LoT) to the LoS globally and across different clinical populations.

3 | METHOD

This is a retrospective clinical case note-based cohort study of adults with intellectual disability admitted to an urban inpatient NHS facility in London, UK between 2010 and 2018. The STROBE criteria and checklist has been adhered to. The inpatient assessment and treatment unit hosts a 16-bed regional specialist unit, admitting adults with intellectual disability with suspected mental health/behavioural issues. Admission referrals are principally from London boroughs. Referrals are considered only when community resources and local mainstream

mental health units are deemed to be inappropriate or inadequate for the management of an individual's mental health needs.

The HoNOS-LD scores of all adult (18 years and above) inpatients admitted between 2010 and 2018 were recorded within 1 week of their admission, time when treatment episode was deemed complete and discharge. Patient sets were excluded if they contained incomplete or missing HoNOS-LD data.

The following variables were extracted for all patients included in the study:

- Gender
- Age
- Ethnicity
- Severity of intellectual disability
- Presence of co-morbid mental health/developmental disorders
- LoS and at the time when treatment was deemed complete-LoT

Severity of intellectual disability was divided into two groups—mild and moderate to severe. The rationale to this is in Appendix A.

3.1 | Ethics approval

The project was registered as an audit and service evaluation project at the host organisation. No patient identifiers were provided outside the direct clinical team who collected the data and anonymised it. Data were pooled prior to analysis. The NHS Health research authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) was used to confirm that no NHS ethical permission or approval was needed for this project.

3.2 | Data analysis

The statistical package R version—Rx64 4.0.2 was used. HoNOS-LD global scores were compared between admission and discharge. Paired *t*-test was used to test for significance. Individual HoNOS-LD item scores were compared by the same method. Additionally, the Benjamini-Hochberg Procedure was used to decrease the false discovery rate for multiple comparisons. These tests were repeated for patients with a comorbid diagnosis of an Autism Spectrum Disorder (ASD) (ICD 10 F84.0), and for patients with an additional mental illness diagnosis (with or without ICD F84.0) and similarly, where challenging behaviour was a principal reason for admission. Scores were compared between patients with different severities of intellectual disability using unpaired *t*-tests.

Scatter plots were utilised to evaluate how HoNOS-LD global and item scores (on admission) influenced LoT and stay. The Pearson correlation test was applied to look for any linear correlations.

Unpaired *t*-tests were used to calculate any significant difference in LoT and stay for all patients and separately for patients with the added diagnosis of ASD, additional mental illness, or challenging behaviour. A *p* value of .05 was used as the threshold for determining significance throughout.

4 | RESULTS

4.1 | Study population

A total of 176 people were admitted to the unit from 2010 to 2018. The data sets of 169 patients were included in the analysis. Data sets for seven patients were excluded due to incomplete or missing data. The demographics of the data set are shown in Table 1.

The mean age of all patients was 30 years (range 17–66 years), and the mean age of female and male patients was 29 (range 17–62 years) and 32 years (range 17–66 years), respectively. The median LoS was 242 days (range 10–1285 days). The mean LoS was 289.11 days (SD 229.54 days).

TABLE 1 Demographic data of all inpatients

	Admissions, n (%)
Gender	
Female	49 (29.0)
Male	120 (71.0)
Severity of intellectual disability	
Mild	98 (58.0)
Moderate to severe	71 (42.0)
Other diagnoses	
Autism spectrum disorder	85 (50.3)
Mental illness	105 (62.1)
Challenging behaviour	127 (75.1)
	Age in years
Mean average age	
Overall	30.81
Female	28.61
Male	31.71
Median average age	
Overall	27
Female	26
Male	28

TABLE 2 Mean HoNOS-LD scores all inpatients and subgroups

Mean HoNOS-LD scores				
Groups (n)	Admission	Discharge	Difference between mean admission and discharge scores	p Value
All inpatients (169)	29.17	13.49	15.68	2.011801e-60
ASD (85)	32.74	15.68	17.06	8.682903e-23
Mental illness (105)	27.98	12.67	15.31	8.947793e-32
Intellectual disability severity				
Mild (98)	25.61	11.00	14.61	3.529123e-25
Moderate to severe (71)	34.07	17.00	17.07	6.728327e-25

The ethnicity breakdown is provided in Table S1. From the data available there were higher numbers of non-Caucasians ($n = 93$) than Caucasians ($n = 75$).

