The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services

PAINTER, Jon <http://orcid.org/0000-0003-1589-4054>, TREVITHICK, Liam, HASTINGS, Richard, INGHAM, Barry and ROY, Ashok

Published version

PAINTER, Jon, TREVITHICK, Liam, HASTINGS, Richard, INGHAM, Barry and ROY, Ashok (2018). The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services. Journal of Mental Health, 27 (2), 103-111.

The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services.

Abstract

Background: A development of a needs-led classification system based on the Health of the National Outcome Scales (HoNOS) has previously been developed (Self, Rigby, Leggett, & Paxton, 2008).

Aims: To extend the needs-based mental health clusters to accommodate the additional needs of people accessing UK intellectual disabilities health services.

Method: Hierarchical cluster analysis was performed on assessment data from 18 NHS provider organisations. The statistical results were clinically shaped through multi-disciplinary workshops. The resulting clusters were combined with six independently-rated measures for a second data collection exercise. Based on these data, refinements were made before performing internal and external validity checks.

Results: Eight additional clusters for people with health needs associated with their intellectual disabilities were produced. Three described primarily physical health needs, four described needs arising from behaviours which challenged (with/without autism) whilst one described people with generally low needs. Together, these covered 83.4% of cases with only a 10% overlap. The clusters were replicable and had clinical utility and validity.

Conclusions: It was possible to extend the needs-led mental health classification system to capture the additional needs of people accessing UK intellectual disability services.

Declarations of Interest: This study received NHS England funding.

Key words: Mental retardation, cluster analysis, Health of the Nation Outcome Scales, HoNOS, Needs-led, Intellectual disability

Background

A consortium of NHS trusts in the North of England worked in collaboration with Monitor, Department of Health and NHS England for over ten years on a novel needs-led classification system for use in mental health services. Fundamental to the work was the rating of individual patient needs using an extended version of the Health of the Nation Outcome Scales (HoNOS) (Wing et al., 1998) which was subsequently named the Mental Health Clustering Tool (MHCT) (Department of Health, 2014).

Initially, data were gathered by using the MHCT to assess a broad range of patients accessing specialist mental health services. Statistical cluster analysis was then undertaken to identify groups of patients with similar scoring profiles across the 18 scales in the tool. Finally, these clusters were refined through multi-disciplinary focus groups and case reviews to ensure clinical as well as statistical homogeneity (see Self, Rigby, Leggett, & Paxton, 2008). Over time these needs-led clusters have been refined and the current mental health set consists of 21 clusters divided into 3 super-classes (psychosis, non-psychosis and organic conditions). Each cluster consists of a brief vignette, salient clinical information and most importantly a scoring profile for the 18 items in the MHCT (each of which are rated on a 0-4 scale). See Painter et al, (submitted) for details.

Since 2010, this needs-led clusters model has been incrementally adopted through national policy as the basis of a move away from block contracts to a national payment system through which complexity of clinical need and associated treatment can be more appropriately recompensed (Appleby, Harrieson, Hawkins, & Dixon, 2013). Locally, the mapping of patient need by cluster has also allowed provider organisations to consider whether their service configurations are optimally matched to the type and level of demand they experience (Brown et al., 2015).

Variability and somewhat arbitrary organisational and commissioning boundaries between mental health and intellectual disability services prompted the view that all patients should be facilitated to access the service which best met their needs (rather than choices being limited by spurious and often detrimental labels/criteria (Chaplin, 2004)). In consultation with multi-disciplinary groups of intellectual disability staff it was agreed that a similar needs-led clustering approach would also be beneficial for patients with an intellectual disability. Importantly, in recognition of the high prevalence of mental health problems experienced by people with an intellectual disability, it was decided to create a seamless extension to the mental health clusters rather than creating a completely separate classification system (Ingham et al., 2013).

In this paper, we report the extension of the mental health clusters to create a comprehensive, empirically-generated, needs-based taxonomy that describes the groups of patients typically accessing specialist intellectual disability health services.

Method

This study of retrospective clinical data from 18 healthcare providers across England was approved for the purposes of NHS service evaluation. The iterative process of data collection, analysis, re-testing and validation took place between 2011 and 2016. Initially, the MHCT was reviewed by a multi-disciplinary group of clinicians working in the field of intellectual disabilities. Their feedback led to the creation of additional scales to ensure all relevant clinical issues could be rated. The resulting learning disability needs assessment tool (LDNAT; Painter et al, submitted) was then felt to cover the six domains of patient need that clinicians deemed necessary to formulate care/treatment plans. These domains were: general ability/disability severity; risk; mental health, challenging behaviour; Autism (ASD), and physical health.

The use of the LDNAT in a broad range of specialist health care intellectual disability settings generated the data analysed for this study as well as the validation of the needs assessment tool itself (described in more detail in Painter et al, submitted). Briefly, the tool was found to have good internal consistency and principal component analysis identified three components describing developmental needs, challenging behavior, and mental health and wellbeing.

Stage 1:

Staff from a range of disciplines working across 18 trusts received training in the use of the LDNAT and cluster allocation. They, in turn trained staff in their own organisations. These trained staff then used the model to rate and allocate a number of their patients over a 9-month period. In addition to the LDNAT ratings, a standardised pseudonymous dataset was developed which also contained a range of basic demographics and other relevant clinical information now routinely submitted as part of the Mental Health and Learning Disability Data Set (HSCIC, 2014). Each trust then sourced the required data from their patients' records before submitting it for analysis using SPSS version22(IBM, 2015).

Allocations made to any of the original mental health clusters were excluded from the remainder of this stage of the project as these clusters had been developed in the previous work on the MHCT. Following the production of a range of basic descriptive statistics for the patients deemed by staff to have a primary need related to their intellectual disability, two-stages of cluster-analysis (Ward's method and K-means) were undertaken as per Self, Rigby, Leggett, & Paxton's (2008) original mental health developments. Similarly, over a number of multi-disciplinary clinical workshops these statistical groupings were explored, shaped and subdivided to ensure the clusters had clinical face validity. Profiles for each cluster were then produced which mirrored the original mental health descriptions and these were integrated into the original taxonomy (fig 3). Expert by experience and carer feedback was also gathered at this stage through four workshops that were facilitated by an independent advocacy service to inform developments.

To gauge the success of the clinical refinements described above, 11 of the original trusts reassessed a number of their patients and allocated them to one of the nine new empirically-derived intellectual disability clusters. Again, pseudonomised data were submitted for central analysis but this time the dataset included clinician ratings of how well the resulting cluster described the person they had assessed as well as allowing for free text comments regarding any patient needs they were unable to capture.

