Learning Disabilities Payment System Development Report

Appendices

1. Additional items added to the MHT to form the integrated MHLD integrated allocation tool
2. Testing of the preliminary version of the integrated tool in NTW (inter-rater reliability)
3. Preliminary learning disabilities units for the pilot
4. List of trusts who participated in pilot
5. Further breakdown of allocation to preliminary units from pilot.
6. Bangor University Statistical Analysis Full Report
7. Example workbook with information about the statistical groupings shared with clinicians shared at the CPPP LD Subgroup workshop
8. CPPP LD Subgroup workshop – tasks and responses.
9. Groupings split following feedback from clinicians at the CPPP LD Subgroup workshop
10. Workbook of information about subdivided groupings shared at the National MDT Workshop
11. Tasks and responses from National MDT Workshop
12. Further subdivision for development of new units
13. Further exploration of unit E
14. Summary of NTW Audit of unit clinical content
15. Allocation to units from CPPP LD sub group review
16. Additional unit description and scoring change from CPPP LD sub group review
17. Instructions and spreadsheet clinician resubmission/review of proposed units
18. Results of clinician resubmission/review of proposed units
19. Clinicians' descriptive feedback full report
20. Inclusion North service user & carer views full report

Appendix 1 Additional items added to the MHT to form the integrated MHLD integrated allocation tool

Current items

- Non-accidental self-injury (associated with cognitive impairment)
- Physical problems with eating and drinking

Historical items

- Social Communication & Interaction difficulties
- Communication and problems with understanding
- Communication and problems with expression
- Seizures

Appendix 2 Testing of the initial version of the integrated tool in NTW (inter-rater reliability)

By June 2011 core training in the use of the new Custer Tool had been established and delivered to a quarter of all the LD service in Northumberland Tyne & Wear (NTW) NHS Foundation Trust. There were plans to deliver further training to the remaining staff through summer 2011. This training was developed by adapting the original mental health curriculum in light of feedback gained through inter-rater reliability checks. These reliability checks were undertaken with 40 clinicians. This was achieved by offering each clinician induction training before applying the tool with a new referral. This initial assessment also involved a trained assistant psychologist. Scores from both parties were then entered into the Trusts electronic care record and qualitative feedback was gathered about how the raters found the process.

To further increase the number of clients being allocated to units a second method was used in which two assistants interviewed a clinician about an existing case then completed the tool separately. Twenty three clients were allocated using these methods.

Following the amendments and the development of the additional guidance, inter-rater reliability was further examined by determining if two clinicians who knew the same client well could complete the tool separately and agree on scores for each item and the same unit profile. The two identified clinicians completed the tool separately using it as a rating scale with the guidance of a trained assistant. Ten clients were allocated in this way.

Many items represent low frequency problems and there were many zero scores across the data set and relatively small amounts of data, which caused problems in statistical analysis. Based on a clinical rationale it was decided to count agreement on each item if raters were within one scale point (0-4) of each other. Two or more apart, or when rates were unknown, was taken as a disagreement. It was agreed that this was a sensible strategy because it allowed for the idea that people were generally agreeing about the level of behaviour/problem.

Inter-rater reliability focused on percentage agreement using the clinical agreement criterion outlined above. Across all items in the integrated tool, agreement was found to be good with some lower agreement on two historical items (see below for discussion). Inter-rater agreement where scores demonstrated more of a range (i.e., where there were smaller numbers of zero ratings) was also explored using non-parametric Spearman's rho correlations between rater pairs and these data also indicated generally good agreement (almost all correlations above .60).

Initially there was a common misunderstanding about the function of the integrated tool that led to inter-rater disagreement. These were particularly pertinent in a number of the original items within the historical section. Many staff also presumed

that it was a new form of assessment measure and there was a fear that it would mis-represent the needs of their clients. Training helped staff realise that the tool was never intended to be a detailed road map that would lead to a new destination. Rather, the tool operates more like a general motorway map that can lead you to the city of direction but the more detailed part of the journey still requires the detail of clinical judgement. Training and practice would appear to allow staff to not only complete the tool more quickly but also to become more comfortable with the inevitable compromises one has to make in decision making and this would appear to increase the level of inter-rater agreement.

Appendix 3 Preliminary Learning Disabilities Units for the pilot

9 **Complex social communication problems**
This group has significant difficulties with social communication, social interaction and social imagination, which have been present since childhood and inconsistent with developmental level. This will be associated with significant psychosocial difficulties including mental health, offending and / or challenging behaviour and require specialist support.

22 **LD complex and multiple needs**
This group has significant cognitive impairment and adaptive functioning impairments present since childhood alongside history of complex psychosocial difficulties which may include enduring challenging behaviour, offending and/or mental health problems. Difficulty managing within normal, mainstream resources requiring recurrent, intensive specialist healthcare services.

23 **Challenging Behaviour**
This group displays behaviours that are of such intensity, frequency or duration as to threaten the quality of life and/or physical safety of the individual or others and are likely to lead to responses that are restrictive aversive or result in exclusion. They often have a lifelong vulnerability.

24 **Vulnerable with poor coping skills**
This group has problems involving emotional distress and vulnerability sometimes associated with impulsive behaviour. They are characterised by having increased likelihood of significant risks and chaotic lifestyles. May present safeguarding issues and severe disruption to everyday living. Poor and/or unsuccessful engagement with mainstream services.

25 **Epilepsy**
This group have epilepsy with seizures that are difficult to manage. They have high levels of risk associated with frequent seizures and poorly controlled epilepsy. They may have significant problems in self-management of their condition requiring support, training, monitoring to improve quality of life and reduce risks.

26 **Dysphagia**
This group have difficulties with eating and drinking safely. They may present with chronic difficulties such as recurrent chest infections, choking incidents and weight loss or more acute difficulties such as coughing whilst eating and drinking: or difficulties manipulating the food or fully participating in the mealtime.

27 **Profound and multiple disability**
This group will present with profound intellectual impairment and additional disabilities. These may include sensory disabilities (e.g. visual impairment or hearing loss), physical disabilities, epilepsy, autism and mental illness. Challenging or self-injurious behaviour may also be present. Most will have communication difficulties and have a range of complex health needs.

Appendix 4 List of Trusts who participated in pilot

- Black Country Partnership NHS Foundation Trust
- Cheshire & Wirral Partnership - NHS Foundation Trust
- Coventry & Warwickshire Partnership NHS Trust
- Croydon Health Services NHS Trust
- Cumbria Partnership NHS Foundation Trust
- Hertfordshire Partnership NHS Foundation Trust
- Leicestershire Partnership NHS Trust
- Mersey Care NHS Trust
- Norfolk and Suffolk NHS Foundation Trust
- Northamptonshire Healthcare NHS Foundation Trust
- Northumberland Tyne & Wear FT
- Nottinghamshire Healthcare NHS Trust
- Oxleas NHS Foundation Trust
- Rotherham, Doncaster & South Humber FT
- Sheffield Health & Social Care NHS Foundation Trust
- Surrey & Borders Partnership NHS Foundation Trust
- Sussex Partnership NHS Foundation Trust
- Tees, Esk & Wear Valley FT

Appendix 5 Further breakdown of allocation to initial units from pilot.

Non-psychotic		N=
Cluster 0	Does not meet the criteria for any other cluster	127
Cluster 1	Common Mental Health Problems (Low Severity)	49
Cluster 2	Common Mental Health problems (Low Severity with Greater Need)	40
Cluster 3	Non-Psychotic (Moderate Severity)	167
Cluster 4	Non-Psychotic (Severe)	33
Cluster 5	Non-Psychotic (Very Severe)	10
Cluster 6	Non-Psychotic Disorders of Overvalued Ideas	7
Cluster 7	Enduring Non-Psychotic Disorders (High Disability)	14
Cluster 8	Non-Psychotic Chaotic and Challenging Disorders	28
Psychotic		
Cluster 10	First Episode in Psychosis	125
Cluster 11	Ongoing or Recurrent Psychosis Low Symtoms)	13
Cluster 12	Ongoing or Recurrent Psychosis (High Disability)	42
Cluster 13	Ongoing or Recurrent Psychosis (High Symptom and Disability)	33
Cluster 14	Psychotic Crisis	21
Cluster 15	Severe Psychotic Depression	8
Cluster 16	Dual Diagnosis	1
Cluster 17	Psychosis and Affective Disorder Difficult to Engage	2
Organic		
Cluster 18	Cognitive Impairment (low need)	10
Cluster 19	Cognitive Impairment or Dementia complicated (moderate need)	67
Cluster 20	Cognitive Impairment or Dementia complicated (high need)	73
Cluster 21	Cognitive Impairment or Dementia (high physical or engagement)	36
LD		
Cluster 9	Complex Social communication problems	54
Cluster 22	LD complex and multiple needs	804
Cluster 23	Challenging Behaviour	285
Cluster 24	Vulnerable with poor coping skills	290
Cluster 25	Epilepsy	65
Cluster 26	Dysphagia	65
Cluster 27	Profound and multiple disability	286
Cluster 99	Not Known	70
Invalid		0

Appendix 6 Bangor University Statistical Analysis Full Report

The Excel spreadsheet sent to Bangor University for statistical analysis was imported into SPSS Statistics. For analysis purposes, young people/children under 18 years of age were deleted from the dataset (so that the sample for analysis was adults with learning disability only). After these deletions and other small edits to clean the data file, there were 2,119 records available for analysis.

Items 14, 15, and 16 were excluded from analysis because they were not going to be included in the final mental health tool.

1. Exploring the internal consistency of the MHLD Tool

For the remaining 24 items (i.e., after excluding items 14-16), the Cronbach's alpha for the MHLD tool as a potential scale to measure total health needs is .75. This is a good level of internal consistency, suggesting that the tool works reasonably well as an overall assessment of health need.

Each individual item in the MHLD tool was also examined for its association with a total score derived from the remaining items. This statistic is the corrected item-total correlations (correlation between each item and the total of all others excluding that item). Only one item had a very low correlation value (Item 3 [Drugs/Alcohol] r = -.009). Removing this item has no effect on the overall value of Cronbach's alpha for the remaining scale (of 23 items).

There could be a case for removing Item 3 from a tool for people with learning disabilities. However, inclusion of the item does not seem to affect the overall properties of the tool as a measure of health needs. We might interpret this simple analysis by suggesting that any Drug/Alcohol problems may co-occur with any other of the needs assessed using the tool. If this item is useful clinically, it could be retained in the MHLD tool.

2. Potentially redundant items

Two pairs of items in particular were of interest in terms of redundancy – that is, whether they may be assessing the same underlying need. In each case, new items (i.e., as added for exploration in the project) are involved.

New item 17 focuses on self-injurious behaviour, and existing historical item B focuses on self-harm. There are clear instructions within the MHLD tool to rate these items using different criteria. Scores on these two items are essentially unrelated with a 14% overlap or shared variance (Pearson correlation = .38). Therefore, the clinical staff completing the tools responded differently to items 17 and B and/or these two items are assessing different constructs.

New historical items G and H assess receptive and expressive communication difficulties. As would be expected, the correlation between scores on these two items is relatively high (Pearson r = .78). This level of correlation represents 61% shared variance. Thus, these two items do not overlap excessively. However, one of the items G or H could be removed from the draft MHLD tool. For the purposes of the remainder of the statistical analyses, both items were retained. The decision to remove one of these items later should be reviewed once there is clarity on agreed final clinical units.

3. Items with limited application to the LD population

Before carrying out a statistical cluster analysis, the distributions of each tool item were examined. Specifically, the proportion of the sample rated zero on each item was calculated. Items with limited application to adults with learning disability may have an adverse effect on the findings from a cluster analysis. Using the whole sample of 2,119 cases, four items had a high proportion of zero scores, defined pragmatically as >85% of cases:

Item number	% zero scores
2	85.5
3	93.9
6	88.6
13	85.8

These four items were, therefore, excluded from the statistical cluster analysis.

A post-hoc analysis of the spread of scores on these items across the five final statistical clusters (see below for final five clusters) revealed that there was no discernable pattern other than the fact that all four of these items were extremely rarely scored above zero for the cluster that may be most closely aligned with individuals with profound learning disabilities. When the cluster analysis was repeated with these four items included, very similar results to those reported below were found. Thus, although there is a sensible rationale to exclude these items from the statistical cluster analysis their removal actually does not affect the overall results found.

4. Final statistical cluster analysis

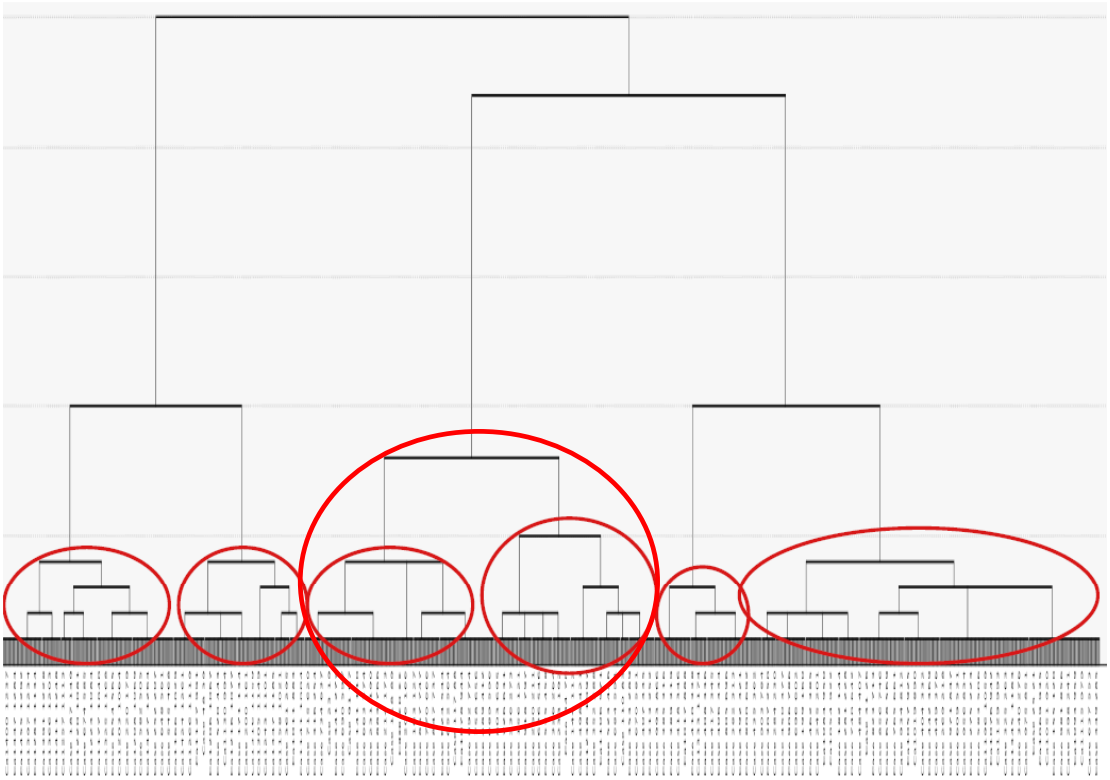
Before reporting the results of the statistical cluster analysis of the MHLD tool, it is important to address a number of assumptions behind the analysis. First, the statistical cluster analysis, as in the research on the development of the original mental health tool, was intended only as a support to clinical decision making. The groupings (clusters) suggested would be a starting point for examination in detail from a clinical perspective.

A second assumption was that the health difficulties of adults with learning disability are likely similar to those experienced by the remainder of the population, although they may vary in terms of degree or frequency. This is important, because one could then make an assumption that the purpose of the current analysis is to consider whether there are clusters of need in addition to those already identified for the general population.

Following these assumptions, adults with learning disability whose profile of needs led clinical staff to allocate them clinically into one of the existing mental health profiles were excluded from the statistical cluster analysis process. This resulted in a final sample for analysis of 1,256. This process was similar to that adopted to explore the addition of units to the original mental health tool for adults with dementia.

Statistical cluster analysis uses two stages to arrive at a final solution. First, the number of likely clusters within the dataset is identified using the output from a hierarchical cluster analysis. At this stage, all of the items in the MHLD tool (except items 14-16) were included in the analysis. All variables were standardized, and Ward's method was used to determine cluster membership. One of the outputs from a hierarchical cluster analysis is a dendrogram, which shows group membership at various levels of distance using a standardized scale. Following the identification of the number of clusters to be extracted from the dataset, the second stage of analysis is to use k means clustering through a series of statistical iterations to organize the cases into the defined number of groups.

The dendrogram from the current analysis is displayed below.



Using cluster analysis to identify additional learning disability cluster groups, it was important to provide a solution that was parsimonious (given that there were already 21 mental health units) but also meaningful. Therefore, a linkage distance of <10 was used to identify the number of clusters. Visual analysis of the dendrogram showed five cluster groupings. These are identified by the purple ellipses on the dendrogram, with two of these joined by the red ellipse.

Given that there were potentially six cluster groupings at a linkage distance of 5 or under, a six cluster solution was explored first. Following k means clustering and extraction of six clusters, two of the clusters were very similar in their profiles. One cluster scored relatively high on items 17, C and I and relatively low on 8, 9, 11, 18, A and G [self-injurious behaviour, others at risk, perhaps moderate learning disability, low other challenging behaviour and mental health problems]. The other similar cluster group scored relatively high on items 7, 17, B, and C and relatively low on 5, 10, E, G, H, and I [self-injurious behaviour/self-harm, depression, others at risk, with probably mild learning disability].

When five clusters were extracted instead, these two similar cluster groupings were essentially joined together into one with the remaining four clusters being fairly similar for both the five and six cluster solutions. Given these findings, and the need for parsimony, a five cluster solution was used as the final version for the statistical analysis.

The table below summarises the five clusters identified (labeled A-E), and the total number of cases clustered into each grouping. Also include in the table is a summary of the MHLD tool items with relatively high or low scores within each cluster group. Scoring “high” or “low” for an item was defined as having a mean score approximately in excess of .50 of a standard deviation higher or lower than the mean for the sample as a whole. Therefore, these “high” and “low” scores, reflect relatively high/low scores for this sample rather than absolute high and low scores (e.g., scores of 3-4 vs. 0-1). The table also includes an initial short text description of each of the five statistical groupings.

Cluster number [size] and initial short description	**High scoring items**	**Low scoring items**
A [N = 241] Autism Spectrum Disorder (ASD), aggression, communication limitations, otherwise cognitively relatively able, low physical problems	A F G H	5
B [N = 247] Profound LD, physical health problems, low challenging behaviour (CB)/ mental health (MH) problems	4 5 10 18 E G H I	1 7 8 9 17 A B C
C [N = 167] Severe LD, ASD, relatively high levels of CB and MH needs	1 7 8 9 10 11 17 A B C D E F	
D [N = 383] Mild LD with relatively low levels of need		4 10 17 C E F G H I
E [N = 218] Mild LD, SIB/self-harm, others at risk/vulnerable	17 B C	E G H

5. Conclusions

The analyses summarized here suggest that the tested version of the MHLD tool (after removal of items 14-16) is a reasonable measure of overall health need (assessed using internal consistency analyses). Adding new items to the tool (for self-injurious behaviour and receptive and expressive communication) did not create items with significant redundancy, although either expressive or receptive communication could be dropped in future unless both are clinical useful. Most of the items assessing health need were also relevant to the population of adults with learning disability.