4.2 | HoNOS-LD scores

4.2.1 | Overall

Table 2 provides the key comparisons. Table S2 provides the p values for each item of the HONOS-LD in each group, that is, mental illness, autism and challenging behaviour.

The mean HoNOS-LD global score among all patients were higher at admission (mean 29.17, SD 10.0) on first assessment compared to discharge (mean 13.49, SD 7.34). The improvement in global scores was significant ($p < .05$), with an overall score difference of 15.68. The improvement in global item scores was also significant for all items ($p < .05$) (Figure S1). HoNOS-LD scores decreased significantly between admission and discharge for all patient category groups (Table 2).

4.2.2 | ASD

Results were further analysed for those with a recorded diagnosis of ASD ($n = 85$). The mean HoNOS-LD global scores at admission (mean 32.74, SD 9.66) were significantly higher ($p < .05$) than at discharge (mean 15.68, SD 7.95). A comparison of admission and discharge of HoNOS-LD scores for individual items in the assessment tool showed significant decrease of scores in all items except the HONOS-LD items of—‘understanding’ (question 10) and ‘expression’ (question 11). This is shown in Figure S2.

4.2.3 | Mental illness

Patients with an additional diagnosis of mental illness ($n = 105$) were compared. The mean HoNOS-LD global scores at admission (mean = 27.98, SD 9.29) were significantly higher ($p < .05$) than at

discharge (mean = 12.67, SD 6.91). All individual score items showed a significant difference, except for the item regarding ‘seizures’ (question 19). This is seen in Figure S3.

4.2.4 | Challenging behaviour

Patients who additionally showed challenging behaviour ($n = 127$) were compared. Those with challenging behaviour showed a significant decrease ($p < .05$) in HoNOS-LD global scores between admission (mean = 30.54, SD = 9.85) and discharge (mean = 14.56, SD = 7.54). Individual HoNOS-LD item scores for those with challenging behaviour also showed significant decreases in all items. This is seen in Figure S4.

4.2.5 | Intellectual disability severity

HoNOS-LD scores were grouped into two groups according to their recorded severity of intellectual disability: mild and moderate to severe. Mean admission scores of the group with mild intellectual disability was 25.62 (SD 9.35), whereas the admission score was higher for the moderate to severe group (34.07, SD 8.70). Both groups showed significant reductions in HoNOS-LD global scores between admission and discharge (Figure S5).

Individual HoNOS-LD item scores for those with mild intellectual disability showed significant differences in all items except for ‘seizures’ (Figure S6). Likewise, for moderate to severe intellectual disability, score changes were insignificant for questions relating to ‘understanding’ and ‘expression’ (Figure S7).

4.2.6 | Length of stay and length of treatment

Results showed no relationship between HoNOS-LD score at admission and LoS in the inpatient unit. Pearson correlation between LoS and global score on admission indicated no linear relationship ($-.01$) (Figure S8). Likewise, LoT and global score on admission was $-.009$, indicating that there is no linear relationship between the two variables (Figure S9). A positive relationship in LoS to LoT was indicated (Pearson correlation $-.69$) (Figure 1).

The LoT was not affected by presence of mental illness, ASD or challenging behaviour respectively in patients. The average mean LoT for 169 patients was 185.68 days (SD = 127.5) and median LoT 167. Service users with a mental illness diagnosis had a longer LoT (186.3 days) than service users without a mental illness diagnosis ($M = 184.7$ days). This difference was not significant ($p = .933$).

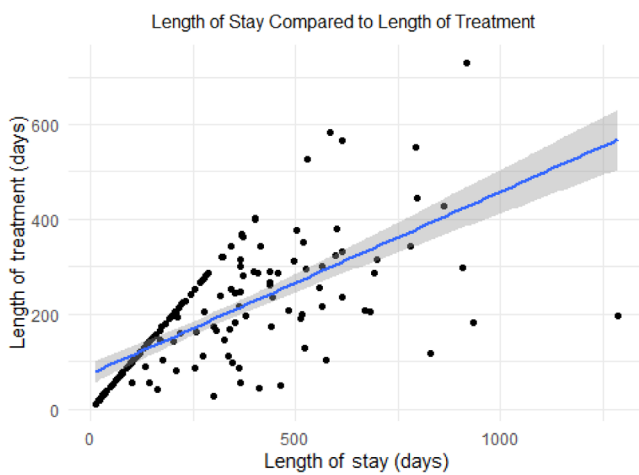


FIGURE 1 Length of treatment compared to length of stay (all patients)