Stage 2:

To test the refined model, a second data collection exercise was undertaken by staff in 6 of the trusts between 01/07/2014 and 31/08/2015. The resulting patient assessments were again submitted electronically for analysis via a standardised dataset. On this occasion, 4 of the trusts also included a convenience sample of concurrent, but independent ratings from 6 routine clinical assessment tools. These tools each addressed a specific treatment domain and were used to validate the clusters against independent measures as well as the LDNAT ratings. Candidate measures were identified from a brief literature review with final selection based on brevity, simplicity, validity, and cost. The final choice of measures was:

The Waisman Activities of Daily Living Scale (**W-ADL**) (Maenner et al., 2013) was used to assess general ability/disability. Raters record whether an individual can complete various activities of daily living independently (score 2), with help (score 1), or not at all (score 0). The tool consists of 17 activities ranging from basic skills (e.g. drinking from a cup) to more advanced tasks (e.g. simple home repairs and budgeting). The tool has been validated on people with a broad range of intellectual disabilities.

The Threshold Assessment Grid (**TAG**) (Slade, Powell, Rosen, & Strathdee, 2000) was selected to provide an overall risk rating. It was originally developed and validated through a series of workshops and a Delphi consultation as a means of prioritising access to mainstream mental health services. Seven items are each rated on 4 or 5 point scales to give an overall rating of illness severity. However, a number of the tool's subscales were deemed by clinicians to adequately capture risks to/from people with intellectual disabilities.

The Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist (**PAS-ADD** checklist) (Moss et al., 1998) was used to rate the severity of mental health problems. The tool consists of 24 items written using lay-terms to allow non-professionals to identify mental health problems in people with intellectual disabilities. Originally developed as a screening tool, the PAS-ADD checklist includes three different scoring triggers for a fuller mental health assessment. Items include irritability, loss of appetite and strange unshakeable beliefs. Items rated on a 4-point scale which combines intensity and frequency, and is based on the previous 4 weeks but specifically excludes long-standing issues.

The Behaviour Problems Inventory for Individuals with Intellectual Disabilities-Short Form (**BPI-S**) (Mascitelli et al., 2015; Rojahn et al., 2012a, 2012b) was selected to rate challenging behaviours. This shortened version captures self-injurious behaviours (e.g. head-hitting), aggressive/destructive behaviours (e.g. verbal aggression) and stereotyped behaviours (e.g. rocking/repetitive body movements) and is based on a longer (52-item) original version. The frequency rating for each of the 30 items was used to provide an overall challenging behaviour total score.

The Social Communication Questionnaire (**SCQ**), (Rutter, Bailey, & Lord, 2003) was selected to provide a rating of the severity of ASD symptoms. Valid for both children and adults (Brooks & Benson, 2013), it consists of 40 ‘yes/no’ questions intended to capture the key features of ASD for example: “Does he/she have interests that pre-occupy him/her and might seem odd to other people (e.g. traffic lights, drainpipes or timetables)?”.

No single suitable physical health measure could be identified and so a bespoke questionnaire was created by the authors (available on request). It consisted of 12 yes/no questions (e.g. Is the person blind/visually impaired?”), three rating scale questions (e.g. “How good is the person’s health in general? Very good/ good/ fair/ bad/ very bad/ don’t know”) and two which ask for height and weight. The yes/no questions were used to create a total score representing the overall level of physical health and disability. Although yet to be fully validated, it was based on the POMONA study (Haverman et al., 2011) and a brief investigation of its internal consistency yielded acceptable results in the present sample (Cronbach alpha = 0.73).

In stage 1 the mental health cluster allocations had been separated from the remainder of cases prior to cluster analysis. To confirm this was appropriate, independent t-tests were performed on each scale for these two groups. Next, cluster stability was investigated by repeating the original cluster analysis procedure on the second data set. Goodness of fit was assessed with the aid of scoring matrices for each cluster showing the percentage of patients fitting within the anticipated ranges. This information was used to make final adjustments to the cluster profiles before cases were re-allocated to the cluster that best-matched their LDNAT scoring. At this point, a check of cluster coverage and overlap was repeated before exploring clinical face and utility validity. Finally, the clusters were validated by examining their demographic information and using the six additional, independently-rated clinical assessment tools to explore intra-cluster properties and inter-cluster relationships.

Results

Stage 1

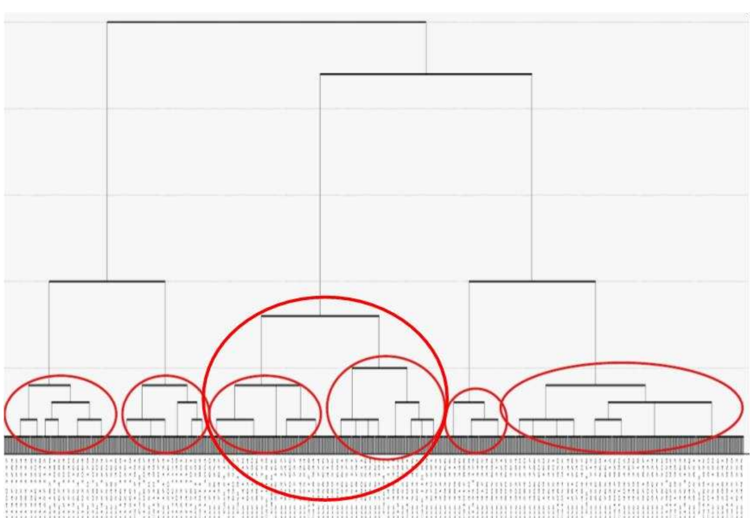
In total, staff from the 18 trusts submitted 2825 patient assessments for analysis. 53.6% were male and 3.8% were inpatients. Assessments were undertaken by nurses, occupational therapists, psychiatrists, psychologists as well as other allied health professionals. These staff allocated 28% of the cases (n=779) to an existing cluster (indicating they felt mental health to be the primary issue) and 65% (n=1849) to an intellectual disability descriptor. 5% (n=127) were allocated to the variance cluster 0 (indicating they required a service but were not adequately described by any of the existing clusters/descriptors) and the remaining 2% (n=70) were unallocated.

Statistical cluster analysis

After removing records for patients under 18yrs, repeat assessments and those with incomplete data, 1256 complete and unique patient records were available for the statistical cluster analysis of LDNAT ratings for the patients deemed by clinicians to have a primary need arising from their intellectual disability (i.e., also excluding those allocated to existing mental health clusters).

Hierarchical agglomerative cluster analysis using Ward's method produced a dendrogram which suggested a 5 or 6 cluster solution (figure 1).

