Correlates for the risk of specialist ID hospital admission for people with intellectual disabilities: development of the LDNAT inpatient index

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Background

Today it is generally accepted that people with intellectual disability (ID) are likely to have a better quality of life in a community setting (Collins, 2015; Modi *et al.*, 2015). Therefore, whilst specialist inpatient admissions may always be needed as a part of an overall pathway of care (Oxley *et al.*, 2013), this should only occur as a last resort and when alternative less restrictive support has been attempted. In the United Kingdom (UK) this notion has been supported by national policy for many years. Valuing People (Department of Health, 2001) set out a clear desire for inclusion and de-institutionalisation with plans to close all long-stay inpatient provision for people with ID by 2004. Valuing People Now (Department of Health, 2009) re-stated these aspirations but acknowledged that more needed to be done. It therefore sought to strengthen the drive with a further 3 year programme. In 2012, the Winterbourne View inpatient scandal (Department of Health, 2012) created public outcry. The UK government responded by pledging to review all inpatient placements within 1 year and to implement a radical national programme of reduction in the number of people with ID in specialist hospitals. Two years later, the Bubb Report (Transforming Care Steering Group, 2014) again highlighted a failure to progress the inpatient bed closure programme. Its author advocated a two pronged approach achieving bed closures through improvements in community support for people with ID focused on facilitating the discharge of existing inpatients but also on working more proactively to reduce the need for new admissions. This report was swiftly followed by the multi-agency Transforming Care for People with learning disabilities - Next steps report (ADASS *et al.*, 2015). This report again sought to revitalise the process by outlining the "right" of all inpatients and their family/carers to have their care provision reviewed, strengthened gatekeeping of beds, skills development for the specialist ID community workforce, and the development of national standards and metrics to track progress.

According to data published from this policy programme, England's ID inpatient population was 1675 in Feb 2015; 2570 in Feb 2016; 2520 in Feb 2017 and 2460 in June 2017 (NHS Digital, 2017).

There is then still considerable discrepancy between the radical aims of the latest policy initiative and actual reductions in the numbers of people in hospital. Even assuming the baseline figure of 1675 was affected by early data quality issues, the Assuring Transformation National Health Service (NHS) figures at best show only a modest reduction in the numbers of people with ID residing in hospital over the first four years of the policy programme. In summary it is clear that simply enshrining de-institutionalisation and bed closure into policy has not worked. This protracted process has, however, provided opportunities for 'grass roots' research into the phenomena which may yet provide useful insights for those charged with delivering on this laudable goal.

To support reduction in specialist inpatient care usage, there is a clear need for higher quality, community-based support and interventions for people with ID that significantly reduce reliance on hospital beds (Wong *et al.*, 2015). Implicit in this notion is proactive and early intervention to avoid crises developing that result in avoidable admissions. One key contribution to the prevention of specialist hospital admission is the early identification of those most at risk of admission.

The presentations of adults with ID at the point of admission to non-forensic hospitals are complex (Oxley *et al.*, 2013) and, to further complicate this picture, Wong et al. (2015) found that, for their wards, some inpatient characteristics (such as length of stay, proportion of admissions under the Mental Health Act (MHA), ratio of first admissions to re-admissions, and the proportion of hospital transfers) had changed over time, in part due to changes in service provision. In 1999, Raitasuo et al. compared the

clinical records and narratives of 40 individuals admitted to a Finnish psychiatric hospital with ID and co-morbid mental health issues to a matched cohort without ID. They described the archetypal inpatient with ID as a male with previous psychiatric diagnoses, who had frequently moved accommodation before requiring hospitalisation for their disruptive behaviour. More recently, Cowley et al. (2005) interviewed 752 referrals to secondary care ID services in London and compared those who were, and were not admitted at some point during the subsequent 18-year period. Ganguly et al's., (2009) UK case note review was a longer study (30 years) but was purely limited to inpatients (n=315). Despite these differences, both found psychosis and physical aggression to be the most frequently identified antecedents to admission. Around a similar time Taggart et al., (2009) undertook a comparative study, interviewing 20 females with ID who had required specialist ID hospital admission in Northern Ireland and 33 who had not. In addition to mental illness, deteriorating mental health and severe challenging behaviour; their study found social circumstances (i.e. type of pre-admission accommodation) to also be significant predictors. Using a similar comparative design, Phillips and Rose (2010) developed the theme of social circumstances, finding that supported accommodation's staff attitudes, motivation, and perception of an individual's challenging behaviour (rather than its severity) were key factors in placement breakdown within their sample of 43 individuals residing in the UK. Whilst this nuanced exploration of challenging behaviour contradicted some previous studies, it did support previous admission hypotheses concerning the impact of mild ID and psychiatric diagnoses.

