Care Pathways and Packages Project

Developing currencies for mental health payment by results

Development of a needs based payment system for specialist Learning Disability health services

Results of a pilot project.

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14/06/2013

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Executive Summary

In recent years, services for adults with learning disabilities have undergone significant changes which have been driven by national policies and guidance (including the Mansell Report, 2007; Valuing People Now, 2009; and more recently Transforming Care: A response to Winterbourne View, 2012) which have promoted inclusion and valued social roles for people with learning disabilities as well as the need to ensure evidence based practice is delivered to reduce the need for out of area inpatient admissions.

In addition, there have been recent advances in developing an appropriate payment system within mainstream mental health services that has created needs-based 'units of purchase' for these services that incentivise good practice and the delivery of demonstrable outcomes as opposed to simply paying for activity. It was proposed that extending the scope of this approach to include specialist health funded learning disabilities services could be an opportunity to:

- improve care pathways to deliver person-centred, individualised care that reduces the need for out of area, inpatient services
- create a case-mix sensitive framework in order to allow meaningful comparison of outcomes to evaluate the effectiveness of services.
- provide greater integration between learning disabilities and other mental health services
- develop common units of purchase to allocate resources in a fair and efficient way
- use units of purchase as a first step in defining need which then directs needs-led interventions through to developing credible tariffs for pathways of care

In addition, the Serious Case Review into Winterbourne View (2011) noted that an appropriate payment system could have improved the care provided to people who had been in Winterbourne View.

An initial pilot project to extend the scope of the mental health payment system into learning disabilities was started within a consortium of NHS Trusts (Care Pathways and Packages Project) and expanded to include a number of other provider organisations nationally to extend the scope of the mandated set of needs-based units of purchase in order to describe the individuals accessing specialist learning disability healthcare services. This project aimed to develop an Integrated Mental Health & Learning Disabilities Tool that captured the additional needs of people with learning disabilities and then administer it within NHS Trusts across England to help develop new learning disabilities units of purchase. At the same time, clinicians, service users and families / carers were consulted about their views of the proposed payment system.

A large number of cases (n=2825) across 18 NHS Trusts were collected within the pilot. The data from these cases was statistically analysed by Bangor University to generate initial groups of individuals that had similar characteristics to each other. A series of multidisciplinary workshops were then held to review the results of this analysis and further develop the statistical groupings to generate a comprehensive set of clinically meaningful learning disabilities units of purchase which described groups of service users with similar needs. These could be used to direct effective, individualised interventions and care pathways and allow meaningful benchmarking of outcomes. These new groups were then reviewed by clinicians that originally submitted data to the pilot project to check that they had clinical utility. This led to the following:

- Nine proposed learning disabilities units of purchase which have good clinical and statistical validity in initial pilot testing.
- Integration of these units of purchase with the existing mental health payment system.
- Inclusion within these new payment units of increasing levels of risk posed to self and others together with varying levels of physical health needs complicated by learning disability.

- Variation across these new units of purchase in levels of cognitive impairment, severity of needs, presence of autism spectrum characteristics and complexity of physical health need.

- The pilot project also highlighted that a significant proportion of cases were clinically allocated to the mandated mental health classification system confirming that these existing units of purchase have value and use for some of the people currently accessing specialist learning disabilities services.

- Collectively the new learning disability and existing mental health units of purchase cover the majority (93%) of people accessing specialist NHS-funded learning disability health services.

The pilot project has demonstrated that it is possible to extend the scope of mental health's needs-based payment system to include users accessing specialist health funded learning disability services. These units of purchase could form the underlying classification system upon which to build an appropriate model for detailed and evidence based care monitored through a qualities & outcomes framework. In this way they help to meet the requirements of learning disabilities policy and guidance (especially post-Winterbourne View) in directing individualised and effective interventions that meet needs and provide greater transparency and comparability that will promote improvement and innovation away from out of area inpatient focussed options.

The new learning disabilities units of purchase now need to be used in routine clinical practice in order to establish their functionality in relation to an overall payment system within learning disabilities services and this report includes proposed next steps to do this effectively. The recommendations within this report are to develop and test a robust needs-led payment system for specialist learning disability services that is based upon the proposed units of purchase. This will include an exploration of how this model fits in with joint commissioning and pooled budgets through providing greater clarity and transparency about the specialist health component of care packages (including the cost and outcomes they can deliver) leading to greater choice and control through personal budgets. This should provide a significant step towards improving the commissioning of personalised

services for adults with learning disabilities.

Introduction

The development of this proposed payment system for learning disabilities services has taken place within a number of different contexts including policy, commissioning and the approach to payment within mainstream mental health services. These will be outlined first before describing the development of learning disability units of purchase..