The most parsimonious statistical cluster analysis solution (five cluster groupings) has good face validity. The initial descriptions of the cluster groupings (based on their scoring profile for the MHLD tool items) make sense clinically and are reasonably distinct from each other. Further exploration is needed using additional variables and examination of the profiles associated with these clusters before these groupings can be more fully described clinically.

Professor Richard Hastings
School of Psychology, Bangor University
4 March 2013

Appendix 7 Example workbook with information about the statistical groupings shared with clinicians shared at the CPPP LD Subgroup workshop on 10 January 2013 in Leeds.

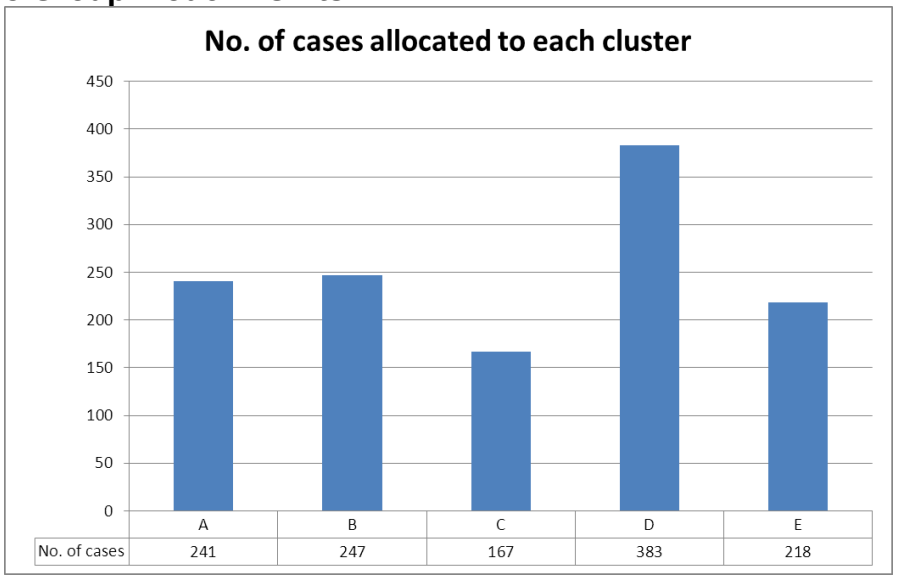
Unit A N=241

Whole dataset N = 1726

Cases allocated to LD units N=1256

Cases allocated to MH Mandated units N = 470

5 Group model – Units A-E



Level of missing data for the whole date set N = 1726

	N	%
Staff Occupation	46	2.7
Banding	604	35
Primary clinical issues	611	35.4
Secondary clinical issues	196	11.4
Current medication-Primary	1254	72.7
Current medication-Secondary	869	50.3
Current medication - additional	976	56.5
Total no. of meds	1370	79.4
IQ	1573	91.1
Primary Diagnosis	976	56.5
Secondary Diagnosis	1396	80.9

Graph showing Group A – Mean scores for each item of the allocation tool

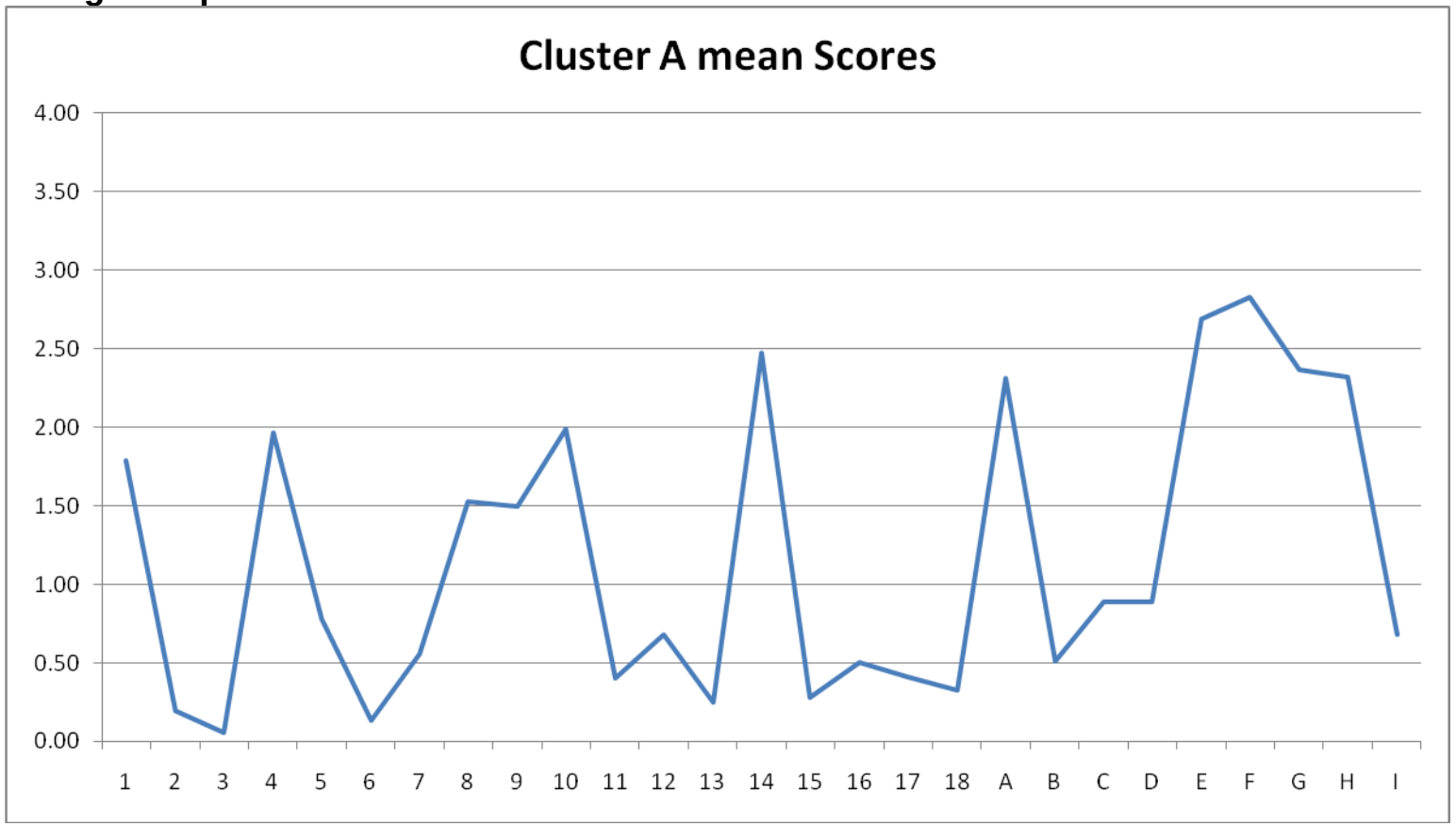


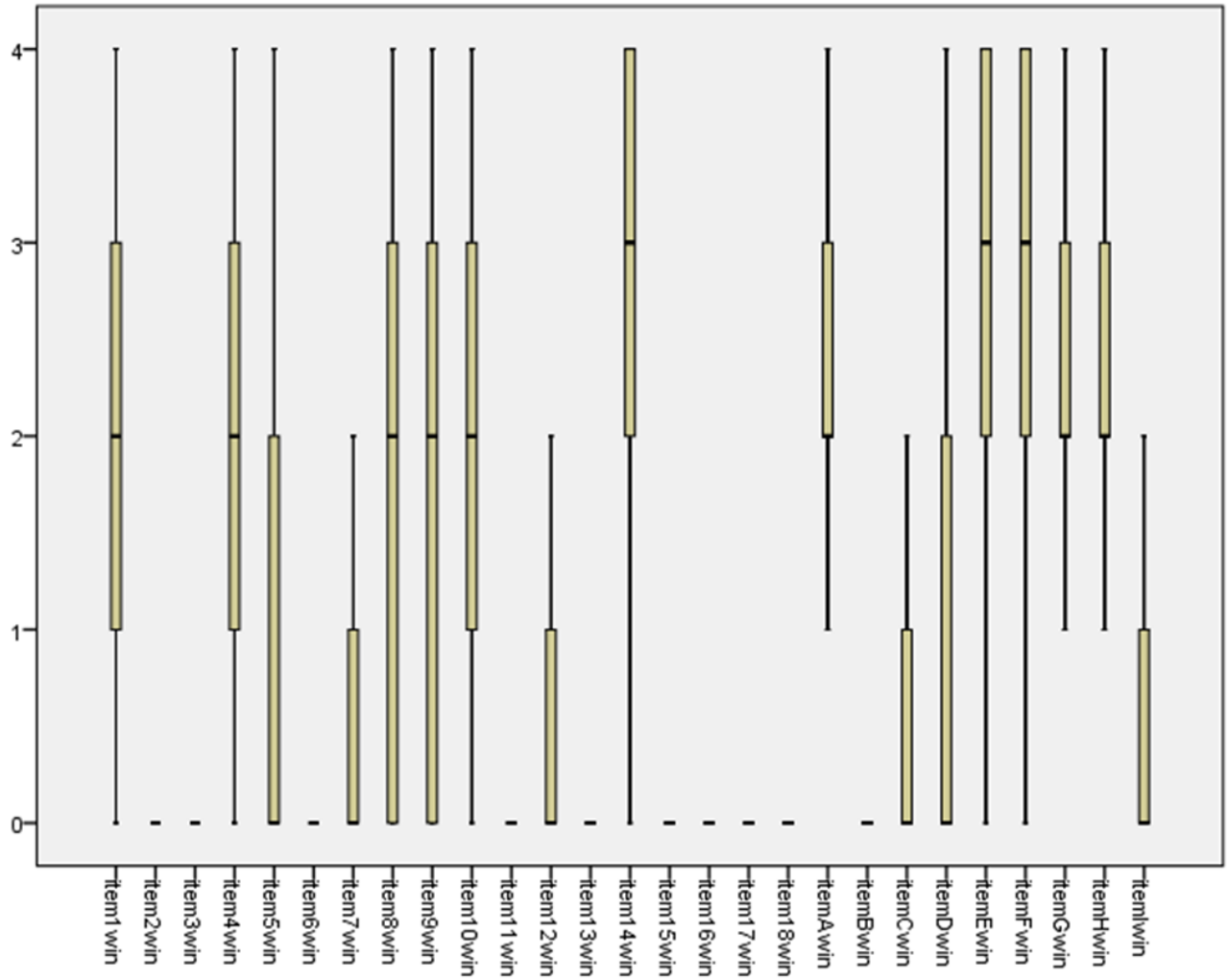
Table 1 shows the scoring distribution for each item for Group A

No.	ITEM DESCRIPTION	SCORE				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	18.3%	19.5%	35.3%	19.1%	7.9%
2	Non-accidental self-injury	88.8%	4.6%	5.0%	1.7%	0.0%
3	Problem drinking or drug taking	97.5%	.8%	.4%	1.2%	0.0%
4	Cognitive problems	23.7%	7.1%	29.0%	29.9%	10.4%
5	Physical Illness	58.9%	14.1%	18.7%	6.6%	1.7%
6	Hallucinations and Delusions	92.1%	2.9%	4.1%	.8%	0.0%
7	Depressed mood	62.7%	22.4%	12.0%	2.1%	.8%
8	Other mental & behavioural problems	35.7%	10.8%	24.9%	22.8%	5.8%
9	Relationships	34.9%	12.0%	26.6%	21.6%	5.0%
10	Activities of daily living	19.9%	10.8%	31.5%	26.1%	11.6%
11	Living conditions	77.2%	9.5%	10.4%	1.7%	1.2%
12	Occupation & activities	60.6%	16.6%	18.3%	3.7%	.8%
13	Strong Unreasonable beliefs	88.0%	4.6%	3.3%	2.9%	1.2%
14	mental capacity	12.6%	12.1%	18.8%	28.0%	28.5%
15	Carer needs	85.8%	4.2%	6.7%	2.9%	.4%
16	Cultural and communication	76.3%	6.6%	10.8%	2.9%	3.3%
17	Non-accidental self-injury (associated with cognitive impairment)	77.2%	12.0%	4.6%	5.0%	1.2%
18	Physical Problems with eating and drinking	81.3%	8.7%	6.6%	2.5%	.8%
A	Agitated behaviour/expansive mood	13.3%	9.5%	27.4%	32.0%	17.8%
B	Repeat Self-Harm	76.3%	5.8%	11.2%	3.7%	2.9%
C	Safeguarding other children & Vulnerable dependant adults	63.9%	12.4%	7.5%	3.3%	12.9%
D	Engagement	55.2%	16.6%	14.5%	11.6%	2.1%
E	Vulnerability	12.4%	2.9%	15.4%	41.9%	27.4%
F	Social communication difficulties	6.2%	2.5%	27.0%	30.7%	33.6%
G	Communication and problems with understanding	2.9%	14.5%	36.9%	34.0%	11.6%
H	Communication and problems with expression	1.7%	22.8%	35.7%	21.6%	18.3%
I	Seizures	71.0%	10.0%	7.1%	4.1%	7.9%

	Age		Gender n(%)		Professions (%)	Bandings (%)	Clinical issues (%)		Medication				Diagnosis		Setting	Accommodation
Group	Mean (Std)	Range	Male	Female			Primary	Secondary	Primary	Secondary	Additional	Total no.	Primary	Secondary		
An=241	37.41(15.3)	66 (18-84)	145 (60.2)	93 (38.6)	Psychiatry (29) Nursing (23.7) Managers (15.8) SLT (10) Clinical Psychology (8.7) OT (7.1) Unknown (2.5) Pre reg Nurse (1.2) Physio (1.2) Psychotherapy (0.4) Nursing assistant (0.4)	10 (24.9) 6(13.3) 7 (11.2) 8a (9.1) 5 (6.2) 8b (1.7) 8c(1.2) 4 (0.4)	None (19.1) AS Conditions (15.8) behavioural problems (15.8) Communication problems (5.4) Epilepsy (3.7) Mental illness (3.3) ADHD (2.5) Social emotional functioning (2.5) Dysphagia (1.2) End of life (1.2) Vulnerability linked to LD (1.2) Mobility & posture (1.2) Primary care and support (1.2) Lifestyles (0.8) Parenting (0.8) Obesity (0.4) Offending behaviour (0.4) Secondary (acute) care support (0.4)	None (25.7) Behavioural Probs (11.2) AS Conditions (10) Vulnerability linked to LD (6.6) Communication probs (5.8) Mental illness (3.7) Social emotional functioning (3.3) Epilepsy (2.5) Primary care support (1.2) Lifestyles (1.2) ADHD (0.8) Dysphagia (0.8) Sensory problems (0.8) Mobility & posture (0.4) Obesity (0.4) Secondary (acute) care support (0.4) Parenting (0.4)	Antipsychotic(15.4) No meds (7.9) Antidepressant (7.1) Anticonvulsants(6.6) Meds for physical health (5.4) Mood stabilizer (2.5) Hypnotics & anxiolytics (0.8) CNS Stimulants (0.4)	no meds(17) Antidepressant(5.4) Anticonvulsants(5) Antipsychotics (4.6) Meds for physical health (4.6) Mood stabilizer (4.1) Hypnotic's & anxiolytics (2.1) Anti-Parkinson's(1.2)	No meds (25.7) Meds for physical health (5) Antidepressant (1.7) Antipsychotic (1.2) Substitute prescription (1.2) Mood stabilizer (1.2) Hypnotics & anxiolytics (0.8) Anti-Parkinson's (0.8)	2(7.5) 1 (6.6) 0 (5) 3 (3.7) 4 (3.7) 5 (3.3) 6 (2.1) 9 (1.7) 7 (0.8) 10 (0.8) 8 (0.4) 12 (0.4) 14 (0.4)	Learning disability (40.7) (Mild = 3.4%, Moderate = Disorders of psychological development (7.5) Congenital malformations and chromosomal abnormalities (2.1) Episodic & paroxysmal disorders (1.7) Mood affective disorders (0.8) Neurotic stress related & somatoform disorders (0.8) Organic mental disorders (0.4)	Learning Disability (9.1) Disorders of psychological development (4.6) Neurotic, stress related & Somatoform disorders (4.6) Mood affective disorders (2.1) Schizophrenia, Schizotypal & delusional disorders (1.2) Disorders of adults personality (1.2) Extrapyramidal & movement disorders (0.4) Congenital malformations & chromosomal abnormalities (0.4) External codes of morbidity & mortality (0.4)	Community (81.7) Both (11.2) Neither (4.1) Inpatient (2.9)	SH/IM (29) SH/IH (10) SM/IM (5) SM/IL (1.7) SM/IH (0.8) SL/IL (0.4) SL/IM (0.4) SL/IH (0.4)

Accommodation status key: SL = Stability Low, SM = Stability Moderate, SH = Stability High. IL = Independence Low, IM = Independence Moderate, IH = Independence High

Graph C: Box plot shows the scoring distribution of Group A. Winsorising was performed to change the value of the extreme values/outliers to the value at the top/bottom end of the box plot, to make the plots easier to interpret:



Appendix 8 CPPP LD Subgroup workshop – tasks and responses

Task one

Review the five statistical groupings then list:

- **Five points about these that make sense about these, and which would be helpful when we build the pen pictures of each unit**
- **Five points that are clinically counter-intuitive, or which require more investigation**

Verbatim Responses

Group A

- Group of high risk/'quasi forensic' individuals. Different clinical intervention group. From less able challenging behaviour (e.g. individual work, risk management work). Fits well into 'must scores' therefore may be high agreement about allocation. Consistency in terms of subdivision (severity, intensity). Would expect higher score in vulnerability. High potential for confusion with Group C unless descriptions are clear. Potential co-morbidity issues with Group E. Uncertain whether must scores for this would be very similar to other Groups. Scoring distribution may not have clinical validity.
- Risk to self should not just be linked to risk to self-harm, need to consider other risk e.g. vulnerability. Descriptive not reflective of Safeguarding, problem drinking or drug taking, occupation, living conditions, engagement.
- Would have expected higher score on safeguarding. – missing problem drink/drug taking issues -would be expecting more chaotic presentation
- A- More impaired than description suggests
  -autism features
  If level of LD was less could be forensic group
  - Could polarising of scores indicate 2 groups (one able; another overlapping with C)

Group B

- Makes sense- and picks up epilepsy and dysphagia.
- Wouldn't want a must score for PMLD. Should be PMLD and Physical health. Can't just be PMLD, needs to have physical health issues for all abilities. Misses out OT, health facilitation etc. for people without PMLD. Catches all physical health issues so a very mixed bag of issues, would need a lot of subdivision.
- B least contentious

Group C

- Makes sense. - Social communication issues not essential
- Cognitive impairment scores more highly than Group A and these are clinically seen as different groups. Similar clinical response, although severity

and speed of response needed would differ. Would not want social communication issues to be a must score. At what point do you discriminate from Group A. Co-morbidity with E?