Figure1: Dendrogram suggesting 5 or 6 cluster solution.



With reference to the squared Euclidean distances used in Self et al's original work (Self et al., 2008) and a clinical review of the LDNAT scoring profiles for the 5 and 6 cluster K-means solutions, the 5 cluster solution was favoured (table 1).

Table 1: Summary details of stage 1's 5 statistical cluster solution.

Cluster size and key features (based on clinical interpretation of LDNAT ratings)	**LDNAT items >0.5SD above the overall mean score**	**LDNAT items <0.5SD below the overall mean score**
A [N = 241] Autism Spectrum Disorder (ASD), aggression, communication limitations, otherwise cognitively relatively able, low physical problems	21,22	5
B [N = 247] Profound LD, physical health problems, low challenging behaviour (CB)/ mental health (MH) problems	4,5,10,15,20,22, 23	1,7,8,9,14,16,17,18
C [N = 167] Severe LD, ASD, relatively high levels of CB and MH needs	1,7,8,9,10,11,14,16, 17,18,19,20,21	
D [N = 383] Mild LD & relatively low levels of need		4,10,14,18,20,21, 22,23
E [N = 218] Mild LD, SIB/self-harm, others at risk/vulnerable	14,17,18	20,22

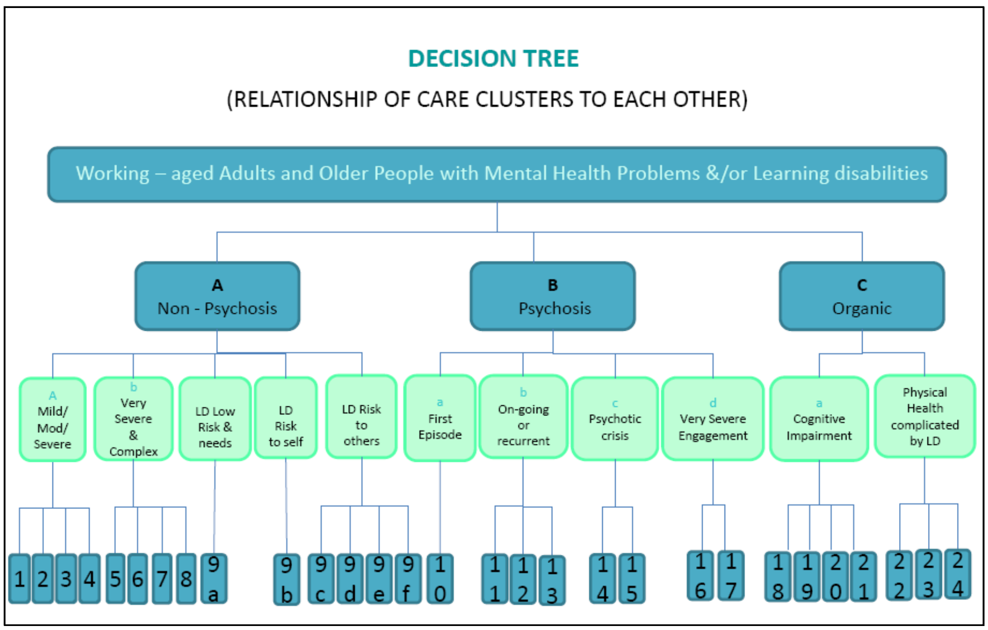
*NB. Items have been re-numbered to facilitate comparison with stage 2 results. Also, item 22 was originally 2 separate communication items

Clinical refinements

With the aid of a range of descriptive statistics and concurrent data, a series of regional and national clinical workshops were held to investigate these results to better understand the nature of each statistical cluster's membership. As with Self et al's (2008) original work, through a number of iterations, the 5 statistical groupings were ultimately subdivided to improve their clinical utility. The resulting 6 'risky behaviour' and 3 'physical health' clusters balanced statistical homogeneity with clinical face validity. These 9 clusters (below), with varying levels of complexity and severity of need were named and numbered to integrate with the original mental health model (see Self, Rigby, Leggett, & Paxton, 2008):

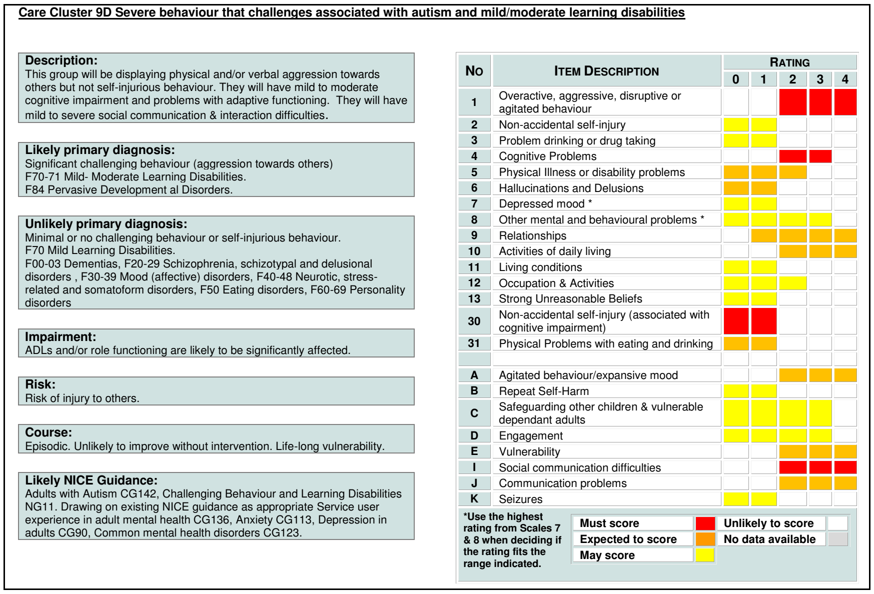
- 9A Maintenance, engagement & minor support needs, complicated by LD
- 9B Risk to self, complicated by LD
- 9C Risk to others, complicated by LD
- 9D Risk to others, complicated by mild LD & ASD
- 9E Risk to others, complicated by moderate - profound LD & ASD
- 9F Risk to others & self, complicated by moderate - profound LD & ASD
- 22 Physical health complicated by mild LD
- 23 Physical health complicated by moderate - profound LD
- 24 Physical health with dysphagia complicated by moderate - profound LD

Figure 2: Decision tree with new clusters integrated into the original mental health model.



Also, based on the LDNAT scoring patterns and multi-disciplinary feedback regarding the most important clinical features of each cluster, a fuller profile page (including a pen picture description) was produced within the same structure as the MHCT (as per fig 3).