Learning disabilities policy context

Over recent decades there have been some notable developments in our understanding of the needs of people with learning disabilities and changes in the way that services for them are provided. Since the start of the 21st century, this has been driven by Valuing People (2001) and a number of subsequent policies and guidance including: Green Light for Mental Health: how good are your mental health services for people with learning disabilities? A service improvement toolkit (2004); Services for people with learning disability and challenging behaviour or mental health needs (2007); Challenging Behaviour: A Unified Approach (2007); Valuing People Now (2009) and No Health without Mental Health (2011). These have emphasised the importance of the principles of: person-centred care; inclusion; facilitating access to mainstream health services for people with learning disabilities as appropriate and that specialist health services are sufficient to meet the health needs of people with learning disabilities.

A key current driver in improvement for services for adults with learning disabilities is the response to the Winterbourne View Hospital abuse scandal. The Serious Case Review into Winterbourne View noted that a payment system *"which holds services to account for the outcomes that they achieve for individual patients, would provide much needed purpose to the out of area, assessment and treatment drift"* (p 145, Winterbourne View Hospital: A Serious Case Review, 2012). As such, it may be that a well-designed Payment system for Learning Disabilities services could have improved outcomes for those who were in Winterbourne View. Any move away from block contracts involves the development of an appropriate

payment system to support the commissioning and contracting of learning disabilities services in a transparent way with a shared qualities and outcomes framework. This may have helped to meet needs in the right way at the right time in the right place for those people who were in Winterbourne View (e.g. through delivering evidence based approaches such as Positive Behaviour Support in their local community and providing greater transparency and comparability that would promote improvement and innovation away from out of area inpatient focussed options). In addition, this could have enabled the use of clearer, demonstrable and shared quality & outcomes metrics to have been set (e.g. lowering emotional distress experienced; improvements in physical health).

This relates closely to the recommendations from the Department of Health final report into Winterbourne View (Transforming care: A national response to Winterbourne View Hospital, 2012) and the Concordat: Programme of action (2012) which both emphasise the need for changes in commissioning and the need for improved quality and safety of care that services provide. Linked with this, the recent mandate for NHS commissioning outlined that one of the objectives was *"to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people."* (p. 16, A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015).

This objective matches with a broader aim within this learning disabilities work stream of linking with personalisation and social care stakeholders to set the right conditions for effective healthcare to take place that increases the use of appropriate, local community services rather than out of area inpatient services. It is within this context that the development work in this report is set. In particular, the development of a payment system for learning that would facilitate improvements in quality of care through a common currency model for commissioning care that is more person-centred and individualised, more effective and more efficient, and having a common language to support transparency in the overall commissioning process. The approach aims to improve the care offered by specialist learning disabilities services and also to facilitate access to mainstream services (e.g. where mental health is the primary need) as appropriate and in so doing would help to meet

the recommendations of national policy and guidance. In particular, an appropriate payment system could reduce use of inpatient beds in two ways. Firstly, a single, setting-independent price would incentivise less inpatient use due to their relative expense in comparison to community-based treatment. Secondly, an appropriate outcomes framework would be an integral part of the model and one of the outcomes measured could relate to service user experience, providing the potential to recognise the increased satisfaction of community-based treatment delivered close to home.

Joint commissioning context

This project focusses on the specialist healthcare services received by people with learning disabilities; however, the needs of people with learning disabilities often cross the health and social care divide. In addressing this, there are a number of barriers to joint and integrated working between health and social care including organisational, cultural and professional issues (SCIE, 2012). Attempts to overcome these barriers have included approaches that support flexible commissioning such as the use of pooled budgets between health and social care and developing the use of personal health budgets (NHS Futures Forum, 2012). A move away from the block contract system towards the adoption of needs based payment system in learning disabilities may offer an opportunity to further facilitate interaction between health and social care. Personalisation is also a central part of meeting the needs of people with learning disabilities (Valuing People, 2001). The development of personalised health care is an important part of this. Meeting individual needs requires appropriate services to be locally available and to this end it is necessary to profile population need. Clearly defined units of purchase enable this to happen in a consistent manner across population groups. This may also provide an opportunity to help achieve greater personalisation of care through needs based decision making for the allocation of resources and delivery of effective and efficient care. The approach also focuses services on clear and shared outcomes which should enable greater coordination across agencies (SCIE, 2012).

The aim is to develop common units of purchase that would support development of clinical pathways of care through services which firstly agree the

spectrum of needs to be addressed, secondly carry out appropriate and effective interventions and finally achieve agreed outcomes. The system allows for complexity of need to be more clearly defined and categorised so that costs of care can be agreed taking into account the intensity and duration of treatment needed. This would then help to inform learning disabilities commissioning to take account of both health and social care components of services that people require. Within this, a robust approach to outcome measures based on the effectiveness and safety of services and a positive user experience will allow providers to achieve high value in relation to cost. An appropriately extended payment system could help health and social care commissioners agree costs of services for individuals and whole populations using standard definitions thus allowing for consistent and explicit standards to be used to commission and benchmark specialist services for people with LD.

In the context of personalisation one possible impact of using units of purchase to describe need is that people are placed into broad categories and their individual and unique range of needs could be obscured. It is important that any development of needs based units of purchase within the context of a payment system in learning disabilities links closely with other areas of commissioning (e.g. the use of personal budgets in social care) to ensure that personalisation is achieved.