Group D

- None
- Preventative and maintenance – 'invest to save'. Combination of factors could make plan for intervention hard – complexity of cases. Although not scoring highly on any one item, it's the combination of factors that makes care difficult. -preventative work to reduce deterioration therefore saving money. Negatives - as there is a low level of need, may be a group who are not targeted for input in times of cuts. The unit doesn't identify interventions. Difficult to make clinical pathway.
- Chronically disabled -A/C who have got better
  -Problems that other services would not treat
  -Long term disability related needs
  -Could become more problematic without input
  Not a lot of autism features (in terms of people moving from A/C – D)

Group E

- Doesn't make sense, would expect a higher score on self-harm, item 17 and safeguarding stand out. More weighted to self-harm.
- Where does the self-harm bit come into this group, should it be more self-injury - odd profile on cognitive problems. DSH & SIB different clinically so may not make clinical sense to put together. No differentiation around cognitive impairment. Co-morbidity with A & C
- Self injury more prominent. Low in social communication. Would have expected higher scores in communication problems
- Could be two units according to communication impairment

Task two

Rank the five items within the MHCTLD tool which you think are most important for membership of each grouping (with a brief rationale for why)

Scales in order of frequency (n= no. of people that recorded this scale as most important)

Group A		Group B		Group C		Group D		Group E	
SCALE	N	SCALE	N	SCALE	N	SCALE	N	SCALE	N
1	5	5	5	1	5	E	4	17	4
I	5	E	5	4	4	5	3	E	4
4	4	4	4	F	4	10	2	9	2
8	3	10	4	8	3	4	2	B	2
A	3	18	4	G	3	8	2	1	1
C	3	G	3	H	3	7	1	2	1
9	2	I	3	9	2	9	1	4	1
E	2	1	1	A	2	A	1	8	1
F	2	8	1	C	2	D	1	C	1
3	1	F	1	E	2				
17	1	H	1	D	1				
D	1								

Task three

Considering the scoring distributions for the scales you have identified then suggest if and how the group should be subdivided to make clinically meaningfully units.

Group A

Two groups **-** Low and high intensity
Scale 1 – score over 3 for high, less than 2 for low – acknowledge impact of
D score of 3 over for high – less than 2 for low.

Common factors around aggressive behaviour and ASD probs
Split by level of intellectual disability – bi-modal distribution
Forensic more able one end – more ld other case
(Autism shows difference between A & C) (C includes additional mental and behavioural problems)

Group B

3 sub groups – (2-4 score on cog and physical illness scales for all)
-epilepsy
-dysphagia
-other category

Group C

One group criteria – high score on 4, 8.9.10 score above 2,A score over 2
Two groups- 1 & A & F score at least 2

Group D

One group (must score 2-3 on cog; vulnerability 2-4 or may score 1;2-3 on two other items
Has to have LD, Vulnerability – significant factor (might have to be vulnerability + something else?). E, D, 9

Two groups: LD Vulnerable; LD Engagement

Group E
Two groups: Self-harm or self-injury
One more severely disabled, one more self-harm
High score on 2 or 17.

2 groups
Low intensity on self-harm and self-injury behaviour would be put into D

Task four

Rate your view on how clinically meaningful each of the statistically generated groups are.

	Mean	Mode
A	5.20	5
B	7.71	8
C	5.44	5
D	6.40	7
E	4.21	6,7,2

Appendix 9 Groupings split following feedback from clinicians at the CPPP LD Subgroup workshop

A – Risk to others

Split by Item 4: Cognitive Problems

Ai – Low impairment *(Item 4: <= 2)*
Aii – High impairment *(Item 4: >= 3)*

B – Physical health

Spilt by: Item 4 Cognitive Problems, Item 5 Physical Illness, Item 18 Physical problems with eating & drinking, and Item I Seizures.

Bi – PMLD *(item 4 >=3, item 5 >= 3, item 18<=2, item I <=2)*
Bii – PMLD with epilepsy & dysphagia *(item 4 >=3, item 5 >=3, item 18 >=3, item I >=3)*
Biii – PMLD with either/OR epilepsy & dysphagia *(item 4>=3, item 5>=3, item 18 >=2 OR Item I >=2 but not both)*

C- Risk to others low stability

Split by item 17 Non-accidental self-injury (associated with cognitive impairment)

Ci – Non-self-injurious behaviour (SIB) *(item 17 <=1)*
Cii- SIB *(item 17 >=2)*

D- Engagement and maintenance

Split by item 9 Relationships

Di- Low need *(item 9 <=1)*
Dii High need *(item 9>=2)*

E- Clinically counterintuitive group

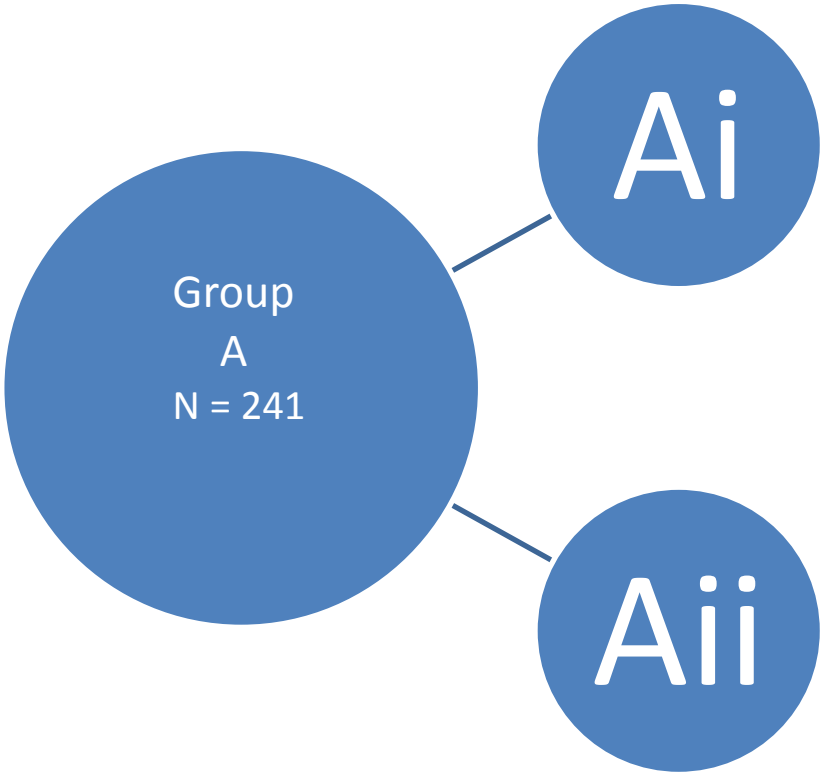
This group was split by a number of items to look for clinically meaningful groups within the overall group. The table bellows shows the items and the spilt by scores that were explored.

	Item 17 non-accidental self-injury (associated with cognitive impairment)	Item 9 Relationships	Item D Engagement	Item E Vulnerability
Ei	*item 17 <=1*	*item 9 <=1*	*item D <=1*	*item D <=1*
Eii	*Item 17 >= 2*	*Item 9 >= 2*	*Item D >= 2*	*Item D >= 2*

None of these ways of splitting the Group produced clinically meaningful units.

Appendix 10 **Workbook of information about subdivided groupings shared at the National MDT Workshop (on 6th February 2013 in London)**

Group A- Risk to others N = 241



- **Low impairment**
- **N = 144**
- **Item 4 <=2**

- **High impairment**
- **N = 97**
- **Item 4 >=3**

Group Ai- Low impairment N = 144

Graph showing the mean score for each item for group Ai – Low impairment

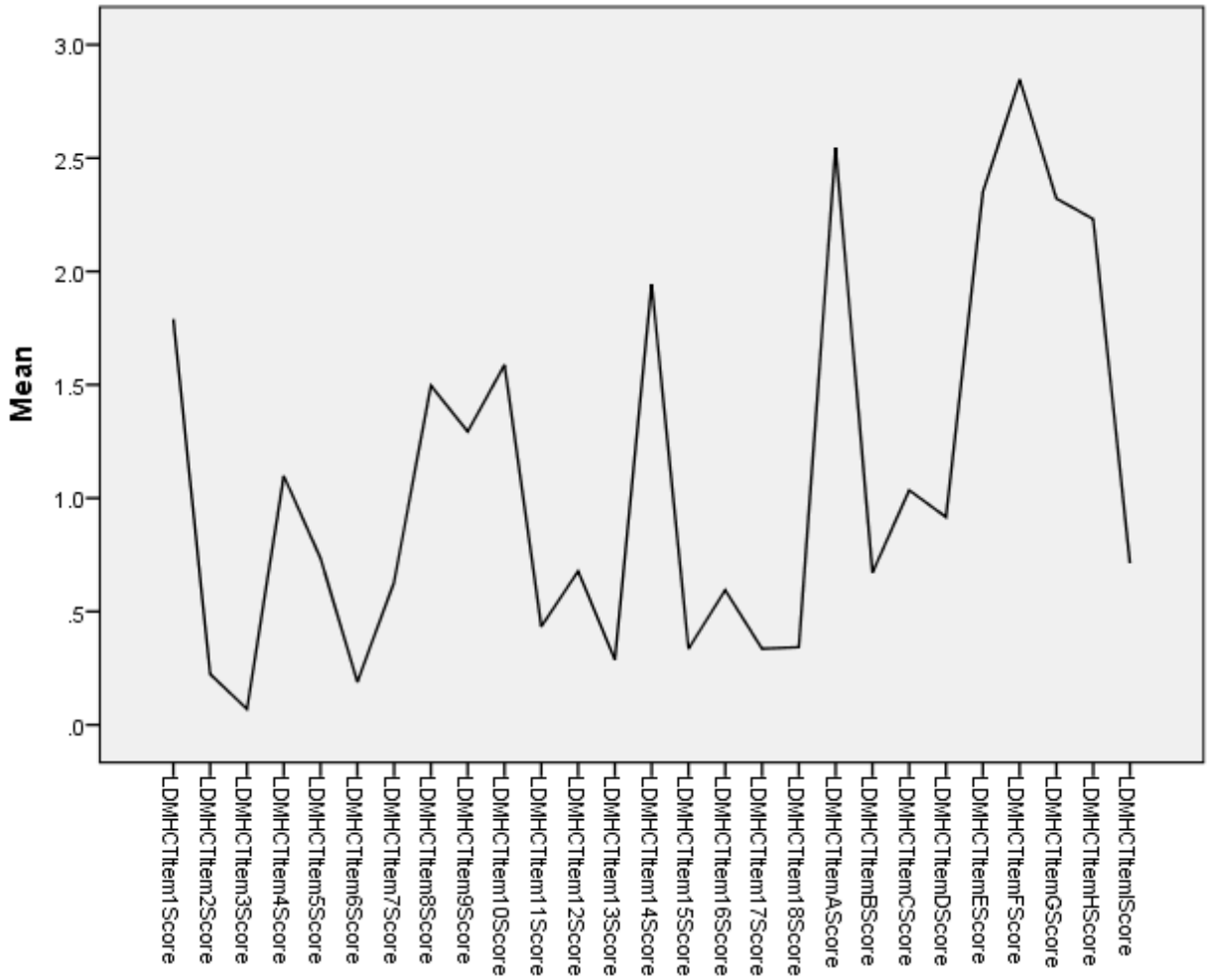
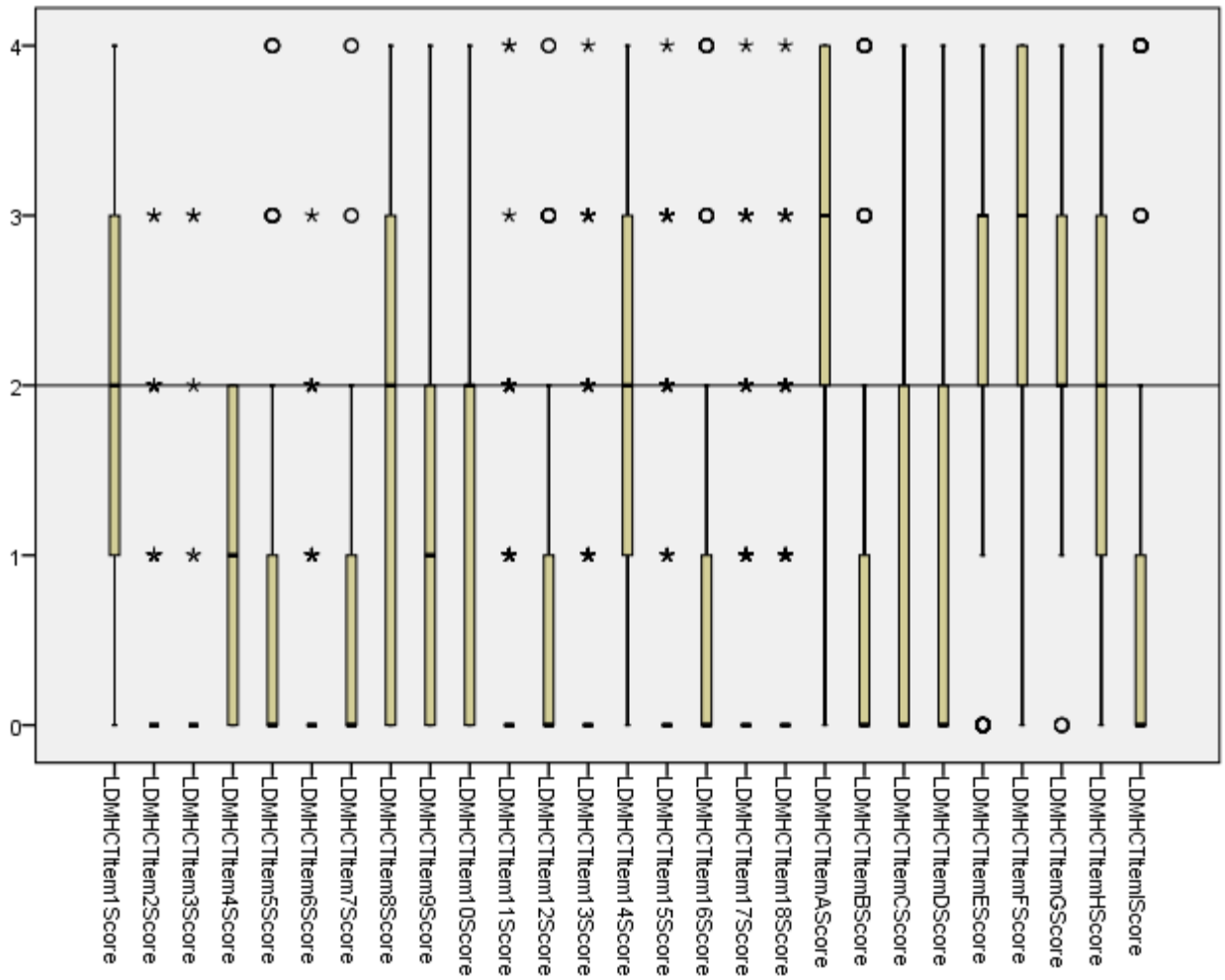


Table showing scoring distribution for group Ai Low impairment:

No.	ITEM DESCRIPTION	SCORE 0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	18.1%	22.2%	32.6%	16.7%	10.4%
2	Non-acidental self injury	86.8%	5.6%	6.3%	1.4%	.0%
3	Problem drinking or drug taking	96.5%	1.4%	.7%	1.4%	.0%
4	Cognitive problems	39.6%	11.8%	48.6%	0.0%	0.0%
5	Physical Illness	60.4%	14.6%	17.4%	4.9%	2.8%
6	Hallucinations and Delusions	88.9%	4.2%	6.3%	.7%	.0%
7	Depressed mood	58.3%	24.3%	14.6%	1.4%	1.4%
8	Other mental & behavioural problems	36.8%	11.1%	26.4%	18.1%	7.6%
9	Relationships	39.6%	13.2%	27.8%	16.7%	2.8%
10	Activities of daily living	28.5%	12.5%	36.8%	15.3%	6.9%
11	Living conditions	75.7%	7.6%	13.9%	1.4%	1.4%
12	Occupation & activities	62.5%	14.6%	17.4%	4.2%	1.4%
13	Strong Unreasonable beliefs	84.7%	5.6%	4.9%	3.5%	1.4%
14	mental capacity	20.8%	18.1%	22.9%	20.8%	17.4%
15	Carer needs	84.6%	2.8%	7.7%	4.2%	.7%
16	Cultural and communication	70.8%	8.3%	13.2%	3.5%	4.2%
17	Non-accidental self-injury (associated with cognitive impairment)	79.9%	11.8%	4.2%	3.5%	.7%
18	Physical Problems with eating and drinking	79.9%	9.0%	6.9%	3.5%	.7%
A	Agitated behaviour/expansive mood	7.6%	9.7%	30.6%	24.3%	27.8%
B	Repeat Self-Harm	69.4%	7.6%	13.2%	4.9%	4.9%
C	Safeguarding other children & Vulnerable dependant adults	61.1%	11.1%	8.3%	2.8%	16.7%
D	Engagement	50.7%	18.8%	18.8%	11.1%	.7%
E	Vulnerability	18.1%	2.8%	22.2%	40.3%	16.7%
F	Social communication difficulties	3.5%	2.8%	31.3%	30.6%	31.9%
G	Communication and problems with understanding	2.8%	17.4%	39.6%	24.3%	16.0%
H	Communication and problems with expression	2.1%	30.6%	30.6%	14.6%	22.2%
I	Seizures	71.5%	9.0%	4.9%	3.5%	11.1%