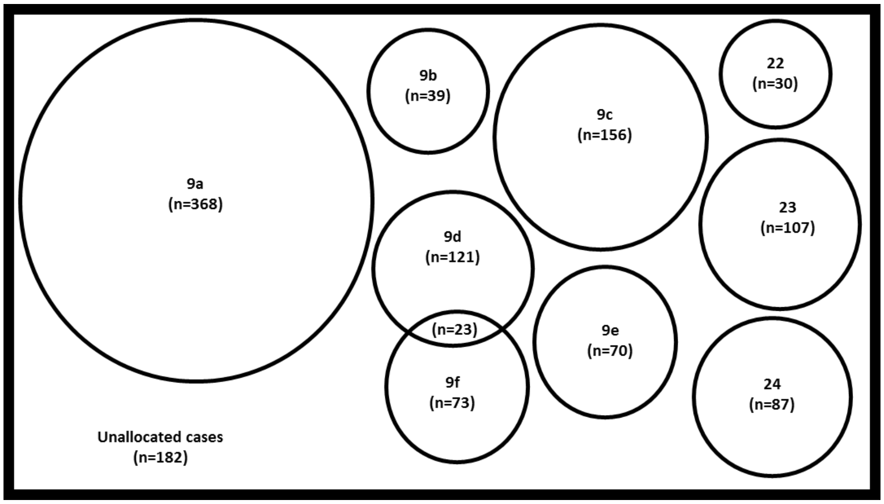
Fig 3: Example of a cluster profile



Overlap and coverage checks

Unlike strictly categorical psychiatric diagnoses (Vieta & Phillips, 2007) the mental health clusters were based on the fuzzy clustering and proportional membership (Nascimento, 2006) which effectively creates a degree of overlap between clusters. A second important balance struck during the creation of the extended taxonomy was the degree of this overlap versus coverage of all cases. As cluster membership was tightened (and overlap completely eliminated) more cases fell outside any profile and vice versa. The final membership was 85.5% (almost identical to Self's original work) with a low (2%) degree of overlap. Based on their scoring profiles, the unallocated cases appeared to be outliers from the new clusters, rather than a homogenous group that had not been captured (figure 4).

Figure 4: Venn diagram depicting membership, overlap and coverage of newly developed clusters.



After the empirically generated clusters with fuller profiles were generated, 829 of the patients from 11 of the trusts were re-assessed and allocated to the best-fitting cluster by clinicians. In comparison with the initial data, fewer cases (12.6%) were allocated to a mental health cluster and slightly more (7.7%) were allocated to the variance cluster 0 (i.e. where no other cluster adequately describes the patient's needs). The remaining 79.7% were more evenly distributed across the intellectual disability taxonomy and the modal staff rating of goodness of fit was 4 (on a 5-point Likert scale).

Qualitative rater feedback was collated thematically and combined with the outputs from 4 user and carer workshops (attended by 32 users and carers together with 20 support staff). These results generated relatively minor refinements (e.g. to the pen picture descriptions) rather than any fundamental changes to the model’s structure.

Stage 2

The final data collection exercise across a 12 month period yielded 2,063 unique patient records from 6 trusts for patients 18years and older. 55% were male, mean age was 41.7yrs and 6% were inpatient. 148 cases also had ratings for 6 additional assessment tools and this subset did not differ significantly from the full submission other than having a higher prevalence of inpatients (21%).

The data were divided into two: the cases allocated by clinicians to a mental health cluster and those cases deemed to have a need primarily associated with their intellectual disability. Independent t-tests for each LDNAT component as well as the overall LDNAT score were performed on these two groups. The LDNAT total score and two of the three components were found to have statistically significant differences (see table 2).

Table 2. Means, standard deviation and t-test for LD and MH clusters. N=1,622.

Items	LD clusters N=1,176		non LD cluster N=446				
	Mean	Std. Deviation	Mean	Std. Deviation	t value	df	Sig. (2-tailed)
LDNAT Developmental needs component	12.52	6.20	9.24	5.02	10.022	1620	<0.001
LDNAT Challenging behaviour component	7.44	5.39	7.14	5.22	1.01	1620	0.313
LDNAT Mental health & wellbeing component	4.41	3.66	5.19	3.85	-3.768	1620	<0.001
LDNAT total	23.35	10.52	20.86	10.19	4.296	1620	<0.001

Goodness of fit

As with stage 1, goodness of fit was examined with the aid of a simple scoring matrix that showed how many of the cases allocated to each cluster by clinicians met the required range for each LDNAT item. Cluster 9b stood out as problematic due to very low fit. After carefully revisiting the full stage 1 report regarding its development (available at http://www.cppconsortium.nhs.uk/ld.php) it was agreed that cluster 9b should be discarded and the other challenging behaviour clusters adjusted slightly to accommodate this.

Due to the relatively small number of cases allocated to cluster 9b, the refinements made were modest and once cases were reallocated on the basis of these updated scoring profiles there was a much improved fit (table 3).

Table 3: Goodness of fit (i.e. percentage of cases fitting each cluster's LDNAT scale ranges)