Payment System in Healthcare context

A discussion paper has recently been published by Monitor and NHS England (2013) which reviewed the progress of payment by results and outlined potential developments towards a more coherent single payment system for healthcare that continually improves quality for patients and provides best value. In recent years, payment by results funding systems have moved healthcare funding in certain areas away from block contracts to a 'cost-per-case'. Within acute health care in England, there has been a rules-based system for provider Trusts consisting of three elements:

1. Activity-based funding instead of traditional block contracts,

2. Work measured through Healthcare Resource Groups (H.R.G.s), whereby diagnostic groupings could utilise similar treatment resources, and
3. Nationally agreed tariffs for H.R.G.s, to eliminate price negotiations between commissioners and providers.

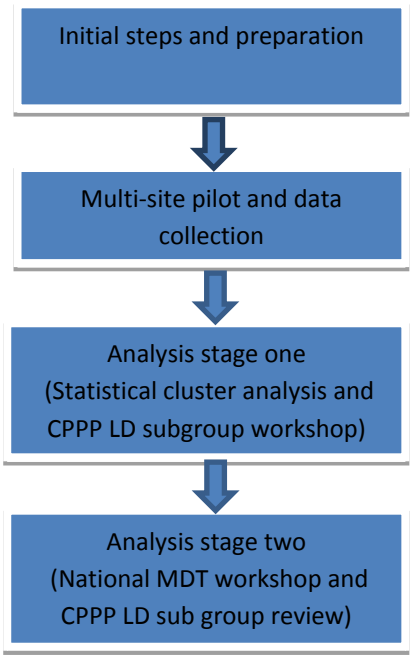
The discussion paper from Monitor and NHS England sets out a proposal to build on the progress of payment by results to develop a single coherent payment system. Alongside this there has been development of an approach that provides units of purchase for mainstream mental health service. However in mental health, diagnostic groupings alone are insufficient due to the vastly differing care that can be appropriate for individuals with the same diagnosis. Instead, a comprehensive range of needs-based groupings have been developed for working age adults and older people with mental health problems which combine factors such as complexity, acuity and severity with diagnosis. This has involved describing patient need within units that determine resource allocation. These purchase units then guide the delivery of evidence-based clinical care packages and pathways (i.e. effective interventions) and provide the basis for outcome measurement. The approach has resulted in the 21 purchase units for mental health services traditionally titled working age and older people's services. Such a national Mental Health payment system assumes that similar needs, as defined within units of purchase, will require similar care and will therefore cost similar amounts to treat. Currently tariffs are locally determined; however, national tariffs may become possible over time. The next steps from this report will link with these more recent developments.

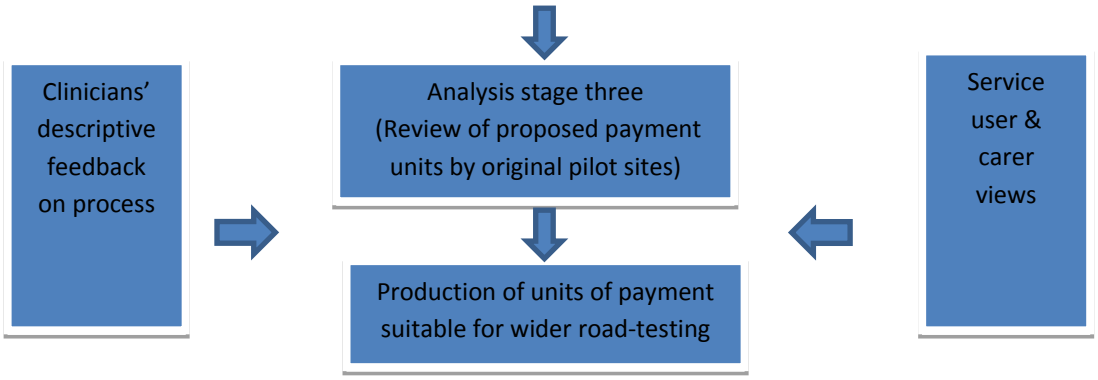
The work to date had excluded a number of other specialist health care areas associated with mental health and broader psychosocial difficulties. One such area is the provision of NHS-funded specialist health care services for adults with learning disabilities. This project has sought to extend the approach used within mental health to make it applicable to learning disabilities services. This involved adapting the existing clinical allocation tool used within mental health services so that it captured the additional needs of people with learning disabilities and extend the range of purchase units (still categorising around need) so that it also described the range of needs of people typically accessing specialist learning disabilities services.

Pilot project on learning disabilities units of purchase development

Currently, the nationally mandated mental health payment system describes the full range of patients seen in traditional working aged adult and older people's Mental Health services. Despite initiatives, such as Green Light toolkit, which promote appropriate access to mainstream mental health services for people with a learning disability, these patients fell outside the scope of the initial mental health work. This proved problematic for the provider organisations in the Care Pathways and Packages Project (CPPP) consortium that provide both mental health and learning disability services. Although the principle of learning disability policy has been to promote full access to generic services wherever possible, people with learning disabilities have tended to either been excluded as a category or being expected to fit into generic services. This raised the need to consider how to develop a payment system within learning disabilities services including the development of units of purchase that would be the pre-cursor to developing high quality, comparable packages of care monitored through a robust outcomes framework. This report outlines the steps taken to address this. The flow chart below outlines those steps.