More recently, Oxley et al's. (2013) London-based case note review of mixed-sex, inpatient samples (n=86) confirmed earlier research findings (i.e. that mental health difficulties, challenging behaviour and, to a lesser extent, poorer social circumstances were the most frequent reasons for admission). In 2015, Wong et al. revisited, and extended

Ganguly et al's (2009) longitudinal study of patients in a UK specialist ID hospital. Unsurprisingly, their case note analysis of 378 admissions again found males displaying challenging behaviour problems, mental health difficulties, or a combination of both to consistently be the most common triggers for admission. Also (as in the Oxley et al study) factors which they termed "social problems" were found to have a moderate impact. Finally, by analysing routine clinical assessment records, Modi et al's. (2015) comparative study identified aggression and psychotropic polypharmacy as the only significant predictors of inpatient admission, explicitly stating that clinical presentation and psychiatric diagnoses were not sensitive enough to predict admission in their Canadian sample of 234 individuals.

Together these studies provide a degree of consistency surrounding some common pre-cursors to hospital admission for individuals with ID (i.e. mental health difficulties and challenging behaviour). However, given the desire to radically reduce the number of people with ID in hospital and the significant costs associated with hospitalisation (Oxley *et al.*, 2013), there is sufficient dissonance and lack of detail to warrant further investigation, particularly as none of the studies have proposed a clinically useable risk index for ID hospital admission.

Finally, as a proportion of the admissions in our study were under civil sections of the Mental Health Act (MHA) it is worth noting that there is a growing body of literature concerning the prediction of risk within the field of forensic ID (Lindsay et al., 2008; Singh et al., 2011). Most is focused on the risk of re-offending behaviours (Nicholls *et al.*, 2006; Lindsay et al, 2011) or the links between ID and offending (Fitzgerald *et al.*, 2011). Hence, whilst the methodologies employed to identify risk factors and develop risk assessment tools are of great value to the current problem, the findings themselves are less

relevant as the threshold and nature of (re-) admission to forensic services is likely to be different from non-forensic settings.

Specific Aims

The aim of this study was to investigate the viability of using items from the newly developed Learning Disability Needs Assessment Tool (LDNAT) (Painter *et al.*, 2016) as a risk indicator of admission to secondary care ID hospitals in the UK (i.e. to find a secondary use for an existing needs assessment tool or a subset of its items). The LDNAT addresses a wide range of health and social needs of adults with ID, allowing a broader test of correlates of mental health hospital admission than has been possible previously. In addition, the present study was the first step, using a cross-sectional design, towards the development of a prospective risk assessment method for hospital admission; building on the methods applied regularly in forensic ID research.

Method

Participants:

Data from a large scale, specially commissioned, dataset from six UK National Health Service (NHS) ID Trusts were used for this study (see Painter et al., 2016). Specialist ID professionals from a range of disciplines recorded a set of demographic and clinical information relating to 2296 assessments of people with ID accessing/utilising secondary care ID services across six NHS Trusts. After cleansing the data to remove incomplete records, duplicated assessments and those for people under 18yrs, 1,692 unique records with a full set of LDNAT ratings remained. Of these, 992 (54.5%) were male and the mean age was 41.7 years (range 18-90 years). 231 (19.7%) lived independently in community, whilst 147 (12.6%) lived with family/friends. A further 491 (42.0%) lived in

some type of supported accommodation (i.e. placements with paid staff input). Ethnicity was available for 1631 individuals and 1540 (94.4%) were White British. In 595 (35.2%) cases a formal primary or secondary ID diagnosis was allocated as the main relevant diagnostic category. 273 (45.8%) of these were for mild ID, 214 (36.0%) moderate, 78 (13.1%) severe, and 30 (5.0%) profound. Treatment setting was available for 1,466 (86.6%) of cases. Eighty four (5.7%) were inpatients (primarily acute assessment and treatment ID specialist inpatient settings); of which 17 were informal admissions, 45 were for assessment under section 2 of the MHA, 17 were for compulsory treatment under section 3 of the MHA and 4 were detained on "other" sections of the MHA.