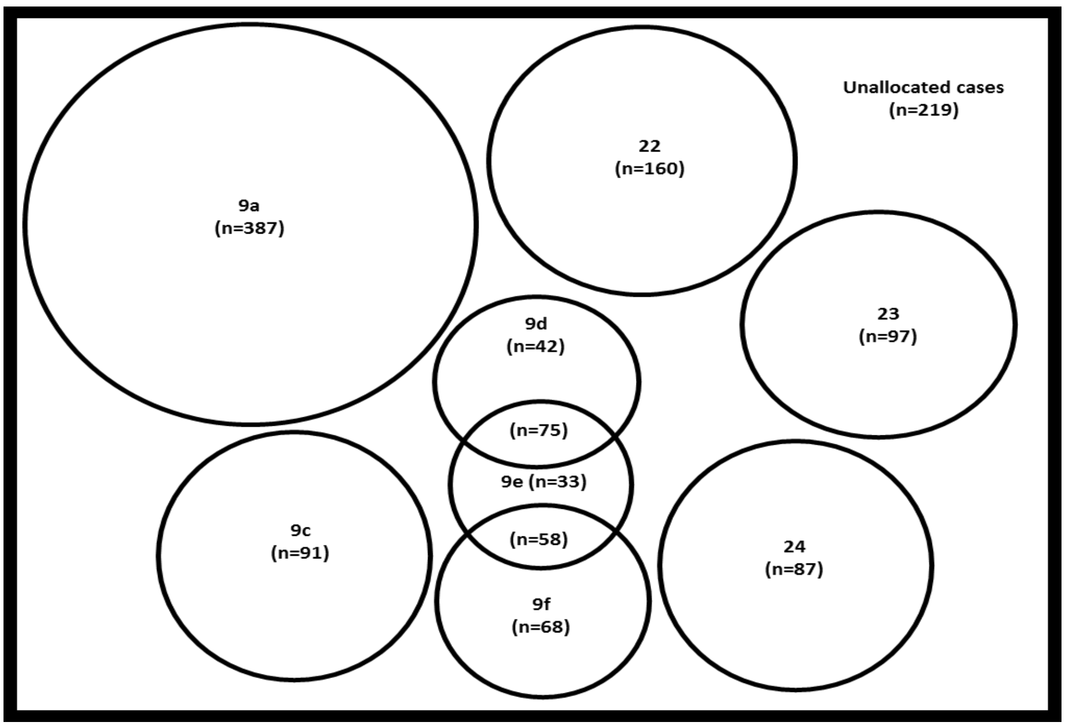
Item	Revised Cluster 22		Revised Cluster 23		Revised Cluster 24		Revised cluster 9a		Revised cluster 9c		Revised cluster 9d		Revised cluster 9e		Revised cluster 9f		CB (9a-f) overall mean % fit	PH (22-24) overall mean % fit	Overall mean fit %
	% fit	N	% fit	N	% fit	N	% fit	N	% fit	N	% fit	N	% fit	N	% fit	N			
1	84%	160	64%	96	84%	87	100%	387	100%	91	100%	117	100%	166	100%	126	100%	78%	94%
2	96%	160	93%	97	100%	87	98%	384	85%	91	82%	117	86%	166	90%	125	91%	96%	93%
3	98%	160	100%	97	100%	87	96%	387	97%	91	97%	117	97%	166	99%	126	97%	99%	97%
4	100%	160	100%	97	100%	87	100%	387	100%	91	100%	117	100%	166	100%	126	100%	100%	100%
5	100%	160	100%	97	100%	87	91%	387	87%	91	91%	117	89%	166	79%	126	88%	100%	92%
6	96%	160	97%	97	98%	87	97%	386	98%	91	95%	116	95%	166	94%	123	96%	97%	96%
7	89%	160	94%	97	90%	87	88%	386	84%	91	97%	117	76%	165	96%	122	87%	91%	88%
8	89%	156	88%	92	66%	85	90%	379	93%	90	94%	117	92%	166	78%	125	90%	83%	88%
9	81%	160	88%	97	83%	87	95%	385	84%	90	78%	117	83%	165	78%	125	87%	83%	86%
10	71%	160	89%	97	93%	87	89%	387	97%	90	82%	117	71%	166	87%	126	85%	82%	84%
11	93%	160	91%	96	94%	87	92%	387	82%	90	93%	117	80%	166	89%	126	89%	93%	90%
12	81%	160	77%	97	83%	87	82%	386	96%	90	91%	117	90%	166	87%	126	87%	80%	85%
13	97%	158	97%	96	99%	87	91%	385	92%	90	74%	116	80%	166	91%	123	87%	98%	90%
14	95%	155	82%	97	89%	87	100%	387	100%	91	96%	116	100%	166	41%	125	91%	90%	91%
15	97%	156	100%	97	100%	87	96%	386	92%	90	94%	117	93%	166	98%	126	95%	99%	96%
16	92%	159	79%	95	87%	86	75%	379	89%	90	94%	117	93%	166	96%	126	86%	87%	86%
17	96%	160	87%	97	90%	86	82%	377	91%	90	73%	117	78%	166	86%	124	82%	92%	84%
18	96%	160	94%	97	95%	86	83%	378	92%	90	91%	117	93%	166	90%	126	88%	95%	90%
19	93%	160	78%	96	79%	86	87%	378	88%	90	69%	117	89%	166	81%	125	84%	85%	84%
20	73%	160	91%	97	88%	86	93%	382	100%	90	89%	116	91%	166	85%	126	91%	82%	89%
21	100%	142	100%	92	100%	84	89%	359	100%	91	100%	117	100%	166	100%	126	95%	100%	97%
22	95%	156	89%	95	93%	87	75%	387	90%	91	77%	117	77%	166	96%	126	80%	93%	84%
23	79%	156	74%	97	83%	83	93%	384	87%	91	85%	117	86%	166	90%	124	90%	79%	87%

.

Overlap and coverage checks

Having confirmed the fit for each cluster, the 1,317 cases with all required data items were re-allocated on the basis of their scoring profiles to confirm coverage and overlap (figure 5).

Figure 5: Venn diagram depicting membership, overlap and coverage of newly developed clusters.