Stages of learning disabilities units of purchase development





Initial steps and preparation

Like a number of provider Trusts across the country, Learning Disability staff in one of the CPPP provider organisations (Northumberland, Tyne and Wear Mental Health Foundation Trust) undertook a brief options appraisal to consider how to develop an payment system for Learning Disabilities services. Having excluded "doing nothing" two main options were considered:

- create an entirely new set of purchase units to describe the needs of all their patients (including those with co-existing mental health needs) or
- broaden the scope of the existing mental health payment system.

The creation of a different set of purchase units was felt to be unhelpful for a number of reasons. First it would have perpetuated silo-working. Secondly it would have gone against the principles of core policy documents noted above. Thirdly, from a national perspective the service boundary between the two systems would be problematic because in reality it is an arbitrary decision, often based more on historical service provision and commissioning than patient need.

In contrast, many teams were keen to foster appropriate integration with mainstream Mental Health Services by encouraging all staff to view a relatively mild learning disability as an added complexity where a primary mental health need was apparent and was adequately described by the existing units. They argued that this dominance could then be reversed by creating units where the primary needs were

related to the patient's learning disability with any additional mental health needs described as co-morbid. In many ways the developments in mental health services have been successful because they were clinically driven and have maintained their face validity even when the cost/pricing agenda became more prominent. It was proposed that a pragmatic, bottom-up development approach should be taken to extending the scope of the existing mental health purchase units to include patients with learning disabilities requiring specialist health interventions. It was noted that other approaches have been explored around developing payment systems in specialist learning disabilities healthcare services. The next steps following this report will continue to learn from these other approaches in order to achieve a model that produces the best value for people with learning disabilities.

This rest of this report sets out the subsequent work undertaken by members of the Care Pathways and Packages Project (CPPP) Consortium and a number of other volunteer Trusts to develop a needs-based classification system for patients with a learning disability who access Mental Health and / or specialist Learning Disability Services. Following the flow chart above, it describes work undertaken by services to ensure that adults with learning disabilities will be represented by the new system and also a series of discrete phases incorporating large multi-professional collaboration and consultation with researchers from Bangor University. This report will outline the methods, results and conclusions from each of these elements and integrate them to help understand the viability of an extended Care Pathways and packages payment system for Learning Disabilities services.

To develop an integrated Mental Health and Learning Disability allocation Tool, work was undertaken at a number of levels. Initial work was undertaken by staff in Northumberland, Tyne and Wear NHS Foundation Trust from the field of learning disabilities. Work with local staff began with two full-day workshops. Seventy senior clinicians, representing all areas of the learning disability service, were involved. To test the face validity of the mandated Mental Health allocation tool, everyone had an opportunity to apply it to case examples from their own practice. The exercise showed the current mental health tool was unable to capture the full range of needs of many people with learning disabilities who use services. Two work streams were established to address this problem:

- Extend the allocation tool to better capture the needs of the learning disability population.
- Creation of a preliminary additional set of clinically derived purchase units that could be applicable to a learning disability population.

The Mental Health allocation Tool was used as the basis to develop an integrated Mental Health and Learning Disabilities allocation Tool (MHLDCT) to ensure allocation to the existing purchase units was unaffected. The first step was the addition of items that would need to be included to capture the needs of people with learning disabilities (e.g. an item covering harm to self as related to cognitive impairment – often described as self-injurious behaviour). A full list of these additional items may be found in Appendix 1. The tool was then initially piloted within Northumberland, Tyne & Wear NHS Foundation Trust. This included a specially developed training programme (which was subsequently used as the basis for training in other Trusts through the development of a virtual training network). Alongside this there was testing with a number of cases rated by more than one person in order to assess inter-rater reliability. This provided opportunities to review the tool and make changes to it in order to improve the reliability and validity of the tool (see Appendix 2 for details).

A set of initial preliminary learning disabilities purchase units were then drafted in order to provide an endpoint to the allocation process. These were solely clinician generated and there was acknowledgement that these would change as a result of the subsequent data analysis (see Appendix 3 for more details).

Initiation of multi-site pilot and data collection

Following a positive meeting in the Department of Health the involvement was extended to include a wider range of stakeholders. This then led to the development of a network of provider organisations and a formal Learning Disabilities work stream of the National Product Review Group.

Once the Integrated allocation tool and extended set of purchase units had been developed, in the absence of any existing standard data sets there was a need to develop an agreed comprehensive data set. Once the clinical requirements for

analysis had been agreed, a series of meetings with informatics leads from participating organisations were held to develop and ensure a consistent approach to data collection. This clearly highlighted the need to establish a national data set to aid future work in this area. After the data set was finalised, data collection work began across volunteer provider Trusts. There was a need to balance inclusivity with progress. To ensure this, it was agreed that any organisation involved would contribute the required, established data set as well as a multi-disciplinary, multi stakeholder perspective.