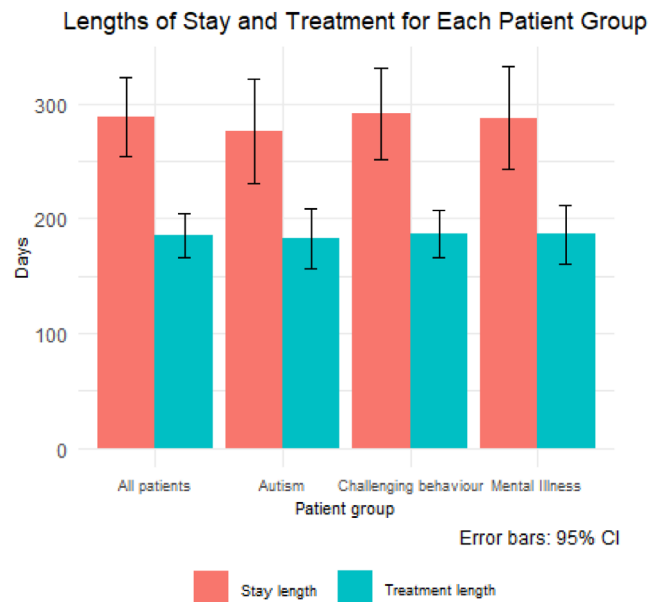


FIGURE 2 Length of treatment and to length of stay for each patient group

TABLE 3 Comparison of length of treatment to length of stay

	Mean length of stay in days (SD)	Mean length of treatment in days (SD)	p Value
All patients	289.11 (229.54)	185.68 (127.65)	2.908e-13
Mental illness	287.58 (234.49)	186.31 (135.15)	1.546e-08
Autism	275.81 (214.92)	183.00 (122.63)	1.243e-07
Challenging behaviour	291.54 (227.65)	186.45 (121.19)	7.657e-10

Service users with an ASD diagnosis had a shorter LoT ($M = 183$ days) than service users without an ASD diagnosis ($M = 188.4$ days). However, this was not significant ($p = .7853$). Service users with challenging behaviour had a lengthier LoT (186.5 days) than those without ($M = 183.4$ days). This difference was not significant ($p = .9026$).

The average duration, in days, of active treatment for people with intellectual disability was compared to their total LoS (Table 3 and Figure 2). It demonstrated that service users were remaining as inpatients for substantial lengths of time post-treatment. This was consistent across all key sub-populations of patients with mental illness, ASD and challenging behaviour.

5 | DISCUSSION

5.1 | Main findings

It is important to base health policy on evidence and not ideology. Our analysis of one inpatient unit in north London, has shown a positive difference in clinical outcomes of patients with intellectual disability and associated mental health/behavioural co-morbidities. The mean global HoNOS-LD score for patients improved between admission and discharge. This reduction was significant when compared for both severity groups of intellectual disability: mild and moderate-to-severe. This significance persisted for all other clinical demographic groups, including: those with additional mental illness diagnoses, diagnosed ASD and challenging behaviour. This suggests that inpatient units can deliver improvement of clinical outcomes in individuals with varying social and cognitive challenges.

LoS and LoT was found to not be associated with HoNOS-LD scores at time of admission or be significantly prolonged by additional comorbid diagnoses. However, a strong positive correlation was found between LoT and LoS. When explored further, there was strong evidence to suggest that post-treatment patients are retained for a considerable period as inpatients without any therapeutic gain and outside the locus of inpatient clinical control. This finding is consistent across all three major patient groups (mental illness, ASD and challenging behaviour) suggesting that there is a considerable delay in patients being discharged from the inpatient unit after treatment completion.

5.2 | Limitations

Intellectual disability severity groups were categorised into mild and moderate-to-severe. Accuracy of the severity assessments and differentiation of moderate and severe could not be verified as this was done by retrospective inspection of pre-existing clinical notes. As a result, data analysis of the moderate and severe patient groups was collated as one clinical group. This potentially removed nuances of outcomes between these two groups that could have indicated a significant difference in impact of admission.

Human factors such as clinician bias and skill in the assessment of HoNOS-LD are an important limitation to consider. All assessments

were conducted by qualified clinicians and HoNOS-LD has been demonstrated to show generally good inter-rater reliability, however, it is difficult to identify and eliminate human bias and adequacy of assessment skill and clinical judgement of inpatients conducted by health professionals (Tenneij et al., 2009).

Any associations made between inpatient unit intervention and clinical improvement should also take into consideration the impact of medication given, patient's support network and the quality and quantity of relationships that a patient has with their caregivers. Undoubtedly, these are all important elements of a patient's care and progress and, therefore, may be one of many factors that confound HoNOS-LD scores.