Box plot showing scoring distribution for each item for group Ai Low impairment



Group Aii- High impairment N = 97

Graph showing mean scores for each item for group Aii High impairment

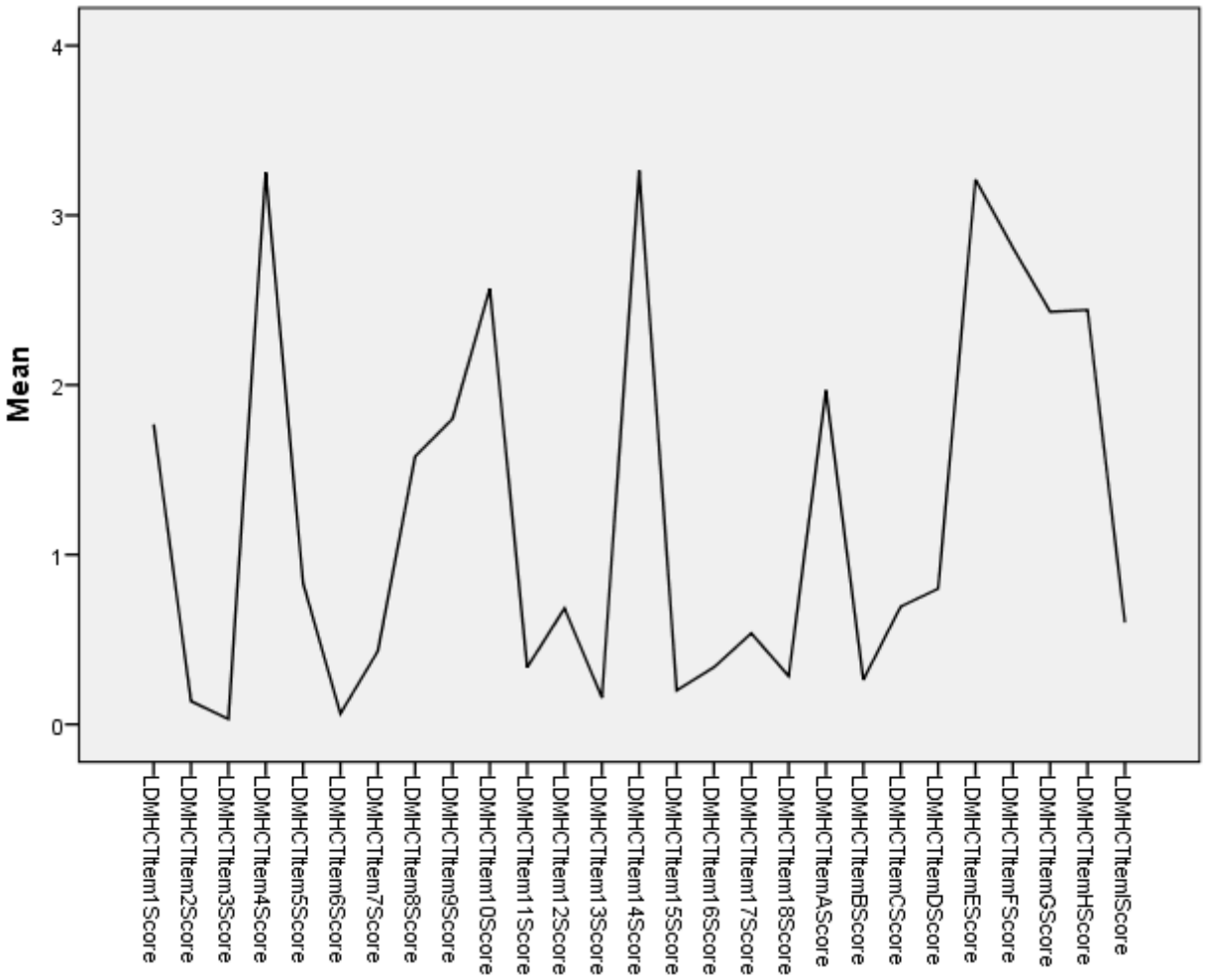
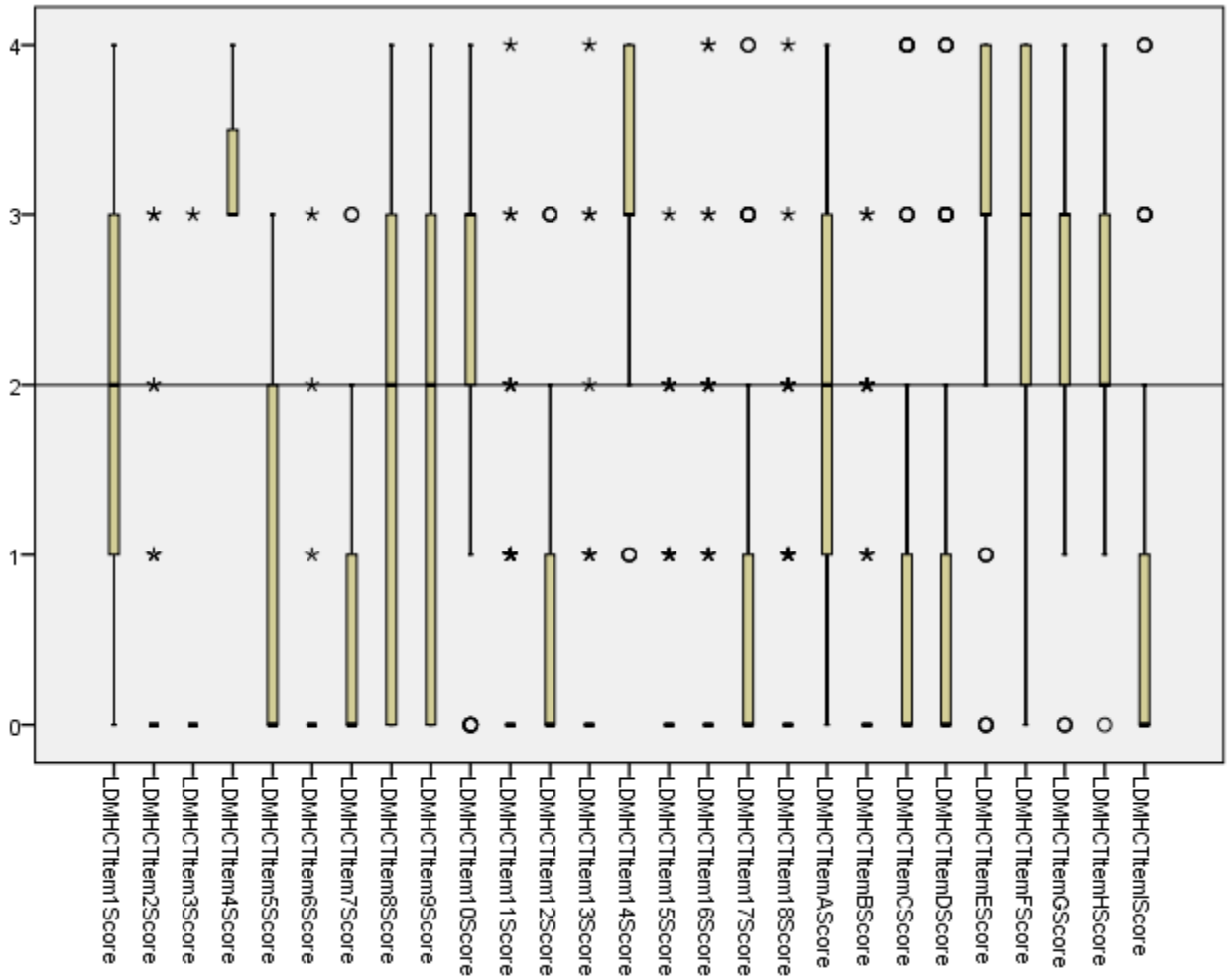


Table showing scoring distribution for Group Aii High impairment:

No.	ITEM DESCRIPTION	SCORE				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	18.6%	15.5%	39.2%	22.7%	4.1%
2	Non-acidental self injury	91.8%	3.1%	3.1%	2.1%	.0%
3	Problem drinking or drug taking	99.0%	0	.0%	1.0%	.0%
4	Cognitive problems	0.0%	0.0%	0.0%	74.2%	25.8%
5	Physical Illness	56.7%	13.4%	20.6%	9.3%	0.0%
6	Hallucinations and Delusions	96.9%	1.0%	1.0%	1.0%	.0%
7	Depressed mood	69.1%	19.6%	8.2%	3.1%	0.0%
8	Other mental & behavioural problems	34.0%	10.3%	22.7%	29.9%	3.1%
9	Relationships	27.8%	10.3%	24.7%	28.9%	8.2%
10	Activities of daily living	7.2%	8.2%	23.7%	42.3%	18.6%
11	Living conditions	79.4%	12.4%	5.2%	2.1%	1.0%
12	Occupation & activities	57.7%	19.6%	19.6%	3.1%	0.0%
13	Strong Unreasonable beliefs	92.8%	3.1%	1.0%	2.1%	1.0%
14	mental capacity	0.0%	3.2%	12.6%	38.9%	45.3%
15	Carer needs	87.6%	6.2%	5.2%	1.0%	.0%
16	Cultural and communication	84.5%	4.1%	7.2%	2.1%	2.1%
17	Non-accidental self-injury (associated with cognitive impairment)	73.2%	12.4%	5.2%	7.2%	2.1%
18	Physical Problems with eating and drinking	83.5%	8.2%	6.2%	1.0%	1.0%
A	Agitated behaviour/expansive mood	21.6%	9.3%	22.7%	43.3%	3.1%
B	Repeat Self-Harm	86.6%	3.1%	8.2%	2.1%	0.0%
C	Safeguarding other children & Vulnerable dependant adults	68.0%	14.4%	6.2%	4.1%	7.2%
D	Engagement	61.9%	13.4%	8.2%	12.4%	4.1%
E	Vulnerability	4.1%	3.1%	5.2%	44.3%	43.3%
F	Social communication difficulties	10.3%	2.1%	20.6%	30.9%	36.1%
G	Communication and problems with understanding	3.1%	10.3%	33.0%	48.5%	5.2%
H	Communication and problems with expression	1.0%	11.3%	43.3%	32.0%	12.4%
I	Seizures	70.1%	11.3%	10.3%	5.2%	3.1%

Box plot showing scoring distribution for each item for group Aii High impairment



Appendix 11 Tasks and verbatim responses from National MDT Workshop

Task one

Review the packs and profiles Ai-Dii

- **Does it describe a group of service users you recognise?**
- **Does the scoring profile have face validity?**
- **Any other observations we should take account of when refining?**

Comments on draft units

Group Ai

- Should this mention the 8 "other problems" scale- frequent and very heterogeneous but will affect need for treatment
- Would expect higher score of vulnerability to be reflected in scores.
- Not sure that the level of impairment should lead to a different unit as level of need may be affected by factors other than level of impairment.
- Danger of people allocating based on description rather than the rating scale. Therefore suggest to add in the description displaying physical aggression towards others and 'property/objects/things' etc. Expand a little.
- This group will have ASD, Agitated behaviour, Overactive/Aggressive, Mild LD, No SiB, Activities of daily living affected but likely to be well supported.
- Recognisable group. More intuitive to have impairment factors, aggression and self-injury in combination? I don't know if this fits but where there no low aggression, self-injurious clients
- Scores 0 on cognitive problems?
- Aii similar to Ci
- Risk is consequence of need
- Impairment poorly defined-open to different interpretation. Low functioning does not equate to high impairment.
- No clean relationship between theses scales and functioning/need. Why do you need to use all the rating scales (which do not define the groups- (they are not psychotic, do not have hallucinations)
- Mild impairment-but poor care setting leads to high need
- General Observation- For both care units Ai and Aii "impairment" needs more definition adapted function, maybe a better description level of disability + environmental support are both significant in determining risk and so used to be reflected in description. face validity-on the face of it-yes should
- Description should include displaying physical aggression towards property/fire starting etc as well as "towards others" (trashing bedrooms, breaking windows)

Group Aii

- See Ai re scale 8
- Should this not be Aiii with Ci becoming Aii?
- The definition should be "severe/profound" LD
- Not sure that the level of impairment should lead to a different unit as level of need may be affected by factors other than level of impairment.
- Anyone who is a risk to others is a risk. No 17 seems to conflict with description (will not be displaying SiB) How does this link with CII and Ci?
- Aii and Ci the same. (not discriminating scores and words)
- Can't we have resource groups with allocation tool (no names-as they force constructs)
- Starting from a blank piece of paper, wouldn't have done it like this.
- Yes recognised in clinical practice.

Group Bi

- By defining this a severe/profound LD will cut out a significant proportion of the physical health care work in LD services as clients have mild and moderate LD.
- Also defining complexity only in terms of additional dysphagia and epilepsy seems problematic. Complexity could be defined as :
    - Bi- mild/moderate LD (red for Cog problems 1+2)
    - Bii Severe/profound LD (red 3+4) but don't need to include dysphagia and epilepsy.
    - Biii Same as Bii but include dysphagia and/or epilepsy."
- Could also include people in mild to moderate LD or otherwise this group of people in significant health problems who cannot access primary/secondary care without help could be lost.
- Not sure of 'low complexity' as part of title. This is based only on presence of absence of epilepsy/dysphagia.
- Epilepsy/dysphagia better integrated makes sense clinically. Would Bii, Biii step down to this unit-not always. -f epilepsy is stable or can be passed down to primary care. Maintenance?
- I like the B's. Good to see level of complexity reflected.
- All groups B's : Intuitively correct- better than having single epilepsy/dysphagia groups.
- Need clarity in definition of complexity, it appears that the difference between Bi, Bii and Biii is the degree of epilepsy/or Dysphagia. The overlap at level 2 between Bi, Bii and Biii means you could choose either. There is an additional yellow box under level 2 for relationships under Bii or Biii?
- Other comment people with mild LD and physical health issues or epilepsy-primary care issue but may need health facilitation through LD services. They don't fit into Bi or Bii or elsewhere."

Group Bii

- See Bi
- See feedback on Biii
- This makes sense clinically.
- Make it clear in Bii that they have to have either Dysphagia or epilepsy.

- Making very clear about dysphagia or epilepsy, concern over downs syndrome and early on set dementia and how these people would get allocated/sign posted. Discussion around dementia clinic may not take this group need bigger discussion about finding/tariffs

Group Biii

- See Bi
- There are a number of services in the country who do not see people with epilepsy. Including this as the differentiation between Bii and Biii could be difficult.
- -Bi-(4)(mild) 1-2. LD (5)(physical needs) 3+4
- -Bii-(4)(3-4) LD + (5)(physical needs) 3+4 (no need to include 18 or I)
- -Biii-(4)(3-4) LD + (5)(physical needs) 3+4 + Dysphagia/Epilepsy"
- This makes sense clinically? Overlap with continuing health care funding as this client group are likely to be Continuing Health Care funded. In descriptor reference to end of life care pathway.

Group Ci

- Should the description mention 8-other +9. relationships?
- This seems okay. Why is this not included under A + Aii? (with current Aii becoming Aiii)
- No changes suggested
- This was felt to be relevant
- We can see the difference in "may scores" but think this would be difficult to differentiate in practice.
- Overlap with Ai? (Should this be renamed and slot into A between proposed A1 and A2.
- How would we differentiate in terms of need for engagement?"
- Please make clearer what "engagement" means. As above include destructive to property.
- Social communication but better general communication than As. Agitated behaviour and mood, problems with mental health, relationship problems, problems with activities of daily living, moderate cognitive impairment, moderate aggression/disruption
- See comments re Ai and Aii and how they link with these units. Contradicted by additional guidance appendix 4 scale 4 cognitive problems.
- "Is this a different unit to A ii? Define the problems with engagement.
- The group with mild LD, personality disorders, with self-harm- but with social communication issues - where scored? In mental health unit or missed."
- Expand on what is meant by "engagement" as D is engagement with services but engagement would be opportunities/activities etc.

Group Cii

- Will be displaying SIB + may show aggression (again may show other problems on scale 8)
- Okay but change descriptor to: display self-injurious behaviours. They may display high levels of physical aggression.

- In the definition change the risk to others as 'may pose' as it is an amber colouring.
- Distinct group mod/severe LD autistic with SIB + aggression to others.
- Is a step down needed if aggressive + SIB was settled/ well managed?
- There needs to be some clarification between self-harm + self-injurious behaviour.
- Really difficult and complex + multiple problems need lots of care coordination)
- Vulnerable, difficult to engage, ASD, activities of daily living, moderate/severe LD, overactive, mental and behavioural. Relationship diffs.
- Engagement not explicit in description for Cii but some score as Ci where it appears in description. Mild LD cannot be classified.
- People with moderate impairment-maybe included in this group
- Clarification/expansion on "self-injurious behaviours". Just further description required.

Group Di

- Vulnerability score goes up to 3. High risk to the person- not low need. Should say mild/mod LD as Ai does for same Cognitive + ADL impairment
- If defining Di and Dii as vulnerable then should vulnerability item not be red. Also low need- this needs redefined. Low cognitive impairment-needs to be rephrased to mild/moderate LD.
- Title change to vulnerable and at risk. Item E should be a red.
- We think item 18 E should be red ie must score.
- We should remove 'low need' from name of unit.
- Change terminology low cognitive impairment to mild/low LD.
- Based on description would we be seeing very many of these people unless mainstream services aren't making reasonable adjustments? Or adaptations to MH services ? Overlap with Units 1-3 ? Is there a maintenance group here.
- Description needs to reflect why need specialist health LD?
- Refers to 'cognitive impairment' where previous Units use LD. We need consistency.
- Worried about the description again- what is ""low need"?.
- Please include may be experiencing anxiety and depression.
- Got a LD, vulnerable, likely to be other services that are referred for eligibility/ additional support, team work on supportive other services.
- Yes it represents a portion of our clinical group. We thought of this as a unit that patients could move to after an intervention (say from unit Ai) to unit (Di) or the other way when support systems break down.
- Better description needed.
- Needs additional support to access generic services
- Depression not mentioned (anxiety is)

- **Group Dii**
- As Di re mild mod LD not impairment + delete "low need"
- See Di
- Take the title low need and call it vulnerable with being at risk.

- Diagnosis could include ASD, ADHD
- Differentiation between Di and Dii should be the additional interpersonal relationship problems
- Need to remove 'low need' from unit title.
- Doesn’t quite reflect these people in crisis. Would expect higher score
- Include anxiety and depression again.
- Mild/moderate LD, relationship diffs, vulnerable, agitated behaviour . These are more borderline people who are having difficulty in knowing their place in the world- employment, friendships, lonely people, hate crime, sexual issues
- This group should definitely be with LD services
- Does not seem to describe clients with e.g. high level of self-harm, PD type presentations, perhaps parenting issues, or forensic without necessarily being changed.
- Is the only expected difference between Di and Dii relationships. Is there a difference between aggression in the past and now between Di and Dii.
- Yes this clinical picture is recognised.
- Put depression as well as anxiety in descriptor?

Task two

Use the Decision Tree diagram to show where these units should be located.

- Seven participants suggested that all LD units should be placed in the organic superclass.
- Five Participants suggested there should be a superclass for all of the LD units.
- One participant suggested A,C and D should be place in the organic superclass, with physical health units as a separate superclass.
- One participant suggested D should be placed between units 4 and 5, unit 9 should be renamed as ASD with A and C placed here, and unit B in the organic superclass.
- One participant suggested B should be in the organic super class and ACDE in a separate superclass

Task three

Consider a new patient on your caseload, quickly rate and allocate them to a unit.

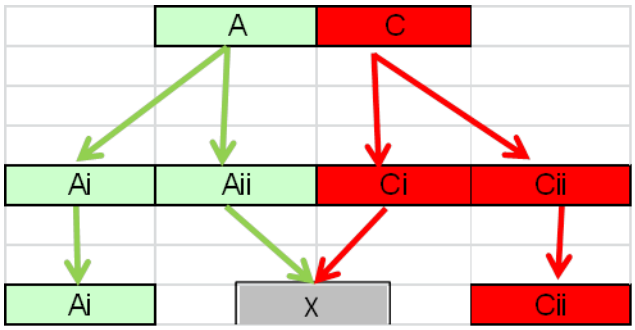
19 people were able to allocated cases to one of the new units. The table below shows the number of cases that were allocated to each unit.