The Learning Disability Needs Assessment Tool (LDNAT):

As well as the routine demographic information described above, individuals' health and social needs were rated using the Learning Disability Needs Assessment Tool (LDNAT) (Painter *et al.*, 2016). This short, holistic needs assessment was developed from the Mental Health Clustering Tool (MHCT) (Self *et al.*, 2008), itself an extended version of the Health of the Nation Outcome Scales (HoNOS) (Wing et al., 1996). The LDNAT consists of 23 items, each capturing the severity of a specific need on a 0-4 scale (see table 1 for item titles).

The LDNAT was developed and validated on adults receiving secondary ID care for a broad range of conditions, demonstrated good internal consistency (Cronbach's alpha = 0.80), and excellent test-retest reliability (ICC=0.91). It also produced clinically and statistically meaningful correlations with several other validated, condition-specific measures including the Waisman Activities of Daily Living Scale (Maenner *et al.*, 2013); the Threshold Assessment Grid (Slade *et al.*, 2000); the Behavior Problems Inventory for Individuals with Intellectual Disabilities-Short Form (Rojahn *et al.*, 2012a, 2012b;

Mascitelli *et al.*, 2015) and the Social Communication Questionnaire (Rutter et al., 2003). The total LDNAT score provides an overall severity rating of need whilst three sub-scores derived from factor analysis indicate the severity of: developmental needs, challenging behavior (CB), and mental health and wellbeing (see Painter et al., 2016).

Procedure:

A range of qualified ID professionals from six NHS provider trusts in England received a day of training in the use of the LDNAT before using standard training materials to cascade this information to other staff in their organisations. The resulting group of trained assessors included front-line nurses, speech and language therapists, psychiatrists, psychologists, and occupational therapists, who worked across a wide range of NHS specialist inpatient and community ID services. As part of their routine clinical assessment documentation, staff were also asked to record LDNAT ratings between July 2014 and August 2015. The six NHS services sourced, collated and submitted the data required for analysis from their patient record systems via a standardised and encrypted dataset. As this naturalistic study solely involved retrospective analysis of routinely collected clinical data, governance approval for the purposes of NHS service evaluation was obtained from the R&D lead in the NHS trust responsible for this analysis. Caldecott Guardian approval was also obtained from the Trusts submitting the anonymised datasets.

Statistical analysis:

All data were entered into SPSS version 24, after which the LDNAT items that differed significantly between the 84 individuals in inpatient settings and the remainder of the sample were identified using independent t-tests. Having identified the subset of LDNAT items that were most likely to help distinguish between people who were inpatients and those who were not, a total summed score for these items was calculated for

the participants in each group. This effectively created an overall score for each person in the sample across a wide range of needs that were associated with inpatient care. Whilst the possible range for the full LDNAT rating was 0--92 (23 items x a maximum score of 4), the possible range for this inpatient index was 0--72 (18x4).

The accuracy of any test which seeks to identify a given condition is judged by its ability to correctly distinguish between two states (Grove and Cipher, 2017). In this project, the test needed to distinguish between inpatients and non-inpatients with four test outcomes possible. The result could be a true positive (an inpatient correctly identified); a false positive (a community patient incorrectly identified as an inpatient); a true negative (a community patient correctly identified as such); or a false negative (an inpatient incorrectly labelled as a community case). If the LDNAT's Inpatient Index was to be a useful (accurate) test it would need to be sensitive enough to correctly identify the inpatient cases whilst also being sufficiently specific (i.e. not falsely labelling too many community cases as inpatients).