Analysis stage one (statistical cluster analysis and CPPP LD subgroup workshop)

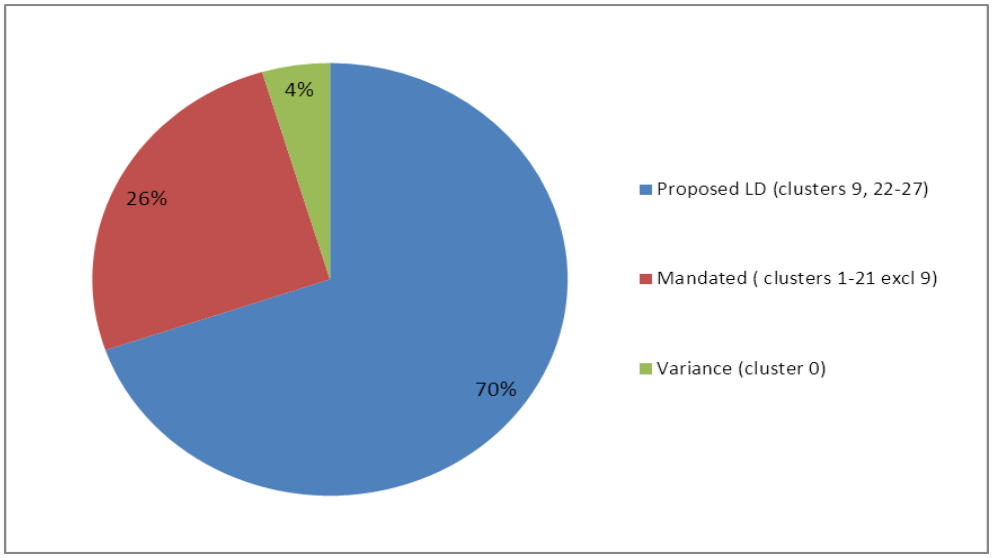
In total, 2825 cases were submitted for analysis across 18 Trusts (see Appendix 4 for list of Trusts). Table 1 summarises the demographic details for the cases that were submitted. This outlines the gender of cases, the setting that they were drawn from, whether they were new or existing patients (i.e. review) and which profession has undertaken the assessment.

Table 1: Gender, setting type, assessment type and assessment profession for cases submitted

Gender	Setting	Assessment Type	Profession
Male **53.6%**	Inpatient **3.8%**	New **63%**	Psychiatrist **14.2%**
Female **43.9%**	Community **83.4%**	Existing **29.8%**	Nurse **37.9%**
	Both **9.8%**		Occupational therapist **4.5%**
			Psychologist **8.1%**
Unknown **2.7 %**	Unknown **3%**	Unknown **7.2%**	Other staff **35.2%**

Figure 1 shows allocation of cases to purchase units. Approximately a quarter of cases were allocated to the mandated mental health purchase units (1-21). Two-thirds of cases were allocated to the preliminary learning disability units. A further breakdown of allocation to different units can be found within the Appendix 5.

Figure 1: Distribution of cases across the payment system



Statistical analysis was carried out by Professor R Hastings (Bangor University), this was intended to support clinical decision making by identifying statistically meaningful groupings as a starting point for detailed examination from a clinical perspective (a full report may be found in Appendix 6).

The data was initially cleansed to remove multiple assessments for the same person, when this was the case the first available assessment for that person was used and all others removed leaving 2221 cases. 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.

Within the analysis, there was an assumption that the health difficulties of adults with learning disabilities were likely to be similar to those experienced by the those people without a learning disability with variations in terms of degree or frequency. This is important because it clarified that the purpose of the analysis was to consider whether there were groups of need in addition to those already identified

for the general population (i.e. the mental health purchase units). As such, adults with learning disabilities whose profile of needs led clinical staff to allocate them clinically into one of the existing mental health purchase units 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 purchase units to the original Mental Health system for adults with dementia. The statistical cluster analysis, as in the research on the development of the Mental Health Tool, was intended only as a support to clinical decision making. The statistical groupings (clusters) suggested would be a starting point for examination in detail from a clinical perspective.

Statistical cluster analysis was carried out and visual analysis showed five cluster groupings as shown in Figure 2.

Figure 2: The resultant dendrogram from cluster analysis highlighting the five statistical groupings