Unit	Number of cases
0	2
8	1
20	1
Ai	1
Aii	1
Ai/Ci	1
Cii	6
Di	2
Dii	3
E	1

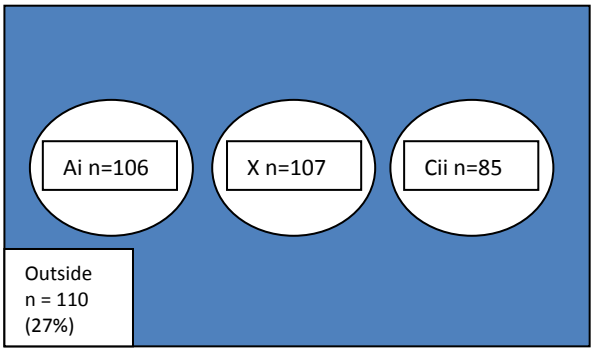
Appendix 12 Further subdivision for development of new units

Feedback from clinicians at the workshops and further exploration of the statistical groupings was then shared with Richard Hastings (Bangor University). Further discussion with Richard led to the following approach to split the groupings.

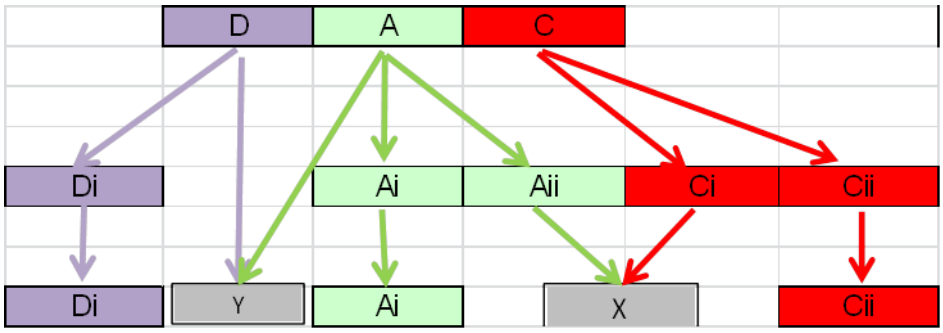
1. Combine A&C, keep clinically generated units at each extreme (Ai &Cii) ; create a unit (x) from the remainder.



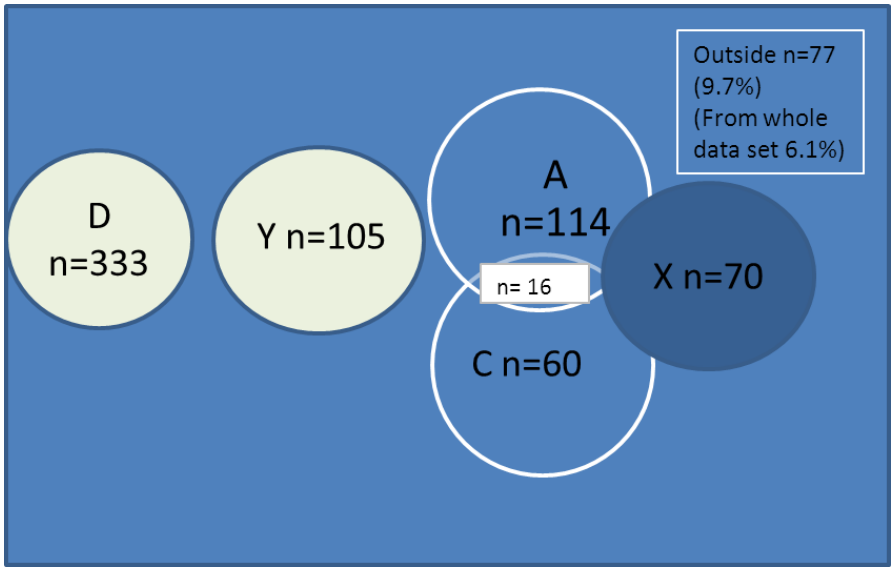
Venn diagram showing coverage of cases by units at stage 1(from groups A & C)



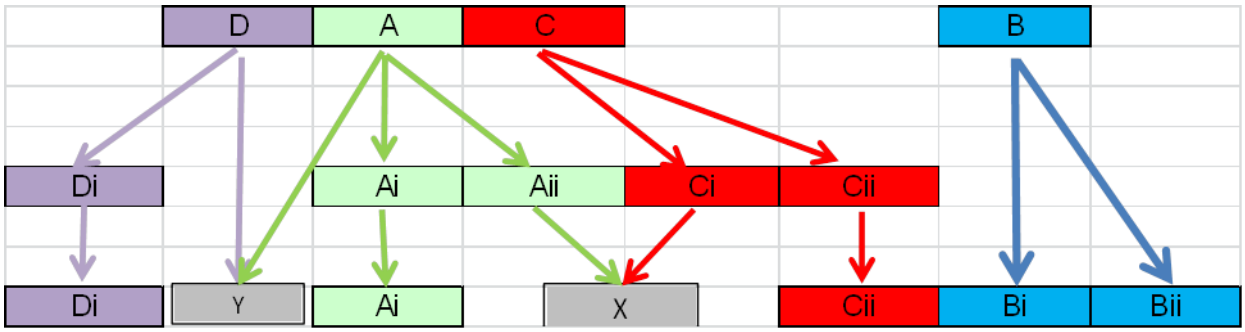
2. Add D to A&C, keep clinically generated unit at lower extreme (Di) ; create a unit (y) from the remainder.



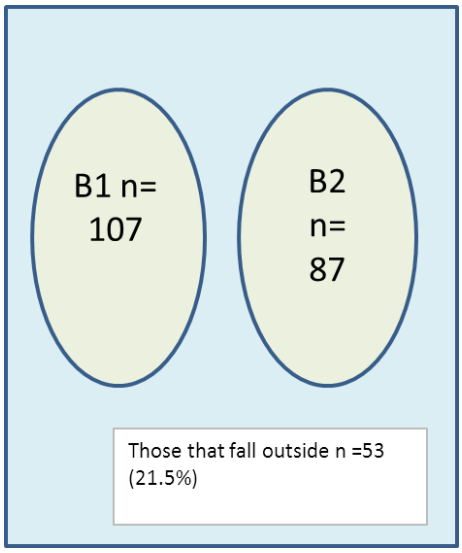
Venn diagram showing coverage of cases by units at stage 2



3. Take B and test a number of different ways of dividing it. After using cluster analysis techniques again decide on using dysphagia rating to create Bi and Bii.



Venn diagram showing coverage of cases by units at stage 3

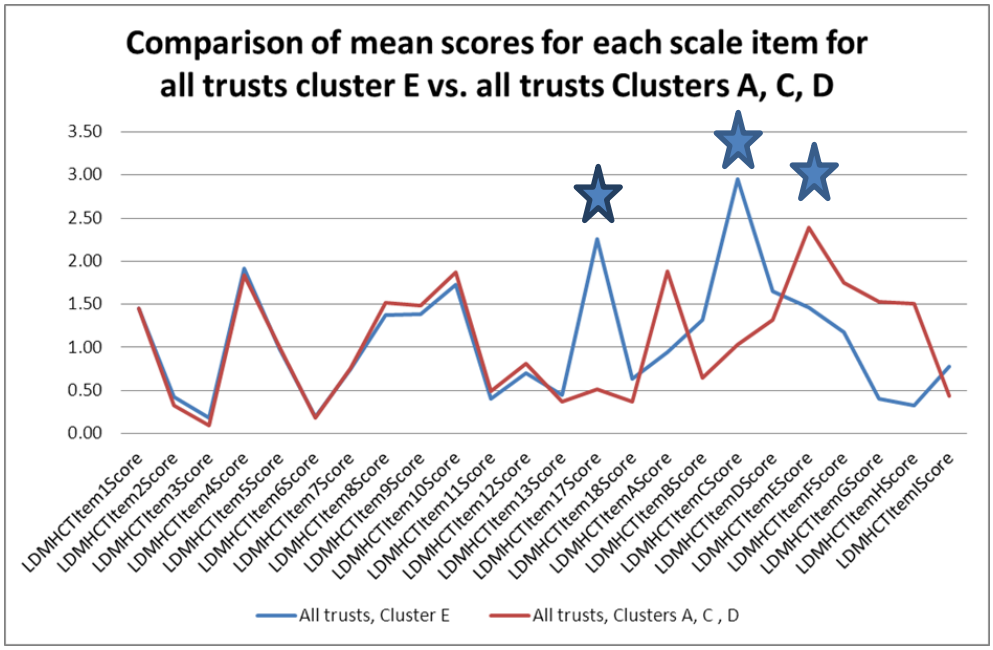


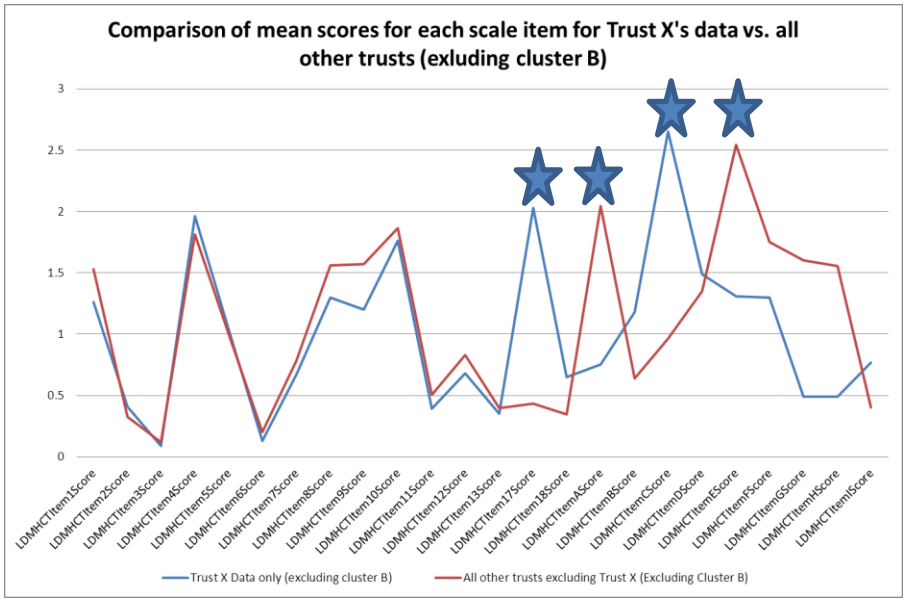
Appendix 13 Further exploration of group E

Group E was found to be clinically counter-intuitive, with lots of needs evident which should not co-exist, e.g. severe LD **and** self-harm (not self-injurious behaviour), no aggression towards others **but** safeguarding risk. It therefore warranted closer analysis.

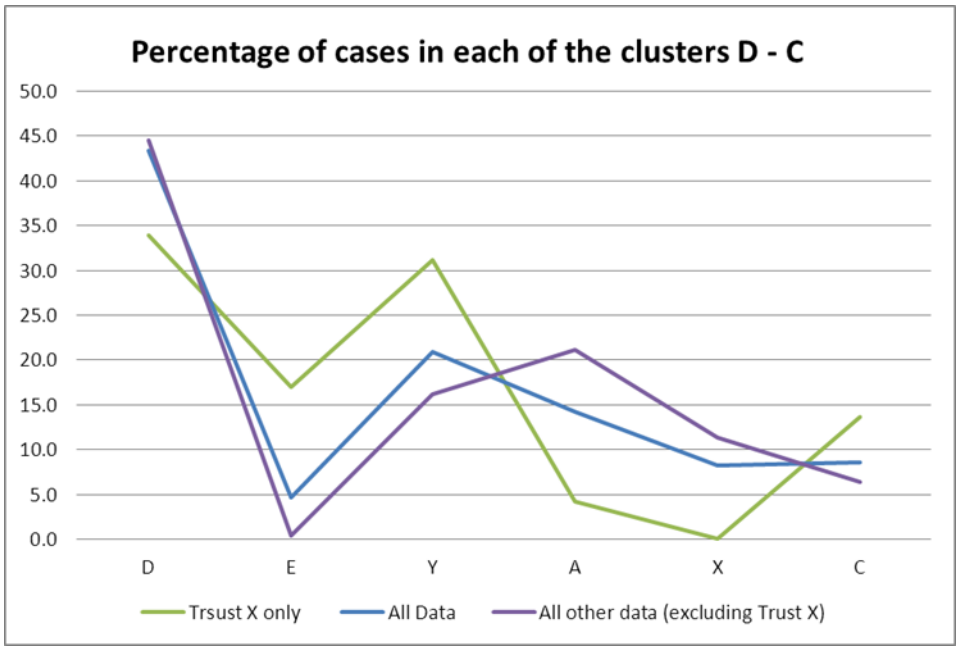
A significant number of group E were from one Trust. Group E represented two thirds of this Trust's data. In summary, most of this Trust's data was being put into one group which seemed odd as we expected a range of presentations given the number of submissions.

As such, was there something about this Trust's patient population, team scope or scoring that was leading statistical analysis to group most of their data into group E?

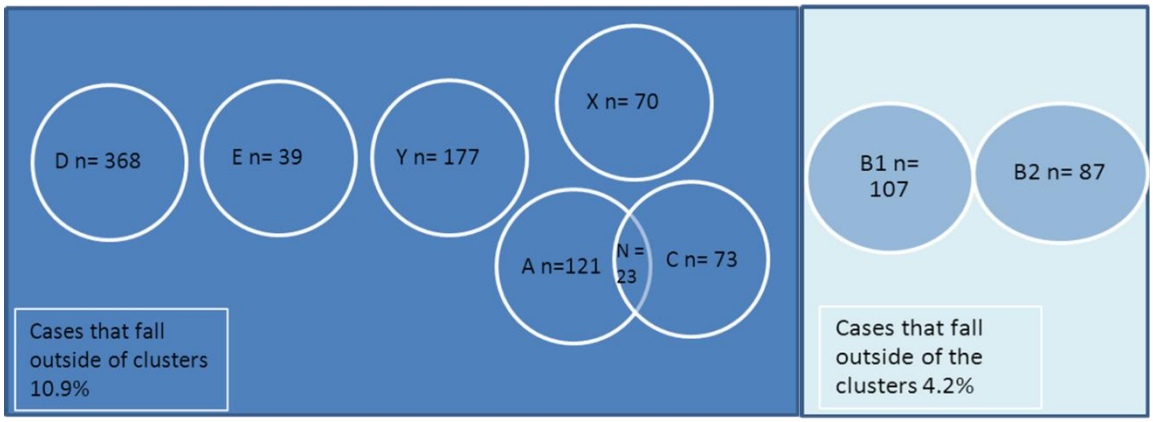


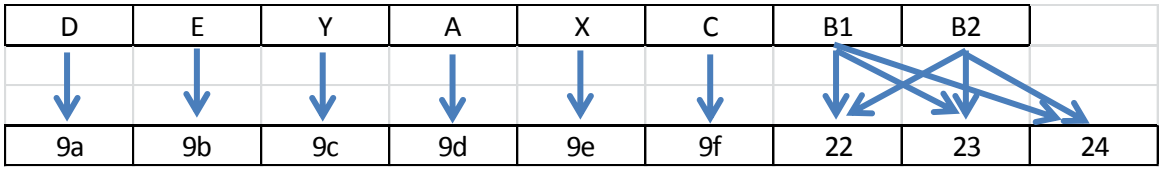


The cases from group E were then taken and the rules from the other provisional units were applied to see how it fits into other provisional units. There were a group of cases that did not fit into the provisional units, but that seemed to add up as a clinically meaningful group. Therefore an additional unit was created from these cases. The allocation pattern was then checked for Trusts & compared. Finally scoring ranges were reviewed and where necessary revised for units to take account of the impact of adding group E's cases



<u>Venn diagram showing overall coverage of cases by proposed units.</u>




D
E
Y
A
X
C
B1
B2
9a
9b
9c
9d
9e
9f
22
23
24

Appendix 14 Summary of NTW Audit of unit clinical content

Unit Ai (9d) Risk to others (& ASD), complicated by mild LD
6 Cases audited

Teams involved
LD Consultant Team, SLT, Psychology, BAIT, Forensic outreach

Current Accommodation
Supported accommodation

Primary clinical issue on referral (do not include LD)
Anxieties, verbal aggression, assessment of communication skills and level of functioning, challenging behaviour, offending behaviour (incident of stealing).

Secondary clinical issue on referral (do not include LD)
Verbal and physical aggression, carer burden, violence and aggression.

Current medications
Circadin, Methylphenidate, Risperidone, citalopram.

Primary Diagnostic Categories
Mild learning disability, Attention deficit hyperactivity disorder, Challenging behaviour

Unit description
This group will be displaying physical aggression towards others but not self-injurious behaviour. They will be experiencing social communication difficulties and have relatively mild: cognitive impairment; problems with adaptive functioning; social communication and interaction difficulties; self-regulation (emotional and/or behavioural).

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
4, 3, 3, 4, 2

Any key statements that are missing/wrong in the unit description in applying this to the patient
Anxieties, incident of wanting to take own life, Verbal aggression, 1:1 support 24 hrs a day

Comments on likely impairment for this patient
Significant impact on all areas of functioning.

Unit Cii (9F) Risk to others & self (with ASD), complicated by moderate - severe LD 6 Cases audited

Teams involved
LD Consultant, Speech therapy, Surgery, ISURT, Psychology, LD Specialist Nurse, LD Bait Team

Current Accommodation
Supported Accommodation, Supported Group Home, Mainstream housing with family/friends

Primary clinical issue on referral (do not include LD)
Not taking medication, On review - settled some reduction in self harm + Challenging behaviour, Self-injurious behaviour, Challenging behaviour/anxiety, Transition to adult services

Secondary clinical issue on referral (do not include LD)
Anxieties, Physical aggression, Communication difficulties, Challenging behaviour, autistic like features.

Current medications
Pregabalin Capsules, Olanzapine tablets, Cetrizine tablets, Sodium Valporate, Melatonin, Risperdone, Lorazapam, Paracetamol, Ranitadine, Tranexamic acid, Pyridoxine,
Propandol, Zopiclone, Fluoxetine, Clonzepam, Depot Provera, Lorazepam

Primary Diagnostic Categories
Severe LD, William Syndrome, Autism, Cerebral palsy, ASD

Secondary Diagnostic Categories
Cyclical Affective mood disorder, ASD, Micro deletion of chromosome 6 and growth delay

Unit description
This group will be displaying physical aggression towards others **and** self-injurious behaviour. They will have moderate to severe: cognitive impairment; problems with adaptive functioning; social communication and interaction difficulties; self-regulation (emotional and/or behavioural).

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
5, 3, 1, 1, 2, 3

Any key statements that are missing/wrong in the unit description in applying this to the patient
Communication problems, Sounds as though client may have fitted into unit better previously, but now symptoms have settled, Self-care, No mention of severe cognitive impairment, Anxieties, Communication problems.

Comments on likely impairment for this patient
Significant, moderate, moderate - severe

Comments on likely risk for this patient
Self-harm, Aggression

Comments on likely course for this patient
Long term

Unit X (9E) Risk to others (& ASD) complicated by moderate - severe LD –
6 cases audited

Teams involved
LD Consultant, BAIT, Speech therapy, Psychology, Physio

Current Accommodation
Mainstream housing with friends/family, Supported accommodation

Primary clinical issue on referral (do not include LD)
Increased anxiety due to uncertainty, Challenging behaviour, Anxiety and fixations, Physical aggression and self-injury, Transition to adult services

Secondary clinical issue on referral (do not include LD)
Challenging behaviour/injury to others, Injury to others - personal care, ASD, Moderate LD

Current medications
Alimemazine

Primary Diagnostic Categories
Epilepsy, mobility problems, ADHD

Secondary Diagnostic Categories
Autism, Tourette's, Anxiety, physical aggression

Unit description
This group will be displaying physical aggression towards others but not self-injurious behaviour. They will have moderate to severe: cognitive impairment; problems with adaptive functioning, social communication and interaction difficulties, self-regulation (emotional and/or behavioural).