Statisticians traditionally produce a receiver operating characteristic (ROC) or ROC curve to understand the balance between sensitivity and specificity for predictive tools (Grove and Cipher, 2017). In essence, these are a graphical representation of this balance for each possible score on the tool. A ROC curve for the LDNAT Inpatient Index was therefore produced and the area under the curve (AUC) calculated to ascertain the utility of the LDNAT in identifying inpatient status. If the LDANT Inpatient Index identified inpatients no better than at chance levels, then the 'curve' would actually be a straight line with 0.5 of the graph's area falling below it, whilst any improvement on random chance would be represented by a curve that arced away from this straight line to accommodate more than 50% of the graph's area (McMillan et al, 2004).

The final stage of analysis was then to apply two different methods to the coordinates of the ROC curve to identify an appropriate cut-off score that could be used in further prospective research before tabulating the LDNAT Inpatient Index test results for this value.

Findings

Eighteen of the LDNAT items differed significantly between inpatient participants and their counterparts residing in the community. Inpatient participants had significantly higher needs on all of these 18 items. Eight of the items were from the LDNAT's Challenging Behaviour factor (e.g. overactive, aggressive, disruptive or agitated behaviour; repeat self-harm; non-accidental self-injury [regardless of cause] and engagement difficulties). Six were from the Mental Health and Wellbeing factor (such as depressed mood; relationships and strong, unreasonable beliefs), whilst 4 were from the Developmental Needs factor (e.g. Vulnerability and communication problems). Only items 3 (substance misuse), 4 (cognitive problems), 5 (physical health problems), 15 (physical problems with eating and drinking) and 23 (seizures) showed no significant difference between inpatients and non-inpatients (see Table 1). Due to the discrepancy in group sizes we also performed non-parametric Mann-Whitney U Tests. The only notable difference in findings was that item 10 (Activities of daily living) showed no statistical difference between the individuals admitted and those that were not. Given the potential clinical significance of this item for admissions, we elected to retain it in the list of items summed for the next stage of analysis.

Insert table 1 here

Using ROC analyses on the summed total of these 18 LDNAT items (the LDNAT Inpatient Index), the AUC was calculated to be .86, 95% CI [.824, .895]. The point on the

ROC curve (Figure 1) closest to the coordinates (0,1) was identified visually. Together with further examination of the curve's coordinates, a cut off for the summed total of the 18 LDNAT Inpatient Index items of 22.5 was deemed to be the optimal balance between sensitivity (.833) and specificity (.750).

Insert figure 1 here

Whilst this visual method is simple and intuitive, there are alternatives (e.g. the Youden Index; Youden, 1950) which can sometimes yield different results (Perkins & Schisterman, 2006) and that may be more appropriate in certain clinical contexts (Bewick et al., 2004). The Youden Index in this case, however, confirmed the cut off to be 22.5 (j= .583). That is that a total score of 22.5 or above for the 18-item LDNAT Inpatient Index was the optimal statistical balance between sensitivity and specificity. By tabulating the performance of the risk index at this level (Table 2) we established that 68% of inpatients and 81% of non-inpatient cases were correctly identified.

Insert table 2 here

Discussion

Secondary use of data from the LDNAT (a recently developed holistic needs assessment tool for people with ID) has provided a new opportunity to create an ID hospital admission risk index which may enable risk stratification and guide proactive community intervention to prevent specialist hospital admission for people with ID. The tool covers a range of individual needs that multi-disciplinary groups of specialist ID staff identified from their practice (Painter et al., 2016). As such it allows staff to identify the salient needs of the person accessing community ID services whilst concurrently rating the

factors identified in the literature (and through clinical experience) as being associated with admission.

The majority (18 of 23) of the LDNAT items differed significantly between inpatients and non-inpatients. Using the total of these items a cut off of 22.5 was identified via two well-established methods. Given its brevity, and lack of complex training requirements this suggests, in addition to its primary use as a traditional needs assessment tool, the LDNAT (via the LDNAT Inpatient Index score) also has utility for community ID practitioners as a clinically useable tool to aid the identification of individuals on their caseloads most in need to proactive intervention to reduce the likelihood of subsequent admission. Other stakeholders however may also find different, but related uses. Commissioners of both inpatient and community services, for example, could use these data to produce a benchmark to aid comparison of caseload complexity/severity and the point at which care is transitioned between these different providers. Educationalists could also use these data to identify the type and level of need that individuals with ID present to services with, in order to produce empirically based training and development plans. As such, the LDNAT and its Inpatient Index may have utility for multiple applications and its use in these ways should be evaluated in the future.