Furthermore, patients with moderate-to-severe intellectual disability may be unable to appropriately express their needs or changes in moods, potentially leading to a consistently lower (floor effect) or higher (ceiling effect) score in certain elements of the HoNOS-LD scale. This is perhaps an unavoidable challenge for the care of those with intellectual disability, for whom communication can be inherently different. However, the HoNOS-LD is a tool that does not predominantly rely on the patient's communication abilities and is an information-based scale.

Finally, although a large study, it is a single-unit study and, therefore, findings must be generalised with caution. However, it is expected that clinical practices and patients characteristics within the unit are consistent with other inpatient settings for adults with intellectual disability across the United Kingdom.

5.3 | Implications for clinical practice

Our study supports the hypothesis that inpatient admission and treatment can be beneficial for adults with intellectual disability and significantly challenging mental/behavioural issues that cannot be managed safely or appropriately in community settings. The care of people with intellectual disability is complicated their various associated co-morbidities. These include increased incidences of ASD, challenging behaviour, and mental illness, in addition to physical conditions such as epilepsy (Cooper et al., 2007; Hughes-McCormack et al., 2017).

The study data show that inpatient admission correlated with significant reduction in HoNOS-LD scores in those with diagnosed ASD, mental illness and challenging behaviour. The mental illness patient group showed significant reduction in all question items, except for the question regarding 'seizures'. This suggests the broad benefit in both behavioural and social functioning that inpatient admission can have on those who live with both intellectual disability and various mental health comorbidities. Additionally, analysis of individual HoNOS-LD items for those with ASD, compared to those without, showed significant reduction, in most items, except for the questions regarding 'understanding' and 'expression'. This is in concordance with the diagnostic criteria for ASD which includes impairment of social interactions and patterns of communication that affect the individual's functioning in all situations (National Autistic Society, 2020). Therefore, the fact that these characteristics did not improve with admission reflects the intrinsic features of ASD.

The difference in HoNOS-LD scores for the item concerning 'seizures' was insignificant in both those with an additional mental illness diagnoses and those with mild disability. It is difficult to come to a firm conclusion regarding this item as the sample of data was potentially underpowered for this. However, services for intellectual disability play a role in managing seizure disorders by potentially improving medication compliance, monitoring drug interactions and side effects, and reducing exposure to triggers. Therefore, this question item may provide a broader insight into the impact of intellectual disability inpatient services on mental and physical issues.

The use of the HoNOS-LD as a form of measurement of outcomes is both well-tested and widely used as shown by the background review. It is comparable with other well-established measurement tools such as the Adult Behaviour Checklist (ABCL) (Esteban-Castillo et al., 2018; Tenneij et al., 2009). Its use has been validated in those with intellectual disability and shown to be more useful than the generic HoNOS scale for those with mild to borderline intellectual disability and severe behavioural issues (Roy et al., 2002; Tenneij et al., 2009). It is used widely in many specialist inpatient units as a method of recording an individual's baseline and their subsequent progress following a therapeutic intervention (Purandare & Gravestock, 2019). The importance of effective and straightforward clinical outcome tools is an essential component of evidence-based clinical care provision. This study, and alongside the other literature reviewed, have demonstrated an effectiveness of measuring clinical outcomes using the HoNOS-LD scale.

Patients showed significant improvement in HoNOS-LD, with mean admission and discharge scores of 30 and 15, respectively. This significance persisted for patients with ASD, mental illness, varying severities of intellectual disability and challenging behaviour. Whilst more research is required, this score change has the potential of becoming utilised as a decision support mechanism to identify and guide clinicians on the possibility of treatment completion and/or a prompt for discharge planning. There are possibly three options to explore with regard to the HONOS scores supporting decision making. First, a score of approximately 15 on the HoNOS-LD scale may be an appropriate threshold and indication for discharge to prevent unnecessarily long admissions. Equally consideration could be given to a 50% reduction in scores prompting discharge considerations. Thirdly and finally a 15 point drop over 6 months should give raise to a serious consideration of discharge planning. It might be that all three or two in various permutations and combinations prove more sensitive and/or specific in reliably predicting discharges better. This is an item for further research to assess if HoNOS-LD scores could be utilised to guide timely and appropriate discharge for certain type of inpatients. The issue of prolonged and unnecessary LoSs is a major challenge of inpatient services. However, clinical tools, such as the HoNOS-LD has the potential to be utilised as a component of discharge criteria to promote appropriate and timely discharge (Laugharne et al., 2018). This, however, requires further research and a prospective multi-unit research case register designed largely on the metrics investigated in this study to validate this.