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
4, 3, 2, 3, 3, 4

Any key statements that are missing/wrong in the unit description in applying this to the patient
anxiety due to uncertainty, self-care,

Physical aggression in the past, anxieties and fixations, no signs of aggression in notes

Comments on likely impairment for this patient
Significant, moderate, moderate impairment of everyday functioning

Comments on likely risk for this patient
Harm to others, outbursts of harm to others, vulnerability

Comments on likely course for this patient
Long term

Unit Y (9C) Risk to others complicated by LD
6 Cases audited

Teams involved
LD consultant, specialist nurse, ISURT, Art therapies, SLT, health facilitation, Psychology Services

Current Accommodation
Temporary Local Authority housing, inpatient (delayed discharge),Tenant LA/Registered Landlord

Primary clinical issue on referral (do not include LD)
Support work in attending appointments, poorly developed social skills, vulnerable, Challenging behaviour, support for transition from Continuing care Unit to community placement

Secondary clinical issue on referral (do not include LD)
Vulnerability - abuse from partner, Seasonal affective disorder, Depression, aggression to others, mood swings, Unpredictable and aggressive behaviours

Current medications
Propanol, amitryptilene, Asprin disperable, Carbamezapine, Isosorbide mononitrate, Levothyroxine, Olanzapine, pregabalin, Priadel M/R, Procyclidine hydrochlorine, sodium Valproate

Primary Diagnostic Categories
Cerebral palsy, Learning disability and 'explosive personality'

Secondary Diagnostic Categories

Unit description
This group will be displaying physical aggression towards others. They will not be experiencing significant social and communication difficulties. They are likely to have mild to moderate: cognitive impairment, adaptive functioning impairment, general communication difficulties, self-regulation - emotional and/or behavioural.

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
3, 3, 4, 5, 4

Any key statements that are missing/wrong in the unit description in applying this to the patient
No info about aggression to others - more vulnerable to abuse from others, Psychosis, vulnerability
Seasonal affective disorder, depression, mood swings

Comments on likely impairment for this patient
Moderate, moving to community care

Comments on likely risk for this patient
Vulnerability, harm to others

Comments on likely course for this patient
Shorter-term, long term, long-term, been in services over 40 years

Unit D (9a) Maintenance, engagement and minor support needs, complicated by LD
6 Cases audited

Teams involved
Health Facilitation, LD consultant, Nurse specialist, health facilitation, CTLD Community Nursing

Current Accommodation
Mainstream housing with family and friends, Supported accommodation, Tenant - LA/registered landlord

Primary clinical issue on referral (do not include LD)
ASD, assistance with personal hygiene and attending physical health appointments, Increase in obsessional behaviours, assistance with monitoring physical health, relationship problems, carer burden, engagement problems

Secondary clinical issue on referral (do not include LD)
Problems separating fantasy from reality, Anxiety, stress and restlessness, mental health (some voice hearing), Autism related anxiety, Adhering to medication

Current medications
Fluoxatine, Risperidone, Sodium Valproate and Lamotrigine

Primary Diagnostic Categories
. F72.1 Severe Mental Retardation with behaviour difficulties requiring attention and treatment, 2. F84.0 Childhood Autism, 3. G40.0 Epilepsy

Unit description
This group will be experiencing minor difficulties with one or more of the following: emotional distress, behavioural dysfunction, vulnerability to others and history of aggressive behaviour. They will be likely to have relatively mild levels of: cognitive impairment; impairment in adaptive behaviours and self-regulation (emotional and/or behavioural). They are unlikely to be experiencing significant social and communication difficulties.

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
3, 2, 4, 4, 5

Any key statements that are missing/wrong in the unit description in applying this to the patient
ASD, assistance with life skills & personal hygiene, more severe level of cognitive impairment - unable to communicate verbally, voice hearing, monitoring of physical health, living in isolation, ASD epilepsy, vulnerability

Comments on likely impairment for this patient
Low, significant, moderate, moderate, moderate impairment of everyday functioning, mild

Comments on likely risk for this patient
Vulnerability

Comments on likely course for this patient
Long term

<u>Unit E (9B) Risk to self, complicated by LD</u>
1 Case audited

Teams involved
LD NotCTLD Psychology, LD Consultant Team, LD NoT BAIT Team Newcastle, LD NoT CTLD, Community Nursing, Newcastle Self Harm Liaison Team

Current Accommodation
Supported Accommodation

Primary clinical issue on referral (do not include LD)
Challenging behaviour/ aggression
Secondary clinical issue on referral (do not include LD)

Primary Diagnostic Categories
LD, Turner Syndrome, Dyspraxia

Unit description
This group will be displaying self-injurious behaviour. They will not be experiencing significant social and communication difficulties. They are likely to have mild to

severe: cognitive impairment, impairment in adaptive behaviours, general communication difficulties, self-regulation (emotional and/or behavioural).

Unit Bi (22) Physical health complicated by Profound Learning Disabilities
6 Case audited

Teams involved
Physio, NR Outpatient, SLT

Current Accommodation
Mainstream Housing with friends/family, Supported Accommodation

Primary clinical issue on referral (do not include LD)
Support using intensive interaction as a communication strategy, Respite care, intensive support from BAIT Team, challenging behaviour, deteriorating mobility, recent falls advice re: exercise and hand and feet positioning, Help needed with communication - Staff not understanding patient and unsure of her understanding

Secondary clinical issue on referral (do not include LD)
Support for new staff, Physical health concerns - amputated leg.

Current medications
Zuclopenthinol decanoate, Clopixol, sodim valproate, mirtazepine, carbamazepine, procyclicline, lithium, benperidol, lorazepam, Paracetamol 1g 4 x daily, Cacit D3 1 sachet daily, Lactulose 10ml
Carbamazepine 100mg/5ml 500mg 2 x daily, Folic acid 2.5mg/5ml 10mg daily, Levetiracetam 500mg/5ml 500mg mane, 250mg, Buccal midazolam 0.5ml as required, Loperamide as required
Hyoscine patch 1mg/72hrs 1 patch every 3 days"

Primary Diagnostic Categories
Profound and multiple LD, Downs syndrome, diabetes, Severe LD, Road traffic accident causing brain injury and learning disability aged 4

Unit description
This group will be experiencing significant physical health problems complicated by difficulties associated with profound learning disabilities (e.g. specific neurological impairments; sensory impairments). They will have severe to profound: cognitive impairment; problems with adaptive functioning, impairments in self-care and communication difficulties.

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
4, 4, 4, 3, 1

Any key statements that are missing/wrong in the unit description in applying this to the patient
Need for respite care, Mobility problems, attends to own self-care. No severe LD

Comments on likely impairment for this patient
Significant impact on all areas of functioning, severe

Comments on likely risk for this patient
Self-care, low

Comments on likely course for this patient
Long-term

Unit Bii (23) Physical health with dysphagia complicated by Profound Learning Disabilities 6 Case audited

Teams involved
Physio, SLT, OT, Communication aid service and Health Facilitation

Current Accommodation
Mainstream housing with family and friends, Supported accommodation

Primary clinical issue on referral (do not include LD)
Problems with eating and drinking, Inpatient - assistance with personal hygiene and care,
Challenging behaviour, development/activity level & communication, Physio input for mobility
Weight loss and chest infections, Decline in physical health

Secondary clinical issue on referral (do not include LD)
Assistance with organising PEG fitted, Physio input

Current medications
Baclofen, Domperidone, Lansoprazole, Fleet enema, Hyoscine patch

Primary Diagnostic Categories
Cerebral palsy, PMLD

Unit description
This group will be experiencing significant physical health problems complicated by difficulties associated with profound learning disabilities (e.g. specific neurological impairments; sensory impairments). They will have definite physical difficulties eating and drinking safely. They will have severe to profound: cognitive impairment; problems with adaptive functioning; impairments in self-care.

Does this description fit for this patient Rate 1 (disagree) - 5 (agree)
4, 4, 4, 4, 3, 4

Any key statements that are missing/wrong in the unit description in applying this to the patient
Feeding assistance, Self-care, Communication help, input from a no. of services, OT, Physio, SLT,
Mobility problems

Comments on likely impairment for this patient
Significant

Comments on likely risk for this patient
Self-care/mobility

Comments on likely course for this patient
Long-term

Appendix 15 Allocation to units from CPPP LD sub group review (on 17 April 2013 in Middlesbrough)

During the meeting, 14 cases were allocated to units using the revised allocation booklet.

The table below outlines the number of cases that were allocated to each of the units.

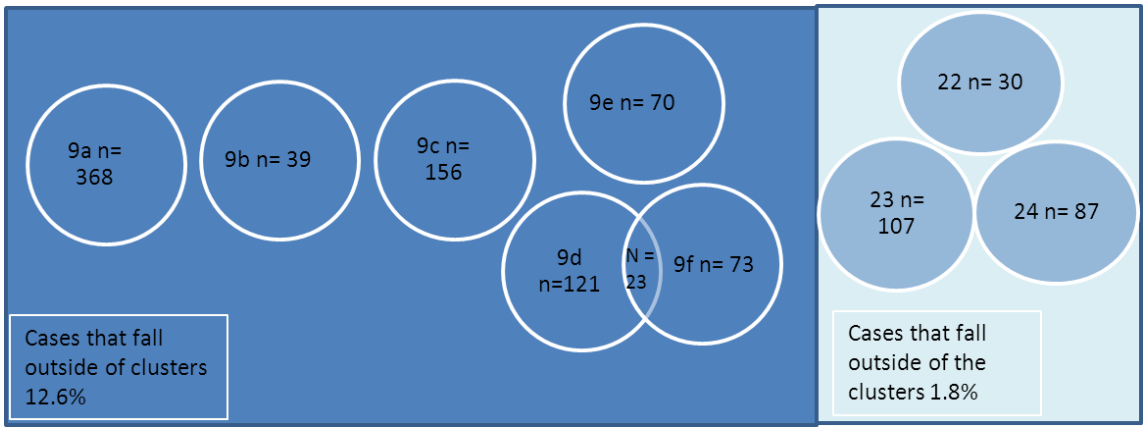
Unit	No. of cases allocated
9A	2
9C	3
9D	2
9E	1
9F	1
23	2
3	1
8	2

Appendix 16 Additional unit description and scoring change from CPPP LD sub group review

Following further analysis and discussion at the roundtable event. The following was agreed:

- An additional unit was identified from grouping B. This was to cover patients with mild learning disabilities and physical health problems who clinicians felt may not be represented by the current units.
- For Unit 9C – agreement to change the red rule for item 4 to scores of 1-4.

These changes increased the overall coverage of cases from 84.9% to 85.6%.



Appendix 17 Instructions and spreadsheet clinician resubmission/review of proposed units (sent on 29th April 2013)

Instructions

Dear Colleague,

Apologies for the slight delay in sending this revised information out to you.

Thank you for the data you submitted for the LD pilot project, it has been valuable in moving the process forwards. Following data submission analysis has been completed and further work with input from clinicians locally, regionally and nationally has led to revisions and the attached units being determined.
Allocations can only ever be made using clinical judgement and so, whilst the results (coverage and specificity) are favourable from a primarily statistical perspective, we need to check them out in the 'real world'. In order to gauge the clinical utility of the new LD units we are asking all trusts involved in the pilot to allocate cases using the revised Integrated Mental Health and Learning Disabilities tool.
Attached are the Integrated Mental Health and Learning Disabilities Booklet, Additional Guidance and a spreadsheet to record your data in.
Your local IT department may be able to pre-populate the grey area of the spreadsheet with ratings from patients previously assessed using the allocation tool. (NB in this case previous scales G&H have been combined and it is suggested that you either re-rate this scale retrospectively or use the highest score of the previous communication scales). Also previous items 14-16 have now been dropped, and the following items re-numbered as can been seen in the revised booklet. These items have been highlighted on the spreadsheet and all columns have been labelled with the item description.
It is also possible to rate cases that did not feature in the initial data collection exercise in which case the grey area can simply be completed for each patient assessed.
In either situation, the green and lilac areas of the spreadsheet should then be completed to allow the units to be assessed for utility and the wording improved. Please follow the usual process of allocating your patients (as outlined in the booklet and additional guidance), please enter the unit allocation based on the scores and your clinical judgement.
We are aware that timescales will be tight but, in order to meet key milestones in the national development cycle we would ask that you complete as many assessments as possible, and return the spreadsheet by 7th June. As the data is fully anonymised we do not envisage any information governance issues but please encrypt the spreadsheet and send it, and the password (in a separate email).

If you have any queries please email us at barry.ingham@ntw.nhs.uk

Thank you

Barry Ingham, Jon painter & Sally Robinson

Spread sheet sent out for completion by trusts

					Based on allocation is there anything you would change about the following								
Date	Integrated MHLD CT scores	Unit Allocation	How well do you think this unit fits for this patient	If you have indicated poor fit please state why	Unit title	Description	Likely primary diagnosis	Unlikely primary diagnosis	Impairment	Risk	Course	Likely NICE guidance	Place within decision tree

Appendix 18 Results of clinician resubmission/review of proposed units

Data re-submitted following initial pilot analysis

829 cases have been re-submitted by 11 of the 18 trusts involved in the initial pilot. Data was re-submitted by the following trusts:

- Black Country Partnership NHS Foundation Trust
- Cheshire & Wirral Partnership - NHS Foundation Trust
- Coventry & Warwickshire Partnership NHS Trust
- Cumbria Partnership NHS Foundation Trust
- Hertfordshire Partnership NHS Foundation Trust
- Northumberland Tyne & Wear FT
- Nottinghamshire Healthcare NHS Trust
- Rotherham, Doncaster & South Humber FT
- Sheffield Health & Social Care NHS Foundation Trust
- Surrey & Borders Partnership NHS Foundation Trust
- Tees, Esk & Wear Valley FT

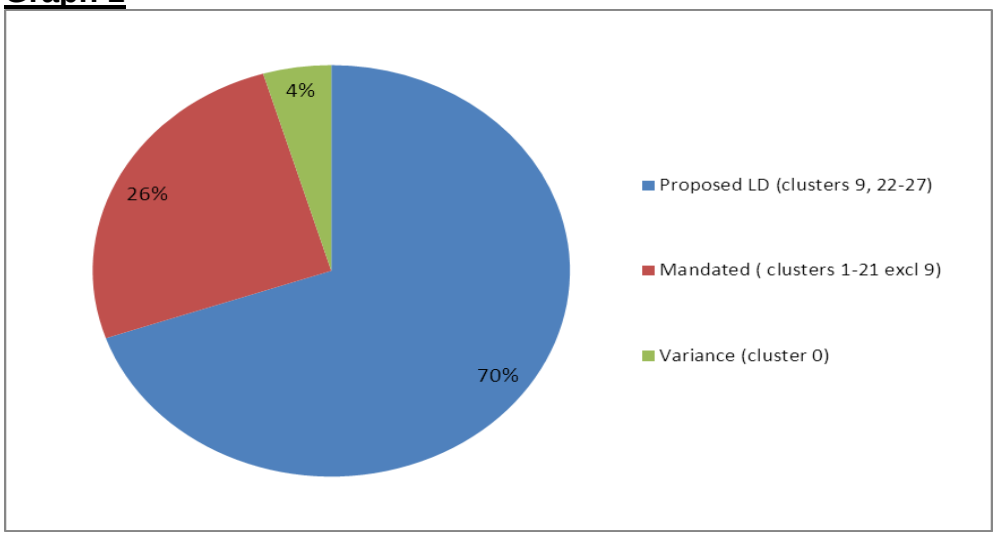
Table 1 shows the breakdown of these cases from the initial pilot and re submission into: the proposed LD units, MH mandated units and Variance (0).

Table 1

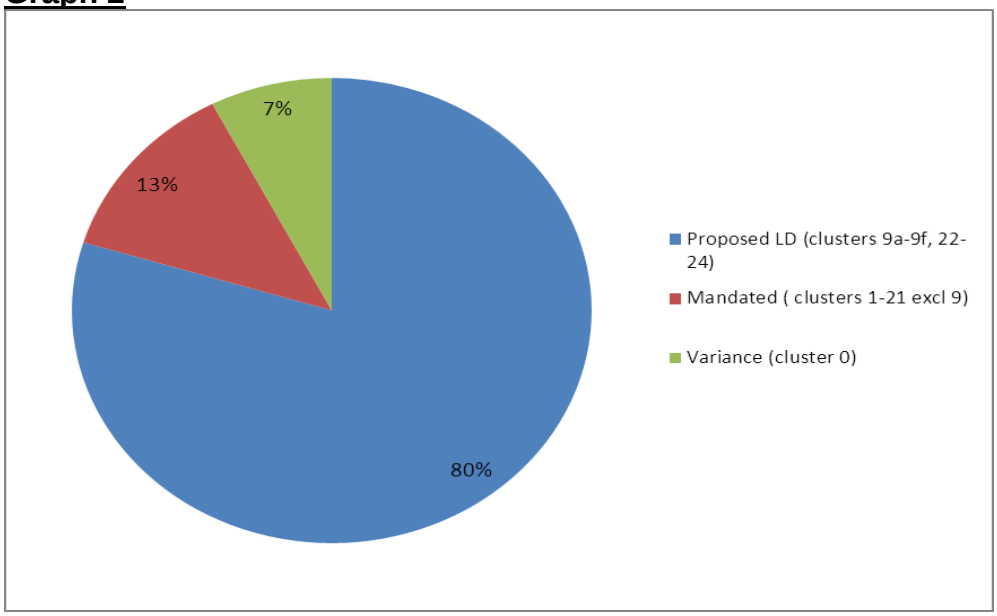
	Initial Pilot		Resubmission based on proposed units	
	N =	%	N =	%
LD units	1920	67.9	661	79.7
MH Mandated units	708	25	105	12.6
Variance (0)	127	4.5	63	7.6

Graph 1 shows the distribution of cases for the initial pilot and graph 2 shows the distribution for the re-allocation based on the new proposed units.