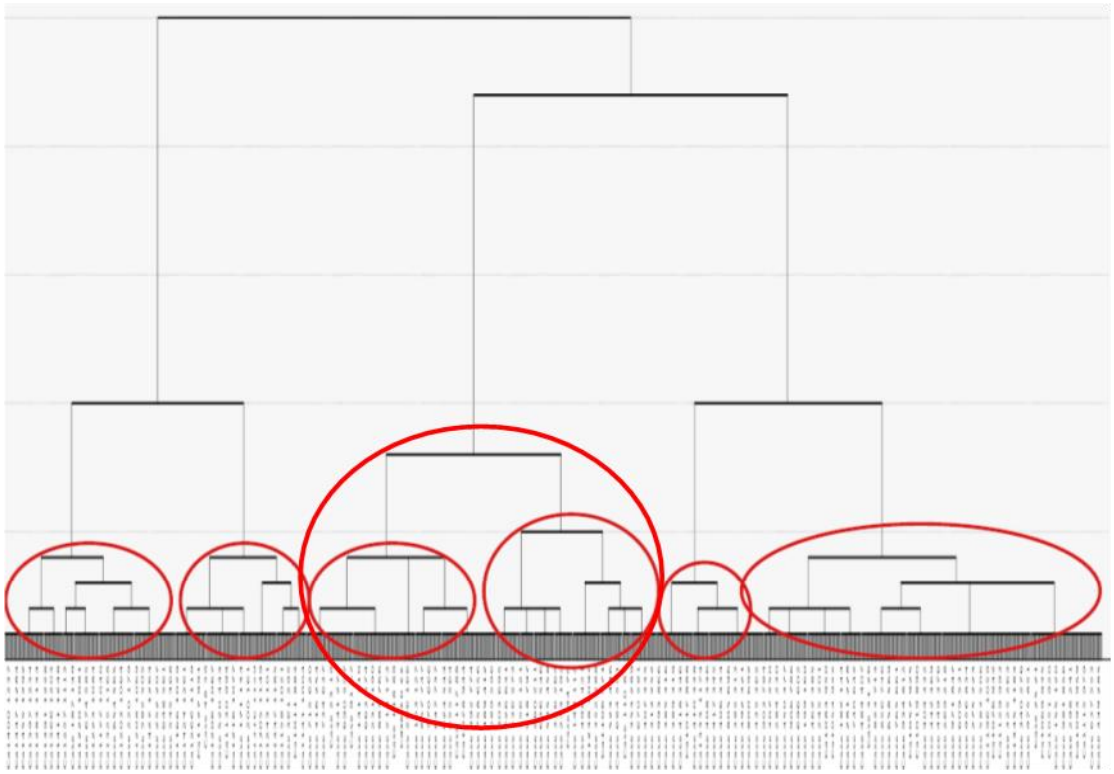


Table 2 below summarises the five groups identified (labeled A-E) from statistical cluster analysis, and the total number of cases clustered into each grouping. Also include in the table is a summary of the LD allocation tool items with relatively high or low scores within each group.

Table 2: Groups identified from statistical cluster analysis

Cluster number [size] and initial short description	Higher scoring items	Lower 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

The results of the cluster analysis were discussed within a clinical roundtable and there was agreement that there was some clinically validity but this needed to be explored further.

The analysis suggested the tool is a reasonable measure of overall health need. The five cluster / grouping solution, identified by cluster analysis had face validity, made sense clinically and produced groupings that were reasonably distinct from each other. However, further explanation was needed of additional variables and scoring profiles associated with these units before they could be described clinically.

Following the statistical analysis, the resulting groupings were examined from a clinical perspective. Scoring profiles (i.e. mean scores and percentage scoring on different items within the integrated tool – see Appendix 7) and demographic information (including diagnosis, presenting problem, professions involved in care) were collated for each of the groupings and shared with clinicians locally, regionally and nationally over a number of meetings and workshops.

The first workshop to explore this was a workshop held for clinicians from Trusts represented within the CPPP Learning Disabilities subgroup. The initial analysis was presented and information (scoring profiles & demographic data) for each grouping (A-E) generated by the statistical analysis was shared with clinicians (see Appendix 7 for full information). A number of tasks were then completed by the clinicians to further their understanding of the groupings and to identify what about the groupings made sense clinically and what seemed counter-intuitive. The tasks and the responses from clinicians to these four tasks are outlined within the Appendix 8. From the tasks, a number of salient clinical themes emerged within the groups that were used to enable a smaller group of clinicians to draft purchase units. However, some aspects remained unclear and needed further work (e.g. the clinically counterintuitive nature of Group E). There was broad agreement around the most clinically salient scales for each grouping (e.g., for Group B most people said that scale 5 relating to physical health problems was most important). However, there were some differences which may have been due to exactly how people interpreted the task (e.g., for Group A a number of people felt that item I relating to seizures was most important, but this may have been emphasising that the lack of seizures was important). People reported that most statistical groups needed sub-dividing into two or more units in order to have better clinical utility. Group B was found to be clearest in terms of rating how much clinical sense they made and this was followed by D. Groups A & C were rated fair but Group E was rated less well perhaps again due to the clinical counterintuitive content of this group.

During conversation throughout the day and on subsequent analysis of responses to tasks, there appeared to be some underlying dimensions to the groups emerging. In particular, there seemed to be a continuum of intensity of need as shown to some extent by differences in scores on MHLDCT items across the five groups. Within this, there were dimensions of cognitive impairment and risks posed

to self and others and these may be related to broader conceptual factors such as self-regulation and vulnerability. These dimensions and concepts were kept in mind in next steps where a small number of clinicians constructed a number of subdivisions on the basis of the themes and items highlighted from this first workshop.