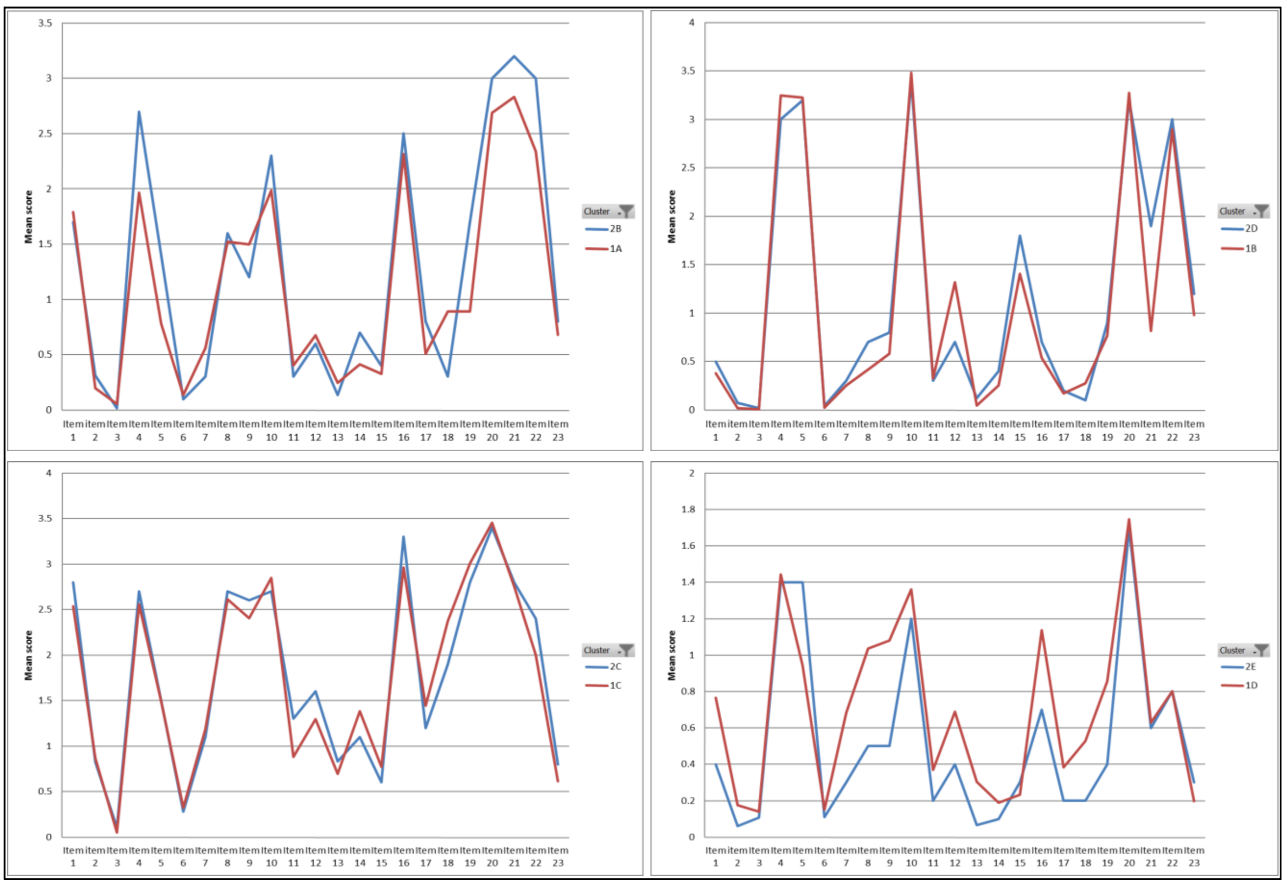
From this it was apparent that, overall level of coverage had remained relatively stable (83.4%) whilst the adjustments made to accommodate the removal of cluster 9b had increased the degree of overlap from 2% to 10%. No further improvements could be made without compromising either fit, overlap or coverage and thus it was deemed the optimal balance between the three had been obtained.

Internal validity

Replicability

To confirm the stability of the statistical clusters (which underpinned the clinical refinements) the stage 1 cluster analysis procedure was repeated on the newly gathered data. The resulting dendrogram confirmed a 5 cluster solution remained appropriate and k-means analysis produced a similar LDNAT scoring profile for 4 of the 5 original clusters. This can be seen in figure 6.

Figure 6: LDNAT mean scores for stage 1 and stage 2 statistical clusters



The only statistical cluster from stage 1 for which there was a relatively poor fit was cluster 1e. Overall, however, the congruence between the two sets of statistical clusters was deemed sufficient to assume that, if a similar process of clinical refinements (from phase 1) had been repeated on the second block of data, similar conclusions would have been reached. This indicated an encouraging level of replicability (Speece, 1994) for both the statistically generated and, by inference, the clinically refined clusters.

External validity

Clinical face validity

Statistical cluster analysis will, by its very nature always yield results (Speece, 1994) these groups will, however, only be of use if they have meaning and utility in the field (Clatworthy, Buick, Hankins, Weinman, & Horne, 2005). To some extent the process of clinical review and refinement had addressed this. However, following the final set of adjustments; descriptive statistics were reviewed to ensure clinical face validity had been retained (table 4).

Table 4: Summary of clinical variables by cluster

Variable	9a	9C	9D	9e	9f	22	23	24
Age (SD)	39.7 (15.4)	39.2 (15.9)	36.3 (14.5)	36.7 (14.7)	34.7 (14.2)	45.7 (15.9)	45.8 (15.4)	44.2 (17.6)
% Male	55%	65%	59%	59%	62%	51%	48%	47%
%IP	2%	6%	9%	11%	12%	0%	3%	3%
Primary need category (most frequent)	Mental health (20%)	Behaviour/CB (60%)	Behaviour/ CB (32%)	Behaviour/ CB (42%)	Behaviour/ CB (70%)	Mobility (20%)	Mobility (43%)	Mobility (30%) Dysphagia (24%)
Secondary need category (most frequent)	Vulnerability (30%)	Vulnerability (33%)	Behaviour/ CB (41%)	Behaviour/ CB (34%)	ASD (24%)	ASD (23%)	ASD (18%)	Sensory problems (24%)
Primary diagnosis (most frequent)	Mild ID (57%)	Mild ID (50%)	Mod ID (35%), mild ID (23%)	Mod ID (52%)	Mod ID (38%) severe ID (32%)	Mild ID (43%)	Mod ID (36%)	Severe ID (33%)
Secondary diagnosis (most frequent)	Affective disorders (31%)	Nervous system diseases (31%)	Nervous system diseases (23%)	Anxiety disorders (24%)	Pervasive develop disorders (26%)	Nervous system disorders (31%)		Nervous system disorders (67%)
Primary current medication (most frequent)	Anti-depressants (26%), anti-psychotics (24%)	Anti-convulsants (24%)	Anti-psychotics (26%)	Anti-psychotics (36%)	Anti-psychotics (50%)	Physical health (45%)	Anti-convulsants (42%)	Anti-convulsants (49%)
Secondary current medication (most frequent)	Meds for physical health (13%)	Meds for physical health (18%), anti-depressant (18%)	Anti-psychotics (24%)	Meds for physical health (21%)	Meds for physical health (16%)	Physical health (29%)	Physical health (28%)	Anti-convulsants (25%)
Mean total number of medications	2.03	2.94	3.94	4.12	4.3	4.5	3.6	5.4
% in employment or voluntary work	13%	14%	5%	5%	2%	16%	7%	2%
Most frequently recorded type of clinical intervention	Coping strategies (31%)	Coping strategies (41%)	Coping strategies (43%)	Coping strategies (39%)	Coping strategies (24%)	Physical health (50%)	Physical health (50%)	Physical Health (36%)

Whilst it must be acknowledged that the level of missing data varied significantly by variable (26-81%), the results remained supportive.

Clinical utility

The mean LDNAT scores for both sets of cluster analyses, together with the resulting clinically refined clusters were scrutinised to gain a better understanding of their relationship. This is depicted in table 5.

Table 5: A mapping of the stage 1 & 2 statistical clusters with the clinically shaped clusters.