Graph 1

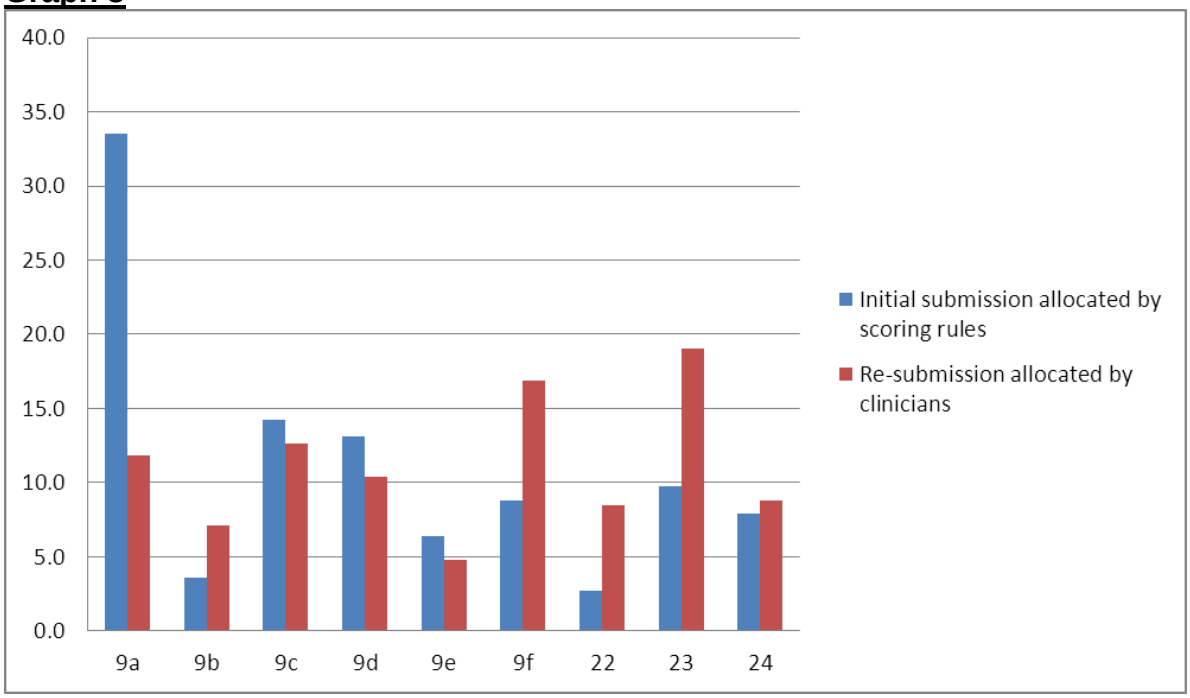


Graph 2



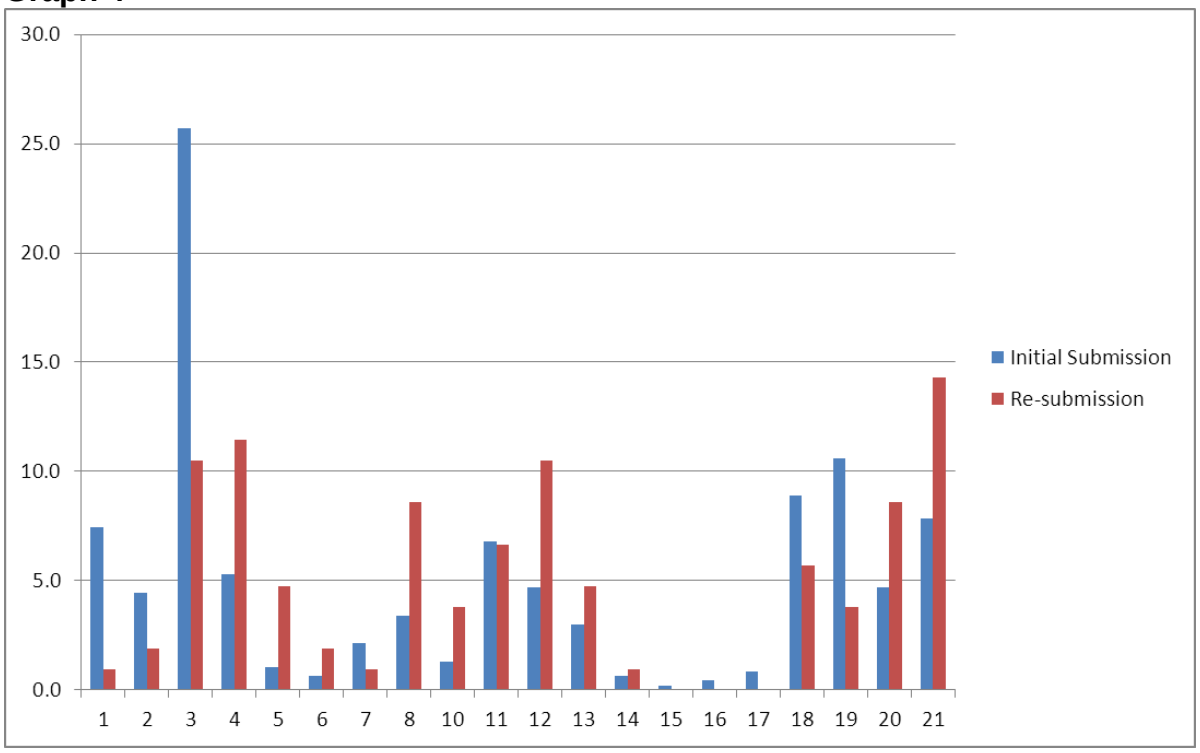
Graph 3 shows the percentage of cases (from those allocated to the LD units) which fall into each of the proposed units. This is shown for cases that were submitted in the initial pilot and allocated to the proposed units based on rules for allocation, rather than clinical decisions (shown by blue bars) and those that have been re-submitted and allocated to the proposed units by clinicians (red bar).

Graph 3



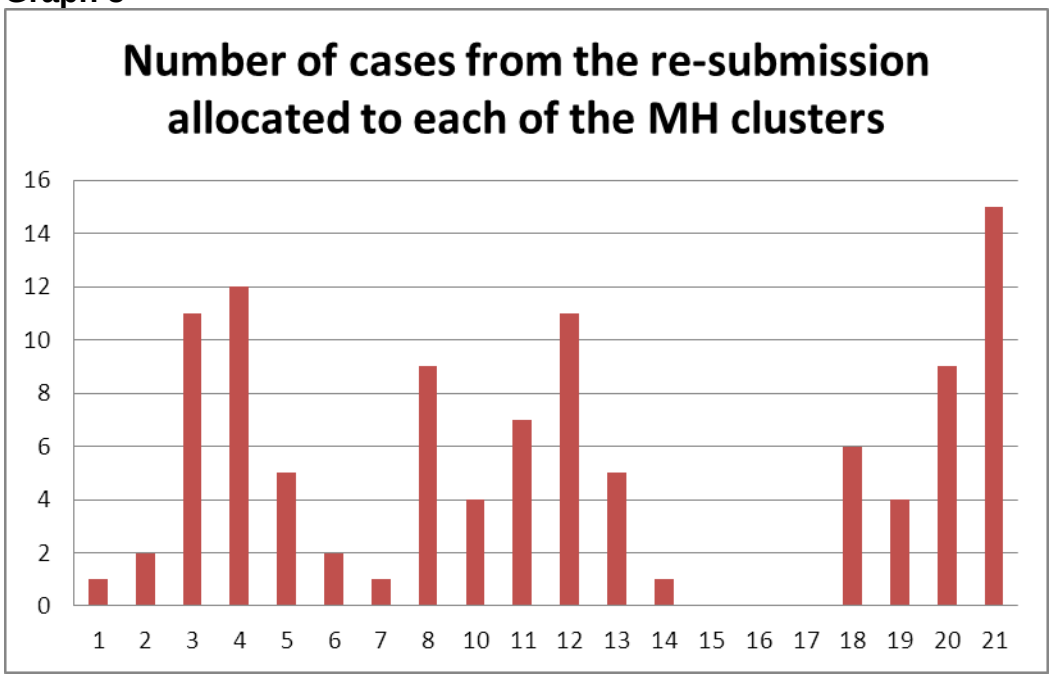
Graph 4 shows from those cases allocated to the MH mandated units the percentage allocated to each unit for both the initial submission and the re-submission.

Graph 4



Graph 5 shows the number of cases from the re-submission that were allocated to each of the mandated MH units.

Graph 5



For the re-submission of cases allocations to the new proposed units have been indicated by clinicians. The number of cases that adhere to the red rules for each unit outlined in the booklet has been assessed.
For the proposed LD units the overall rate of agreement with the red rule was 52.8% whilst for the MH Mandated units the overall rate of agreement was 57.1%

Clinicians were asked to rate how well they thought the unit allocation fitted for their patient on a 1-5 scale, 1(poor fit) – 5 (good fit). Table 3 shows the ratings from clinicians by unit.

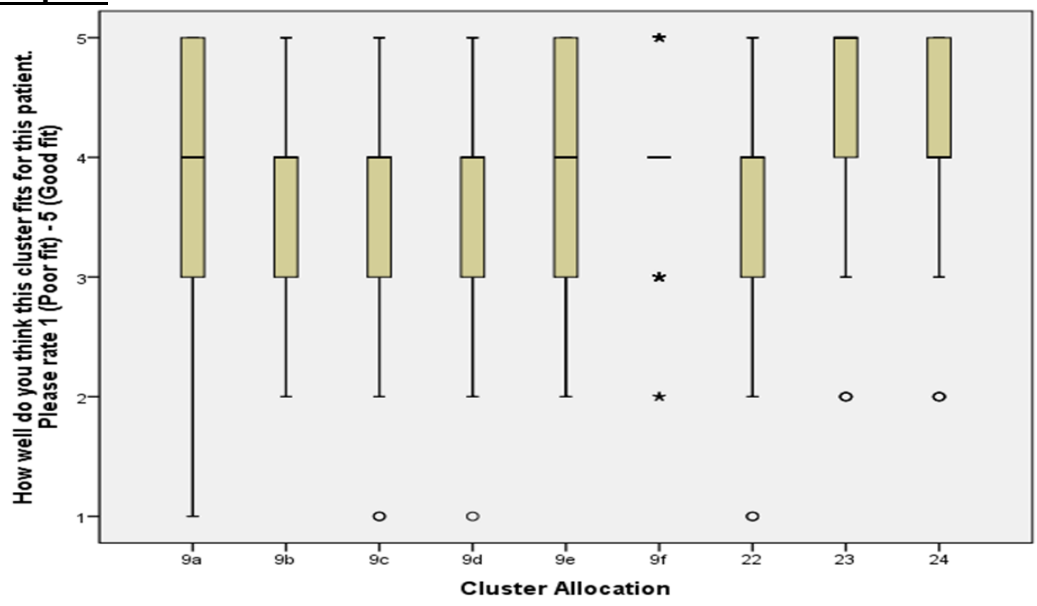
Table 3

	% for each rating				
Cluster	**1 (Poor Fit)**	**2**	**3**	**4**	**5 (Good fit)**
9a n = 78	7.7	12.8	19.2	29.5	29.5
9b n =47		6.4	36.2	44.7	10.6
9c n=83	2.4	3.6	19.3	51.8	18.1
9d n=69	1.4	1.4	24.6	60.9	11.6
9e n=32		3.1	34.4	31.3	31.3
9f n=112		2.7	17	58.9	14.3
22 n=56	3.6	1.8	26.8	53.6	12.5
23 n=126		3.2	11.9	31.7	50.8
24 n=58		6.9	10.3	36.2	43.1
Overall	4.6	4.3	18.2	40.4	27.1

Overall the mean rating = 3.85, mode = 4.

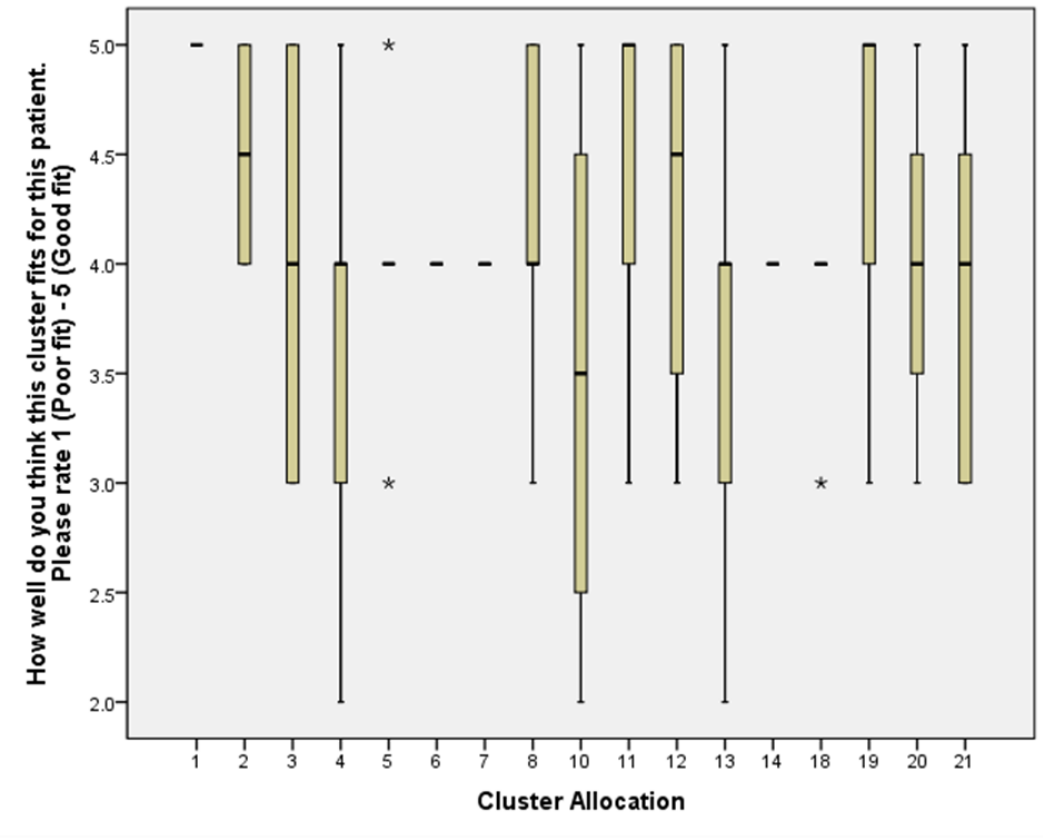
Graph 6 shows a box plot of ratings for each of the proposed LD units

Graph 6



Graph 7 shows a box plot of ratings for each of the MH mandated units

Graph 7



Descriptive analysis

Clinicians were asked to give descriptive responses about any changes they would suggest to the following for each of the proposed units:

- Unit title
- Unit description
- Likely primary diagnosis
- Unlikely primary diagnosis
- Impairment
- Risk
- Course
- Likely NICE guidance
- The placement of the proposed units in the decision tree.

Clinicians made comments about the following units: 9A, 9C, 9D, 9E, 9F, 22 & 23 (no comments were made about 9B & 24).

Comments about each units are presented and then themes that arose from the more general comments about the proposed units.

Unit 9A

Description field

Some concerns that this group were being described as having minor difficulties. Clinicians thought they may be a group who are vulnerable to exploitation, have difficulties maintaining usual levels of activity, and on-going support would be needed.

Likely primary diagnosis

Possible primary diagnoses that were listed for this unit by clinicians included: Anxiety, mild/moderate learning disability, Autistic Spectrum Disorder, genetic syndromes, health anxiety, sensory integration disorder, depression, Asperger's syndrome.

Impairment

Clinicians commented that this group may have temporary but significant impairment in social functioning and more significant impairment to Activities of Daily Living than described.

Risk

This group were described as displaying safeguarding risk, risk of physical and mental health deterioration. Also comments about the fact that risk can be very high even with low scores due to 'latency'.

Course

Involvement may be on-going due to latent risk that would be manifest if clinician closed case.

Likely NICE Guidance

Autism guidance, mainstream MH guidance e.g. anxiety, possibly include depression

Unit 9B

No comments

Unit 9C

Unit Title

Clinicians commented that the unit title could include dysregulation and severe relationship problems.

Description field

It was highlighted that the description seems to contradict the red 'must scores' in the scoring profile for this unit. Also some confusion within the description as it indicates individuals will not be experiencing communication and social difficulties, but later indicates general communication difficulties.

Likely Primary diagnosis

This group does not fit with mild or moderate LD, but more severe challenging behaviour.

Risk

Query raised regarding scope in terms of risks other than injury to self or others as this seemed to relate to physical injuries rather than the psychological and social impact of challenging behaviour or the risk of limiting participation in activities.

Unit 9D

Unit Title

Suggestions were made to include terms such as challenging behaviour, relationship difficulties, personality disorder and to include "social communication difficulties"

instead of ASD in order to capture people who are very ‘ASD-like’ but don't meet the diagnostic criteria.

Description field

Clinicians highlighted the following may also be useful in the description field: self-injurious behaviour, ADHD, problems with emotional self-regulation, risk of harm to self and others.

Likely primary diagnosis

Clinicians commented Williams Syndrome, autistic traits, Personality Disorder.

Impairment

There was a suggestion that Activities of Daily Living are likely to be significantly affected in this group but it was noted that in the scoring profile they were unlikely to score 3 or above in this area.

Risk

Clinicians raised that risk to self should be included in terms of vulnerability to assault from others.

Course

Queries were raised around inclusion of significant and enduring support needs (e.g. to maintain placement/independence/community presence) and that inclusion of a multi agency approach is often indicated. Also it was raised that some clients have long term not episodic presentations.

Unit 9E

Unit Title

The potential for including challenging behaviour, anxiety, dysregulation, poor engagement with services was raised.

Description field

Clinicians suggested including Fragile X syndrome within this.

Likely Primary diagnosis

Personality disorder was an additional possible diagnosis suggested.

Risk

Clinicians suggested emphasis on risk to self.

Unit 9F

Likely Primary diagnosis

The exclusion of physical health within this section was raised.

Risk

The inclusion of risk to own health could be considered.

Course

Clinicians felt that episodic or chronic presentations were possible here.

Unit 22

Likely Primary diagnosis

Clinicians commented that cerebral Palsy and no genetic issues could be included.

Impairment

Clinicians highlighted that more severe impairment were present in this group than had been described.

Course

This group were described as not necessarily episodic and that problems could relate to a one-off condition with vulnerability not necessarily being life-long.

Likely NICE guidance

Clinicians felt that inclusion of guidance on physical health issues should be considered.

Unit 23

Description field

Clinicians suggested reference to possible challenging behaviour, ASD or mental health problems associated with primary diagnosis.

Likely Primary diagnosis

This group could include more examples of physical health problems – not just epilepsy

Risk

This group were described as presenting risk of harm to others if challenging behaviour is present.

Course

Clinicians commented that there could be some episodic fluctuation in severity of related problems

Likely NICE guidance

There were suggestions for inclusion of adult autism and challenging behaviour here.

Place within decision tree

A suggestion was made that this unit overlaps with 9E and 9F and that it could be positioned next to them.

Appendix 19 Clinicians' descriptive feedback on initial allocation exercise full report

The extension in scope to include services for people with LD initially involved a small number of clinicians developing additional items within the tool and creating new units of need in relation to people with LD. The adapted tool and units were then routinely used within clinical practice as part of the data collection pilot project. This provided an opportunity to help understand and develop the face validity of the adapted tool for learning disabilities. In order to achieve this, it was agreed that those Trusts (and clinicians) who were participating in the Pilot Project should be asked their view of the tool through a questionnaire. This would enable a larger and potentially more diverse group of clinicians to provide their judgements on the usefulness of the process with particular focus on the perceived gaps within the process

Clinicians working in Learning Disabilities Services within the NHS Trusts participating in the data collection Pilot Project were invited to complete a questionnaire via the project leads within each Trust. A reminder was sent to improve response with 145 respondents in total.