As noted above, responses from the workshop suggested that subdivisions of the initial groupings should be made. Taking into account all feedback from the clinicians the groupings were split (details on these splits can be found in the Appendix 9) and scoring profiles and demographics were developed for the new subdivisions. These new subdivisions and descriptions were used as the basis for a subsequent national MDT workshop.

Analysis stage two (national MDT workshop and CPPP LD subgroup review)

As noted above, the newly subdivided groups were used to as the basis for discussion within a national DH-sponsored workshop that included representatives from the Trusts that submitted data to the pilot project. The initial statistical analysis was presented at this workshop and information (scoring profiles & demographic data) for each of the new, subdivided groups was shared with clinicians (see Appendix 10 for full information). A number of tasks were then completed by the clinicians to further their understanding of the groupings and to check the subdivided groups' validity. The tasks and the full responses from clinicians to these tasks are outlined in the Appendix 11. There were a range of responses to these tasks in relation to the validity and clinical meaningfulness of the subdivided groups. There was a lot of discussion around the different ways in which these groups might relate to clinical practice with a number of suggestions for changes. These responses were helpful in shaping up the groups into proposed purchase units.

Following input from clinicians nationally within the workshop, a further meeting was held with Professor R. Hastings. This was an opportunity to explore the scoring profiles and demographics of the new units particularly to check that they maintained their basis within the statistical analysis. Anomalies within the new units were highlighted through this process (e.g. there was significant overlap between certain subdivided groups; splitting group D did not create clinically distinct purchase units; group E was clinically counterintuitive). This meeting guided the next steps for

developing the purchase units with a plan to combine and subdivide groups further (see Appendix 12 for details)

On further exploration of Group E (see Appendix 13) it emerged that a significant amount of data from this came from a single Trust. This was explored through allocating cases to the other purchase units where possible. Those cases that were left were then explored and it was agreed with clinicians from within the Trust that a new unit should be developed from that group of cases.

In total, eight purchase units were proposed at this stage. It was decided that six of these were more related to risk to self and others (especially in terms of display of challenging behaviour) and there was some consensus that these best fitted into the non-psychosis super class of the current decision tree for the mandated MH payment system. The two physical health units were included under the Organic super class. The units were then renumbered in order to fit in with the decision tree. Scoring rules profiles were developed for each of these units. This was done by exploring the integrated tool scores for each unit and examining where the majority (approx. 75%) scores were located. 'Must score' scales were then decided by using information from the MDT workshops and subsequent discussion. Using these new scoring profiles, the final coverage of learning disability (as opposed to primary mental health) cases from the pilot project under these proposed learning disability purchase units was then 84.9% (i.e. 15.1% were not able to be allocated to one of these units). Once the scoring profiles and the location within the decision tree had been agreed, each unit was given an appropriate title and description (in the same format as the other mandated units – see separate document – Integrated MHLD Tool). An initial check on the validity of the proposed rating profiles for each unit was undertaken by undertaking a small audit of local cases (see Appendix 14). This was then used to make some minor changes to the unit descriptions but did not significantly alter the membership criteria for each unit. The Integrated MHLD allocation tool was updated and revised to take account of the clinical feedback gathered and statistical analysis. Most notably, the two communication scales were amalgamated to create a single historical communication scale (see New Integrated MHLD Tool) due to the similarity of scoring on the separate scales. A revised Additional Guidance document was also produced with changes to instructions on how to score different items relating to clients with learning disabilities (see Separate document).

The initial MDT workshop highlighted the potential underlying dimensions to the statistically generated groups. These dimensions were consolidated in the new units with variation in intensity of need, cognitive impairment and risk to self / others. The concepts of impairments in self-regulation and vulnerability also remained as a conceptual underpinning to the units. On completion of these changes, an initial clinical validation of the new proposed purchase units and allocation tool was conducted using a roundtable with representatives from Trusts within CPPP LD sub group.

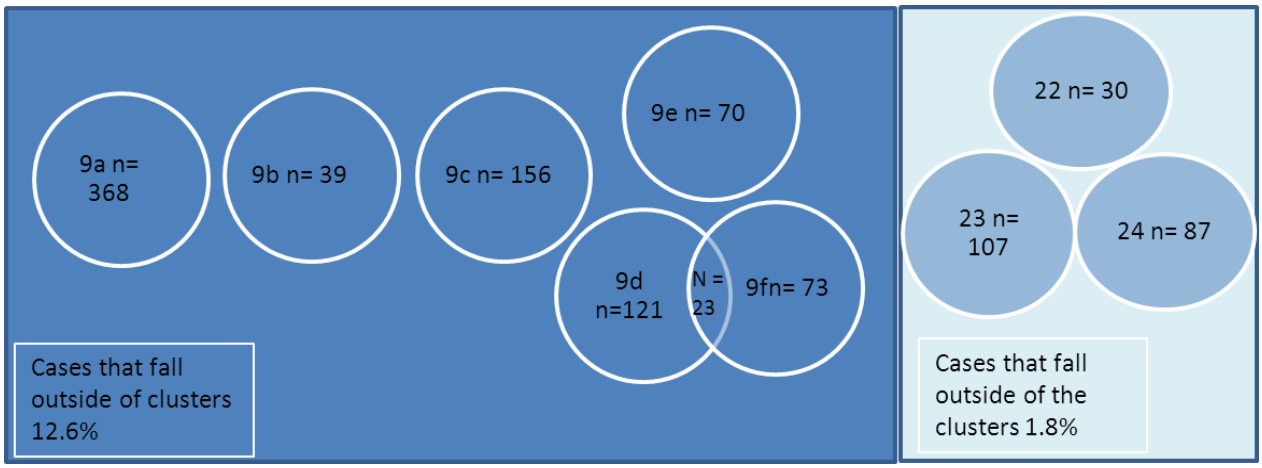
Roundtable discussion and initial purchase unit validation