Another important finding of this study has been the significant difference in-between LoS and LoT. It is important to stress, as in line with the Transforming Care report, that inpatient units should be a place for patients to attend for care and treatment and not a place to live (Department of Health, 2012). In addition, it is important to note that some of the factors identified by other studies, such as absence of robust community placements, disputes over funding and lack of trained community staff, were also found to be relevant in increased inpatient stays in this study and could have influenced the delayed discharge evidenced (Devapriam et al., 2015). Discharging and rehabilitating patients back into community services as soon as it is appropriate is as essential to good care as appropriately admitting patients to inpatient services (Department of Health, 2012). Inpatient units should be a last resort service in a pathway of care that should be the least restrictive and predominantly community-based (Department of Health, 2012). However, our study highlights that delayed discharges are unlikely due to clinical need nor possibly fall within the locus of control of clinicians but sit outside it. This highlights the need for integration of more local specialist inpatient units into local care pathways. The issues faced in one inpatient unit are undoubtedly mirrored in other units across the country. Delayed transfers of care and delayed discharges have been the subjects of a large body of work and continue to be an issue of concern.

5.4 | Implications for research

Research has suggested that demographics such as poorer levels of functioning, rates of self-harming and challenging behaviour are more prevalent in adults who are admitted to inpatient units than those managed within local community services (Pearce et al., 2011). This has correlated in adults with higher HoNOS-LD scores being admitted compared to adults commencing community-based psychiatric/behavioural intervention (Pearce et al., 2011; Sandhu & Tomlins, 2017). Future research could assess if community services are as effective as inpatient units in improving clinical outcomes of the demographic of patients, who often have higher baseline HoNOS-LD scores, that are often referred to inpatient services.

Research is also needed into the duration of delayed discharge based on distance they are place from their local communities (Care Quality Commission, 2019; Department of Health, 2012; Purandare & Wijeratne, 2015). An analysis of intellectual disability inpatient units from 2006 to 2010, found that 18% of patients were in hospitals 50 miles or more from their residential homes (Devapriam et al., 2015). Similarly, the skill levels of local community services needs exploring as they can influence discharges.

5.5 | Implications for policy

To ensure equity of clinical outcomes for adults with intellectual disability, the role and policy of inpatient units should be founded and driven by evidence that this and other studies have demonstrated.

6 | CONCLUSION

Mental health inpatient units for people with intellectual disability face many challenges. Historic and modern-day failings in care have, rightly, put these facilities under intense scrutiny and reform. However, these units require a greater level of local and national government support to improve the quality of facilities, staff numbers and education. Since 2015, the number of patients within inpatient services reduced by almost 20%, with an additional 635 long-stay residents having been supported to transition back into the community (National Health Service, 2019). However, despite the decreasing numbers of inpatients, and the rightfully increased funding and provision of community-based services, inpatient services remain beneficial for those that cannot be managed in the community and so should remain as an option of care that is available for all intellectually disabled patients, in all regions of England and the United Kingdom.

Being able to provide inpatient services, both generic and specialist, that are beneficial for the whole spectrum of people with intellectual disability is a necessary component of providing equity of healthcare outcomes in this population.

CONFLICT OF INTEREST

Kiran Purandare and Anusha Wijeratne are inpatient consultants at the Kingswood Centre—the inpatient unit being reviewed in this study. Ashok Roy and Rohit Shankar are part of the international group to update the HONOS-LD. The HoNOS-LD is an outcome scale made freely available by the Royal College of Psychiatrists. Rohit Shankar has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Averelle and GW pharma outside the submitted work. No other author has any declared conflict of interest related to this paper.

AUTHOR CONTRIBUTIONS

All substantially contributed to the design, analysis, interpretation of the work, drafting and preparation of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work. All authors meet all four ICMJE criteria for authorship.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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APPENDIX A

Rationale for examining the mild and moderate–severe intellectual disability as two groups (King et al., 2009):

1. Moderate to severe intellectual disability have a low prevalence and together they would combine to form 15% of the total intellectual disability population. Taken individually it would be difficult to achieve satisfactory power to deliver meaningful conclusions.
2. Moderate to severe intellectual disability is difficult to assess and classify which causes significant issues with accuracy of specific diagnosis of severe or profound intellectual disability.