<table>
<tr><th>Brief descriptions of the statistical clusters.</th><th>Stage 1 statistical clusters</th><th>Stage 2 statistical clusters</th><th>Clinically refined clusters</th></tr>
<tr><td rowspan="3">Physical health (low-high need)</td><td rowspan="3">1B</td><td rowspan="3">2D</td><td>22</td></tr>
<tr><td>23</td></tr>
<tr><td>24</td></tr>
<tr><td>General low need without ASD</td><td>1D</td><td>2E</td><td>9a</td></tr>
<tr><td></td><td>1E</td><td></td><td>(9b)</td></tr>
<tr><td>Challenging behaviour (Moderate need without ASD)</td><td rowspan="3">1A</td><td>2A</td><td>9c</td></tr>
<tr><td rowspan="2">Challenging behaviour (Moderate need with ASD)</td><td rowspan="2">2B</td><td>9d</td></tr>
<tr><td>9e</td></tr>
<tr><td rowspan="2">Challenging behaviour (High need with ASD)</td><td rowspan="2">1C</td><td rowspan="2">2C</td><td>9e</td></tr>
<tr><td>9f</td></tr>
</table>

Having established the crude relationship of the clusters to each other (figure 5 and table 5) it was possible to construct a number of hypotheses as to how these clusters might perform against the 6 independently rated measures. When integrated into the decision tree (figure 2) the clusters had been divided into two groups: challenging behaviours (9a-f) and physical health (22-24). In general, it was anticipated that levels of need should increase incrementally across both of these groups of clusters. N.B. Clusters 23 and 24 were combined due to the relatively small number of cases in each.

The W-ADL mean scores decreased through both the challenging behaviour (CB) and physical health (PH) sets of clusters. This confirmed the anticipated increases in general impairment (also indicated by the LDNAT developmental needs component mean scores). The mean scores for the bespoke physical health tool showed a logical increase across clusters 22-24 which was again reflected in the LDNAT's developmental needs component. In terms of mental health, whilst the PAS-ADD mean scores showed less of a clear trend, in general the CB clusters scored more highly than the PH clusters (a finding that was mirrored with the LDNAT mental health and wellbeing component). The SCQ means were obviously lower in clusters 9a and 9c in comparison to 9d-f (where social communication difficulties were a pre-requisite). The increasing levels of challenging behaviour anticipated across the CB clusters (and apparent in the LDNAT challenging behaviour component scores) was matched by the aggression subscale of the BPI. Finally, the safety and risk subscales of the TAG were notably higher in the CB clusters than the PH set. Overall therefore the clusters performed largely as anticipated across the 6 independently-rated, domain-specific measures used in the study (table 6).

Table 6: Performance of the final clusters across 6 treatment domains.

Cluster		LDNAT components			LDNAT total	WADL total	Physical health tool total	PAS-ADD total	SCQ total	BPI	TAG		
		Developmental needs	Challenging behaviour	Mental health and wellbeing						Total frequency score	Safety	Risk	Needs & disabilities
9A	Mean	8.0	5.3	3.6	16.3	21.2	1.8	5.0	14.0	10.3	1.3	1.7	3.3
	N	352	363	376	340	28	19	27	30	16	30	30	30
9C	Mean	9.0	9.8	5.3	23.2	20.9	2.3	3.3	12.3	24.9	1.8	2.6	4.2
	N	89	89	88	87	11	9	11	12	8	13	13	12
9D	Mean	11.6	11.7	7.2	28.7	19.6	2.0	4.9	16.3	70.8	1.3	2.8	5.3
	N	116	116	116	113	18	13	13	18	6	19	19	19
9E	Mean	13.9	11.6	7.0	30.8	19.4	1.8	5.1	16.4	56.0	1.6	3.3	5.8
	N	166	166	164	164	20	14	18	19	2	20	20	22
9F	Mean	18.0	13.9	6.9	36.6	11.6	3.4	4.9	18.7	78.7	2.3	2.9	5.7
	N	124	123	119	117	16	12	13	16	9	16	16	16
22	Mean	12.4	3.6	2.9	17.9	12.6	4.3	3.6	11.8	4.0	0.4	1.0	1.9
	N	142	150	154	134	11	9	10	11	7	11	11	11
23	Mean	19.0	6.0	3.5	28.3	8.9	5.8	4.3	17.9	37.2	1.1	1.3	2.9
	N	90	89	90	83	8	5	7	8	5	7	7	7
24	Mean	23.2	4.3	3.3	30.6	6.3	6.0	2.0	17.7	18.7	1.3	2.0	8.0
	N	79	84	85	77	3	3	2	3	3	3	3	2
Combined clusters 23 &24	Mean	21.0	5.2	3.4	29.4	8.2	5.9	3.8	17.8	30.3	1.2	1.5	4
	N	169	173	175	160	11	8	9	11	8	10	10	9
	ANOVA	F(7,884)= 219.6, p<0.001	F(7,906)=91.7, p<0.001	F(7,922)=26.1, p<0.001	F(7,845)=107.8, p<0.001	F(7,73)=7.2, p<0.001	F(7,52)=4.3, p=0.001	F(7,63)=0.2, p=0.990	F(7,77)=3.5, p=0.002	F(7,48)=5.1, p<0.001	F(7,77)=1.7, p=0.123	F(7,77)=2.2, p=0.044	F(7,75)=4.1, p=0.001

Discussion

This paper describes the development of eight clusters of need for people with an intellectual disability. The five 'challenging behaviour' and three 'physical health' clusters each represent group of people with similar needs in a way which extends the pre-existing mental health clusters. These have been developed through an iterative process of participatory action research that has involved service users, carers, statisticians, academics and multi-disciplinary groups of clinicians from 18 NHS provider organisations. Over two main stages more than 5000 individuals have been assessed and their data utilized in a variety of ways.

The final version of the clusters, complete with pen pictures, scoring profiles and associated clinical information is available on request. Having reached the final stage of this study these have been re-numbered and re-named as follows:

- 9a Engagement & minor support needs associated with mild learning disabilities (no autism)
- 9b Behaviour that challenges associated with learning disabilities (no autism)
- 9c Behaviour that challenges associated with autism and mild learning disabilities
- 9d Severe behaviour that challenges associated with autism and mild-moderate learning disabilities
- 9e Severe behaviour that challenges associated with autism and moderate-profound learning disabilities
- 22 Physical health problems associated with mild learning disabilities
- 23 Physical health problems associated with moderate - profound learning disabilities
- 24 Physical health problems associated with moderate - profound learning disabilities & dysphagia

Cluster 9a has generally low levels need whilst clusters 9b-9e describe increasing levels of challenging behavior (with or without ASD). The physical health-related clusters (22-24) are split into two levels of severity with the higher level (clusters 23 and 24) distinguished by the presence / absence of dysphagia.