A questionnaire was developed in conjunction with members of the core team involved in the Pilot Project. It included a range of questions that aimed to explore clinicians' views on the process and barriers/boosters towards completing the allocation tool; How is it being used?; Does it capture need?; Are there gaps?; How could it be improved?). There were also questions on demographics identifying the Trust that the respondent clinician was employed by, their professional background and the service they worked in.

An online survey was created using the clinicians' views on the process as above. Data was then collated from respondents and descriptive analysis was used to understand responses.

Figure 1 below summarises the responses by profession. The largest proportion was qualified nursing staff followed by psychological services practitioners, followed by physiotherapist then speech and language therapists and a number of other smaller represented professions.

Figure 1: Proportions of professional groups within the sample

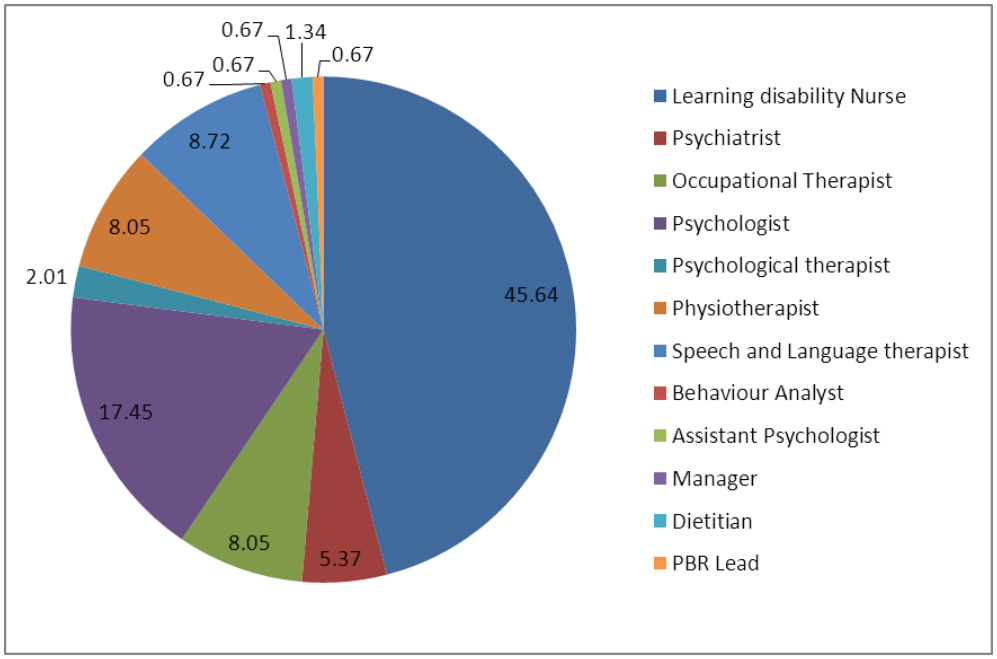
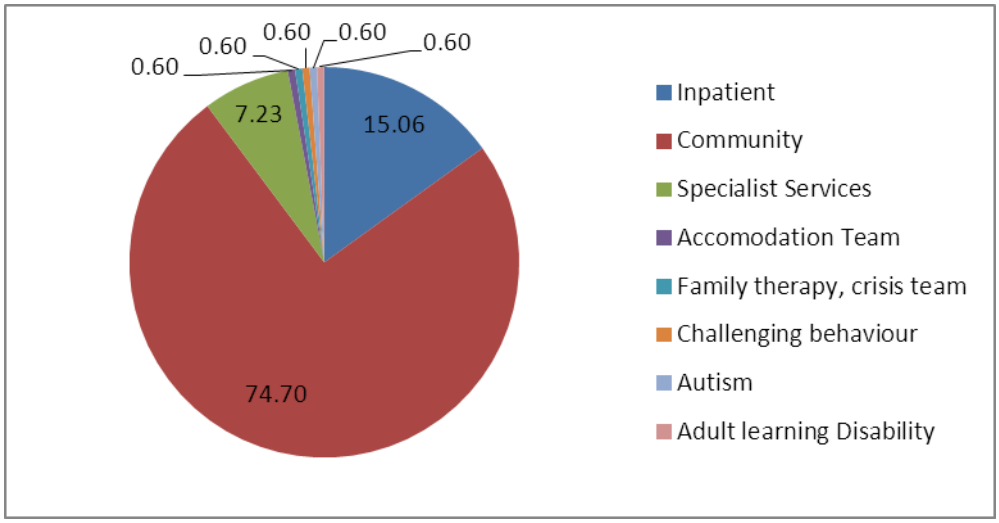


Figure 2 outlines the distribution of service settings that respondents were based in. The largest proportion was generic community teams followed by inpatient areas.

Figure 2: Proportion of different service settings where respondents were based within the sample



The majority of respondents reported they had some understanding of the process (n=99; 67%) while none reported no understanding. Approximately half had been using the tool for up to three months (n=77; 52%), a third (n=49; 33%) had been using the tool for three to six months and the rest had been using it for longer. The majority had used the tool with up to 10 people (n=96; 65%) and 35 (27%) had used it with 10-15 people and the majority (n=93;63%) had used the HONOS/HONOS-LD before.

Clinicians were asked to rate the relevance of the different items within the tool to three areas of clinical need: mental health; challenging behaviour; physical health. There was differentiation across the items in terms of clinical relevance (e.g. "Physical problems related to eating and drinking" was thought to be relevant to physical health but not mental health; "Problems with hallucinations and delusions" was thought to be relevant to mental health but not physical health; "Carer needs" was not felt to be specifically relevant or irrelevant to any needs). This suggested that the tool has reasonable face validity in regard to initial differentiation need.

Participants were asked in what ways they would suggest improvements to the tool that could help better capture need. A series of questions were asked with quantitative data on the extent to which the tool was fit for purpose and captured need. Almost half of the participants reported that the tool was predominantly fit for purpose (n= 64; 44%); however, the rest felt that the tool was not yet completely fit for purpose (n= 81; 56%). This indicated that there was further work to be done on refining the tool to ensure that it meets needs. The majority of participants felt that the tool captured at least some needs of the clients within their service (n=136; 94%) though a smaller proportion felt that the tool captured all needs (n=3; 2%) so respondents felt that not all needs were necessarily captured by the tool. Finally, over a quarter of participants felt that the tool was applicable to most or all settings such as community and inpatient areas (n=41%; 28%) with two thirds seeing it as only applicable to some settings (n=99; 68%). Again, this suggests that the tool has reasonable face validity but requires further work to increase the likelihood of it being fit for purpose, capturing needs and being applicable to different settings.

Participants were also asked to provide descriptive data on any frequently encountered clinical needs/risks that were not covered by the tool or areas where the tools was not fit for purpose. A thematic analysis was then completed and the following themes emerged from the responses. The summary of themes is included below along with data extracts attributed to each theme:

1. *General concern that complex multiple needs not fully captured*
    a. "It is very difficult to [allocate] people with complex and multiple needs particularly when there is both a learning disability and MH need or personality disorder."
2. *Range of physical health needs not captured*

a. “Physical health issues are generally not accounted for very well using the tool.”
b. “It could include more questions about weight and physical disability”

3. *Developmental disabilities related complexity not covered*
    a. Autism
        i. “Needs which require a lot of supervision and guidance related to autism spectrum disorder are not adequately covered (e.g. repetitive behaviours which could be risky e.g. running to the middle of the road; running off; unintentional self-injury).”
    b. Communication
        i. “Many of our clients have very complex communication difficulties”
        ii. “Tool needs to take account of current communication difficulties associated with understanding/expression/social communication - only option in historical context currently.”
    c. Sex education/relationships
    d. Abstract conceptual understanding
        i. Bereavement
        ii. End of life care
    e. Sensory issues

4. *Complexity related to broader mental health and risk related needs not captured*
    a. Forensic/offending behaviour
        i. “something is needed on risk of offending within the tool”
    b. Dementia
    c. Personality disorder
        i. “Repeated threats of self-harm and suicide (not actual attempts) as in clients with personality disorder”
5. *Service related issues*
    a. *Failing to reflect work done*
        i. capacity and cognitive assessment and health access teams
        ii. “it fails to reflect work done by OT, SLT, physiotherapy and health access teams”
    b. Consideration of multiagency working
        i. “We are a joint LD service and the tool is not used by local authority colleagues.”
    c. Burden on workload
        i. “Unfortunately I don’t have the time as I am swamped with the paperwork that is actually essential to my actual work and immediate client care, so that will take priority.”
        ii. “If this process is necessary at all, I would suggest that a list of units and their inclusion criteria would be sufficient, since the tool itself adds nothing to the allocation of a unit.”
6. *Need for more differentiation to capture the ranging severity of needs*
    a. Different severity levels of challenging behaviour
        i. “Needs to better discriminate between levels of behavioural problems”
    b. Lack of intensity measure

        i. “There is nowhere to highlight the likely intensity of support required or the length of input both of which are significant indicators of cost to service both in terms of time and money.”
7. *Tool more specific to LD is needed*
    a. Insufficient sensitivity
        i. “It is interesting to note that some clients on paper had minor difficulties but there were high levels of distress within the family which will impact on the client over time and this is harder to capture”
    b. Lack of specificity
        i. “If someone who presents with challenging behaviour and has a diagnosis of autism, which may well influence the behaviour and intervention plan, the tool does not help clarify which unit they should be in.”
    c. Better descriptions needed
        i. “More work on the anchors specific to relevant to learning disability clients would be helpful.”
    d. Uncertainties on how to rate impact of support
        i. “It is unclear how to rate items where support is in place. For example an individual who has full support with ADLs but who could not manage anything without support - are they to be rated as having no problems (because of the support already in place) or as having significant problems?”
8. *Some general positive responses*
    a. “It captures the service user’s needs”

Appendix 20 Inclusion North service user & carer views full report

Care Pathways and Packages Project

Developing currencies for mental health payment by results

Report

What's it all about?

This is a report about what people said about the allocation process in services for people with learning disabilities in the NHS.
People had their say at some workshops in October 2012.

These are the views of people with learning disabilities and their family members and family carers. Other people took part in the workshops such as direct support staff and commissioners. However, their job was to help with the conversation and make sure that people could get involved.

What is it?

The NHS is testing out a way to work out how much it will cost to provide specialist health services to people with learning disabilities.

It wants to make sure that people know what they are getting for the money being spent on specialist services and to make sure these services are done by the right people in the right place at the right time.

They use a tool to work out what services people will need. The tool has a list of things people often need help with. These needs are put into groups.

For example, lots of people who need a lot of support in their lives every day need help with:

- Swallowing
- How they tell people what they think and feel
- Making day to day decisions and big ones, for example about their health or where they live
- Epilepsy
- Acting in a way that keeps them and others safe and well.

The NHS has looked at what kinds of services people often use by looking at what has happened in the past. This means they can tell what services people will use and be able to say how much this should cost.

The NHS has been doing this in other services for some time (they have already done this in Mental Health).

This is not about services you get from going to the

opticians or your G.P. (sometimes called primary care services) It is about specialist services. Some people that work in specialist services are:

- Learning disability nurses,
- Clinical psychologists
- Psychiatrists
- Physiotherapists
- Speech and language therapists
- Occupational therapists

The work shops were held so that people could have their say about what they thought about the process. This included:

1. Understanding how it works

2. Saying whether they thought there are any opportunities from this.

3. Saying if there is anything people are worried about

Some people did not know what specialist services were. We talked about specialist services and how they work if people in the workshop did not know.

This was useful as some people were using specialist services but did not know they were.

Who took part in the workshops?

The 4 workshops were aimed at:

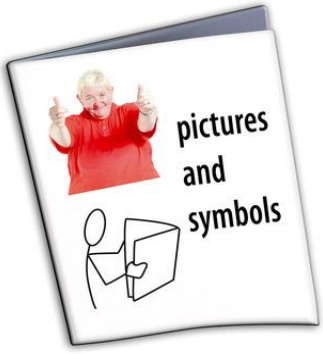
1. People with learning disabilities with direct experience of specialist services

2. Family members and family carers of people with learning disabilities using specialist health services

Lots of other people joined in the workshops including commissioners, speech and language therapists and more. This included staff who worked in health, social care and the voluntary and community sector.

There were four workshops/sessions. Three were held in the North East and one was held in Sheffield for people from South Yorkshire. In total there was:

- 24 people with learning disabilities
- 8 family members and family carers
- 20 staff members



We used a number of different exercises and accessible materials so that we could make the workshops make sense to ‘who was in the room’. These materials come with this report.

What did people say?

The next two sections of this report talk about the big ideas or things people talked about. The same big ideas came up at the workshops in the North East and in Yorkshire and Humber.

The first section talks about the things that people thought might be an opportunity. The second section is a list of things that people are worried about.

Lots of the things that people said were ‘ideas’ about what this might look like or what it might do in the future. Some of the things people said which are in this report were more about people ‘getting their head around’ what this really means and might not be how it works at all.

We thought it was important to include this as it helps us to understand what is important to people and families.

Lots of these ideas or issues started with a question from family members and carers and people with learning disabilities so we have written the report in this way.

The things below are the ‘big questions’ that came up in all the workshops.

Is there a chance that this might work in a similar way to self- directed support?

People talked a lot about where this sits with self-directed support and personalisation in general. For example one way that it might be seen as being similar is that people will know how much their supports cost.

However, lots of people thought this needed to be talked about more and that it should not work against the good work happening around personalisation.

Will this mean we can use the money in the best way possible?

People thought this might be a chance to watch every penny and make sure that we are getting what we pay for. It might also be a chance to make sure that the service is the best that it can be and all the Trusts are charging the same for their services.

Can we use this to make sure we use the skills of staff in the best way possible?

Lots of people talked about using staff in the best way possible. For example, many people are referred to psychiatrists to talk about issues around sex and sexuality. People thought that this was an ‘expensive over reaction’ to the issue and that other people could help people talk about issues about sex and sexuality as well if it wasn’t too serious.

Could this help us plan and buy the right kinds of services for people?

Having good information about people such as that on a case register can help us buy and plan the right kinds of services in the future. The process could help with this as it will help us work out how much money we will need for people's services and what kinds of services there should be.

Will this help us work more closely with social care?

The Trusts and social care can use this to have a stronger conversation and work more closely together but the tool would need to be looked at to allow this

"As a commissioner I do not want a tool just about health we want to work out things together".

Is this a chance to get what people really need?

We hope evidence based pathways will mean people will not be given a service just because 'its there'. It will be based on what they really need.

Could this show that keeping people connected is a good way of preventing people becoming unsafe or unwell

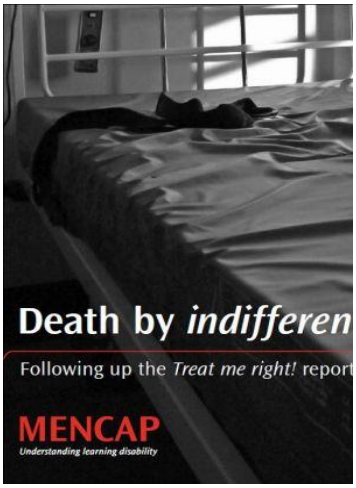
Is this a chance to ‘cost’ the value of people having meaningful relationships in their lives? Some people will need to use specialist services but maybe this will help us look at prevention and how family and friends and connections in the community can help with this.

What are the big worries?

Is the tool too big? Does it stop people getting a person centred service?

Lots of people were worried that the tool and range of questions were too broad and would not enable staff to work in a way that is person centred. This would be driven by the ‘labels’ that people had rather than treating them as a ‘person first’.

Will the tool allow real person centred care and support for people who might ‘move’ between units or have needs that fit in different boxes?



If somebody sits in one unit will they easily be able to move into another if their health needs change? Some people were worried about something called ‘diagnostic overshadowing’.

For example, If they have a learning disability their depression might be seen as ‘challenging behaviour’ and they might not be in the right unit and might not get the right service.

Specialist services are important but should we be making sure we try other things as well?

Although people understood that some people would need to use specialist services, many people thought this might would stop people being creative about how people are supported and always use service land solutions i.e. ‘therapy’ rather than having ‘mates to talk to’.

Can the tool be more positive about people?

People wanted something in the tool about working out what was important to the person, their likes or what they were good at. They thought it should say if they had natural supports in their life such as family and friends. If they did not have any friends then the services available should facilitate people getting more friends and community connections.

Can we really tell what services people will have to use? Costing services based on what we know from the past

Some people thought that this might be a ‘false economy’ or not a good ‘evidence base’. People talked about how people may not have been in control of the supports that they got or things such as individual service design or person centred planning had not been used in the best way or at all.

This meant that what we ‘know’ about people might not be the truth and that people are not as ‘risky’ as everyone believes for example. People may have been ‘over supported’ or not been supported in a way that made sense to them and did not help them be as independent as they could be. This could affect how much money is spent on services or the kind of services people use.

Is this a set menu of services for people?

Some staff said they felt that lots of people keep coming back to their service for the same thing that does not seem to work. If it works like a ‘set menu’ does this mean that we cannot work in a flexible and creative way?

Will people keep getting the same options that do not seem to work for them? Could there be a section in the around trying something different? Could there be a ‘pot’ of money about ‘just trying stuff’?

Keeping people and families In Control

Lots of work has been done around person centred planning, self-directed support and other things that put people and families in control. People felt that this way of 'organising' peoples' support would go against this or good things may get lost and forgotten.

Is this about saving money?

Many family members were worried that this was a way to 'cut' services. It was felt that these feelings may not have been as strong if it had happened in a time when money was not as tight. There would have to be a lot of telling people that this was not about cutting services to make sure people felt safe and secure.

The skills of people doing this.

People talked a lot about how getting the right services for people depended on who was doing the process. Good communication and being able to ask the right questions in a way that made sense to each person was very important.

People felt strongly that we should make sure that staff doing the process should have the right skills and training so that they make sure people use the right service and get good outcomes in their lives.

This was really important for those people who might not communicate in traditional ways for instance not using words to communicate. It was felt that people's friends and families or circles of support should be part of working out what is important to someone.

Will everybody understand what is being talked about?

The NHS needs to make sure that everybody understands the words that are used. This includes people and families and people from different services such as those in social care and in the voluntary and community sector.

Does the NHS need to work more with other people who plan and buy services (commissioners)?

A tool that just talks about health services is not going to be useful to people who plan and buy services. This needs to fit with what social care services are doing and people who self-directed their support.

Where does this fit with the big changes?

Everybody felt unsure about where this would fit with the big changes happening in health and social care. Lots of people felt that more work needed to be done about where this fits with things such as clinical commissioning groups and personalisation.

The Big Messages

Lots of the things people talked about were about how we get a good balance between using the money in the best way we can whilst still treating people as citizens with a right to a good service.

Lots of people thought it was a good idea to be able to say how much money things would cost and that people should be able to know how much they are entitled to.
At the same time people felt that this should never just be about the money but about making sure people get access to good quality specialist health services if they need it that supports them to be citizens of their community.