There are a number of limitations to this study which must be acknowledged. For example, the relatively small proportion of people who required an admission meant it was not possible to limit this subset purely to those where the LDNAT had been rated at (or close to) the point of admission. If admissions are effective, an individual's needs should reduce over time, potentially making longer-term inpatients harder to distinguish from their community counterparts. This may well have negatively affected sensitivity and specificity and therefore should be specifically addressed in future studies. Furthermore, although the tool's inter-rater reliability has previously been shown to be acceptable, due to

the naturalistic study design it was not possible to make extensive checks on the consistency of staff training in using the tool (though regular meetings were held to review practice) and so data quality may have varied across the six NHS organisations. Also, whilst the LDNAT covers a broad range of needs and includes some contextual factors, the research suggests that there may be others which can influence admission that were not captured. Finally the cross-sectional nature of the study precludes the cause(s) of hospital admission from being unequivocally established.

Looking to research studies within forensic ID services relating to risk identification (e.g. Blacker et al, 2011; Lofthouse et al., 2013), cross-sectional analyses are nonetheless valued as pre-cursors to inform subsequent longitudinal studies. Therefore, despite its shortcomings, the results of this study are encouraging and warrant further investigation. In future, longitudinal cohort studies should be undertaken using LDNAT data that are gathered periodically to better gauge the LDNAT's ability to identify people with ID living in the community who are most at risk of future hospital admission.

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Figure 1 Receiver Operator Characteristics (ROC) Curve for the LDNAT Inpatient Index score.

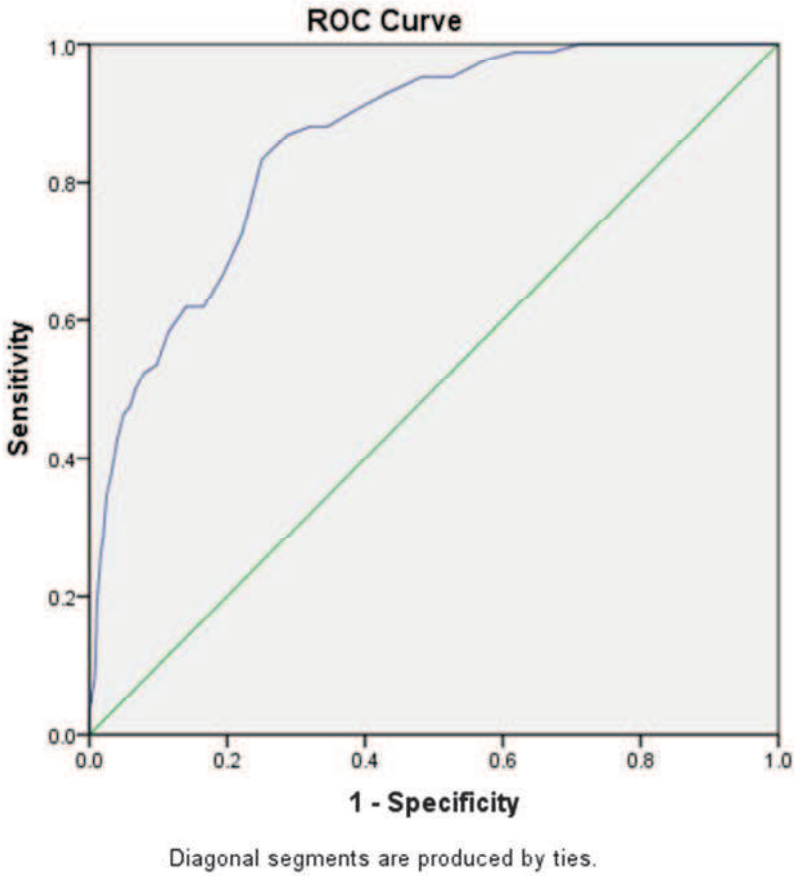

Table 1: Means (SD) and tests of difference for inpatients and non-inpatients for individual LDNAT items