Cluster analysis has much to offer the field of intellectual disability (Speece, 1994) but, with no absolute rules as to which methods to select and exactly how to apply them the approach has an unusual level of subjectivity (Clatworthy et al., 2005). Over and above this are understandable and legitimate concerns as to how the resulting classification system could be used as part of a move away from funding specialist intellectual disability health care through block contracts where there is a lack of assurance about how resources are allocated to need (Monitor, 2013). This paper demonstrates a considered approach has been maintained throughout with judgements made and decisions taken cautiously and transparently.

The dimensional and fuzzy properties of the clusters may have clear advantages over a strictly categorical diagnostic approach (Vieta & Phillips, 2007). The validity of both approaches can be challenged but it is also important to avoid conflating issues of validity with utility (Kendell & Jablensky, 2003). In this way, the two systems should be viewed as complimentary (Trevithick, Painter, & Keown, 2015).

Overall, with a lack of absolute standards for the validity of classification systems researchers have a degree of freedom in how they proceed provide "practical reasoning and good old-fashioned logic" are applied (Zachar & Kendler, 2007).

References:

Appleby, J., Harrieson, T., Hawkins, L., & Dixon, A. (2013). *How can payment systems help to deliver better care ? Authors Payment by Results*.

Brooks, W. T., & Benson, B. A. (2013). The validity of the social communication questionnaire in adults with intellectual disability. *Research in Autism Spectrum Disorders*, *7*(2), 247–255. http://doi.org/10.1016/j.rasd.2012.10.002

Brown, C., Craig, B., Duncan, J., Green, C., Hunter, R., Ingham, B., … Whitelock, T. (2015). *CPPP - The Legacy*. *Care Pathways and Packages Project: Developing Currencies for Mental Health - The Legacy*. Wakefield. Retrieved from http://www.cppconsortium.nhs.uk/admin/files/1427122592CPPP The legacy - March 2015.pdf

Chaplin, R. (2004). General psychiatric services for adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research : JIDR*, *48*(1), 1–10. http://doi.org/10.1111/j.1365-2788.2004.00580.x

Clatworthy, J., Buick, D., Hankins, M., Weinman, J., & Horne, R. (2005). The use and reporting of cluster analysis in health psychology: a review. *British Journal of Health Psychology*, *10*(Pt 3), 329–358. http://doi.org/10.1348/135910705X25697

Department of Health. (2014). 2014 / 15 National Tariff Payment System Annex 7C : Mental health clustering tool booklet. London: Department of Health. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300663/Annex7C_consultation.pdf

Haverman, M., Perry, J., Salvador–Carulla, L., Noonan Walsh, P., Kerr, M., Van Schrojenstein Lantman-de Valk, H., … Weber, G. (2011). Ageing and health status in adults with intellectual disabilities: Results of the European POMONA II study. *Journal of Intellectual Disability*, *3*(1), 49–60.

IBM. (2015). SPSS Software. Retrieved December 11, 2015, from http://www-01.ibm.com/software/analytics/spss/

Ingham, B., Painter, J., Roy, A., Hastings, R., Robinson, S., & Green, C. (2013). *Development of a needs based payment system for specialist Learning Disability health services Results of a pilot project .* Wake. Retrieved from http://www.cppconsortium.nhs.uk/admin/files/1372952288LD payment system final report 28june13.pdf

Kendell, R., & Jablensky, A. (2003). Distinguishing between the validity and utility of psychiatric diagnoses. *American Journal of Psychiatry*, *160*(January), 4–12.

Maenner, M. J., Smith, L. E., Hong, J., Makuch, R., Greenberg, J. S., & Mailick, M. R. (2013). Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability and Health Journal*, *6*(1), 8–17. http://doi.org/10.1016/j.dhjo.2012.08.005

Mascitelli, A. N., Rojahn, J., Nicolaides, V. C., Moore, L., Hastings, R. P., & Christian-Jones, C. (2015). The Behaviour Problems Inventory-Short Form: Reliability and Factorial Validity in Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities : JARID*, *28*(6), 561–71. http://doi.org/10.1111/jar.12152

Monitor. (2013). *Closing the NHS funding gap : how to get better value health care for patients*.

Moss, S., Prosser, H., Costello, H., Simpson, N., Patel, P., Rowe, S., … Hatton, C. (1998). Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, *42*(2), 173–183.

Nascimento, S. (2006). *Fuzzy Clustering via proportional membership model*. London: IOS Press.

Rojahn, J., Rowe, E. W., Sharber, A. C., Hastings, R., Matson, J. L., Didden, R., … Dumont, E. L. M. (2012a). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: Development and provisional clinical reference data. *Journal of Intellectual Disability Research*, *56*(5), 527–545. http://doi.org/10.1111/j.1365-2788.2011.01507.x

Rojahn, J., Rowe, E. W., Sharber, A. C., Hastings, R., Matson, J. L., Didden, R., … Dumont, E. L. M. (2012b). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part II: Reliability and validity. *Journal of Intellectual Disability Research*, *56*(5), 546–565. http://doi.org/10.1111/j.1365-2788.2011.01506.x

Rutter, M., Bailey, A., & Lord, C. (2003). The Social Communication Questionnaire: Manual. Western Psychological Services.

Self, R., Rigby, A., Leggett, C., & Paxton, R. (2008). Clinical Decision Support Tool: A rational needs-based approach to making clinical decisions. *Journal of Mental Health*, *17*(1), 33–48.

Slade, M., Powell, R., Rosen, a, & Strathdee, G. (2000). Threshold Assessment Grid (TAG): the development of a valid and brief scale to assess the severity of mental illness. *Social Psychiatry and Psychiatric Epidemiology*, *35*(2), 78–85. http://doi.org/10.1007/s001270050011

Speece, D. (1994). Cluster analysis in perspective. *Exceptionality*, *5*(1), 19–30. http://doi.org/10.1207/s15327035ex0501

Trevithick, L., Painter, J., & Keown, P. (2015). Mental health clustering and diagnosis in psychiatric in-patients. *BJPsych Bulletin*, *39*(3), 119–23. http://doi.org/10.1192/pb.bp.114.047043

Vieta, E., & Phillips, M. L. (2007). Deconstructing bipolar disorder: a critical review of its diagnostic validity and a proposal for DSM-V and ICD-11. *Schizophrenia Bulletin*, *33*(4), 886–92. http://doi.org/10.1093/schbul/sbm057

Zachar, P., & Kendler, K. S. (2007). Psychiatric Disorders : A Conceptual Taxonomy. *American Journal of Psychiatry*, *164*(April), 557–565.