LDNAT Scale	Treatment setting	Group Mean rating (SD)	t	Sig. (2-tailed)
1.Overactive, aggressive, disruptive or agitated behaviour	Non-inpatient	1.007(1.0208)	-10.266	0.000
	Inpatient	2.190(1.1137)		
2.Non-accidental self-injury	Non-inpatient	0.260(0.6549)	-4.198	0.000
	Inpatient	0.833(1.2402)		
3. Problem Drinking or drug taking	Non-inpatient	0.116(0.4734)	-0.062	0.950
	Inpatient	0.119(0.3609)		
4. Cognitive problems	Non-inpatient	2.009(1.0686)	-1.316	0.189
	Inpatient	2.167(0.9797)		
5. Physical Illness or disability problems	Non-inpatient	1.378(1.2903)	-0.021	0.984
	Inpatient	1.381(1.0744)		
6. Hallucinations and delusions	Non-inpatient	0.171(0.5621)	-4.281	0.000
	Inpatient	0.750(1.2309)		
7. Depressed mood	Non-inpatient	0.596(0.8103)	-3.349	0.001
	Inpatient	0.964(0.9872)		
8. Other mental and behavioural problems	Non-inpatient	1.179(1.2174)	-7.700	0.000
	Inpatient	2.238(1.3319)		
9. relationships	Non-inpatient	1.115(1.1130)	-8.490	0.000
	Inpatient	2.179(1.1424)		
10.Activities of daily living	Non-inpatient	1.709(1.2925)	-2.064	0.042
	Inpatient	1.988(1.1973)		
11. Living conditions	Non-inpatient	0.422(0.7859)	-6.139	0.000
	Inpatient	1.250(1.2211)		
12. Occupation and activities	Non-inpatient	0.744(0.9811)	-3.265	0.001
	Inpatient	1.107(1.1303)		
13. Strong unreasonable beliefs	Non-inpatient	0.273(0.7688)	-5.115	0.000
	Inpatient	1.095(1.4613)		
14. Non-accidental self-injury (assoc.	Non-inpatient	0.312(0.7353)	-3.579	0.001

with cognitive impairment)	Inpatient	0.726(1.0454)		
15. Physical problem with eating and drinking	Non-inpatient	0.469(0.9792)	0.480	0.631
	Inpatient	0.417(0.7638)		
16 Agitated behaviour/expansive mood	Non-inpatient	1.706(1.3086)	-9.908	0.000
	Inpatient	3.036(1.1867)		
17. Repeat self-harm	Non-inpatient	0.568(0.9913)	-4.912	0.000
	Inpatient	1.310(1.3619)		
18. Safeguarding other children/vulnerable dependant adults	Non-inpatient	0.572(1.0684)	-7.569	0.000
	Inpatient	1.917(1.6073)		
19. Engagement	Non-inpatient	1.141(1.2825)	-7.333	0.000
	Inpatient	2.321(1.4409)		
20. Vulnerability	Non-inpatient	2.331(1.1449)	-5.303	0.000
	Inpatient	3.012(1.0921)		
21 social communication difficulties	Non-inpatient	1.396(1.3129)	-3.250	0.002
	Inpatient	1.952(1.5360)		
22. Communication problems	Non-inpatient	1.473(1.2952)	-2.716	0.007
	Inpatient	1.869(1.3243)		
23. Seizures	Non-inpatient	0.490(0.9907)	-0.729	0.466
	Inpatient	0.571(1.0787)		

N.B. Inpatient n= 84, non-inpatient n=1591

Table 2: Sensitivity and specificity results for the statistically optimal cut-off score on the LDNAT Inpatient Index.

	Inpatients	Non-inpatients	Total
Inpatient Index score >22.5	57 (true positives)	262 (false positives)	319
Inpatient Index score < 22.5	27 (false negatives)	1120 (true negatives)	1147
Total	84	1382	1466