This roundtable allowed an in depth discussion of the development of the payment system and work done so far. The focus was using the revised MHLD Tool and proposed purchase units to allocate clinician's current clinical cases. Clinicians were able to allocate 14 randomly selected cases using the new system (see Appendix 15 for results). There was a spread of allocation across the purchase units (including use of the mandated mental health units). There were also a number of positive responses to proposed system with clinicians who had attended previous workshops reporting that the new purchase units made greater clinically sense. Some minor revisions were also suggested at the roundtable which it was possible to accommodate. More significant was the generation of an additional physical health unit which improved coverage (see Appendix 16). Following changes as a result of the roundtable, the units were finalised with the titles as below.

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

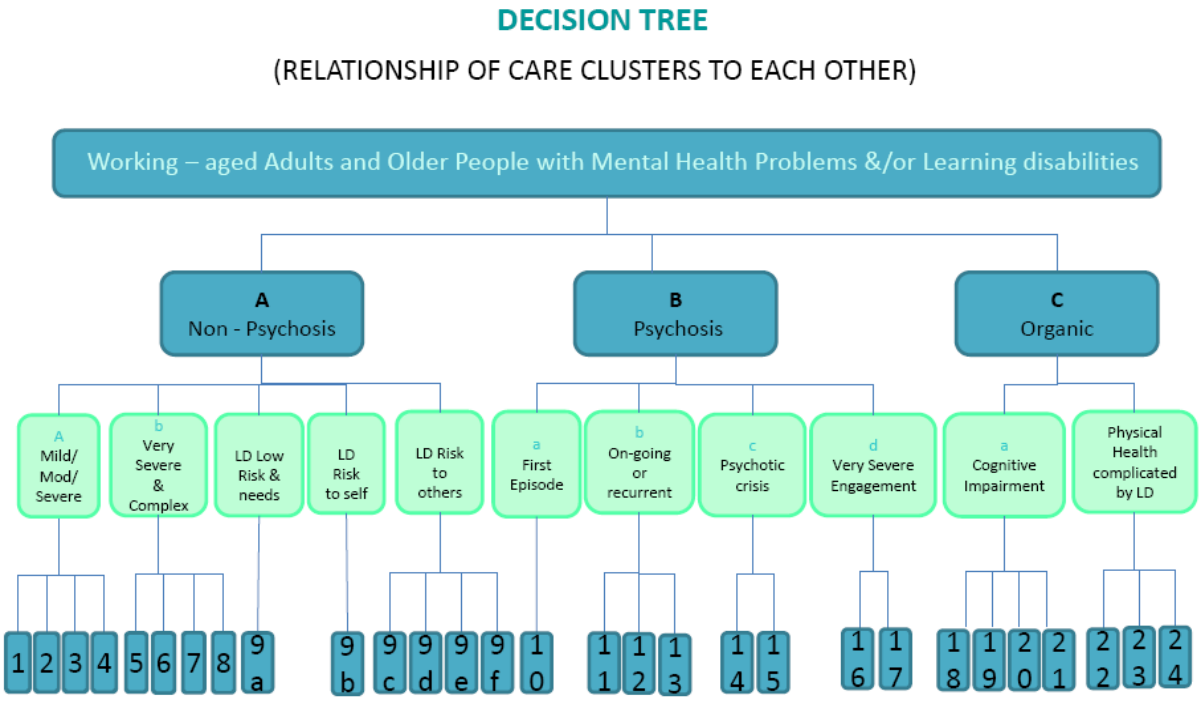
The coverage of the new units was subsequently rechecked and found to have increased slightly to 85.6%. The coverage of these units is shown in more detail in Figure 3 which shows the breakdown of numbers of cases included in each.

Figure 3: Venn diagram showing overall coverage of cases by proposed units.



The new units were also integrated into the mental health decision tree with the existing mental health set (see Figure 4). Six (9A-F) were incorporated into the non-psychosis superclass and the other three (22-24) under the organic superclass.

Figure 4: Decision tree showing relationship between units of purchase including new learning disabilities units



These units were then finalised within the revised Integrated MHLD booklet and a validity check (see below) was undertaken by the clinicians who had been previously trained and had submitted cases for the pilot project.

Analysis stage three (Review of proposed units of purchase by original pilot sites)

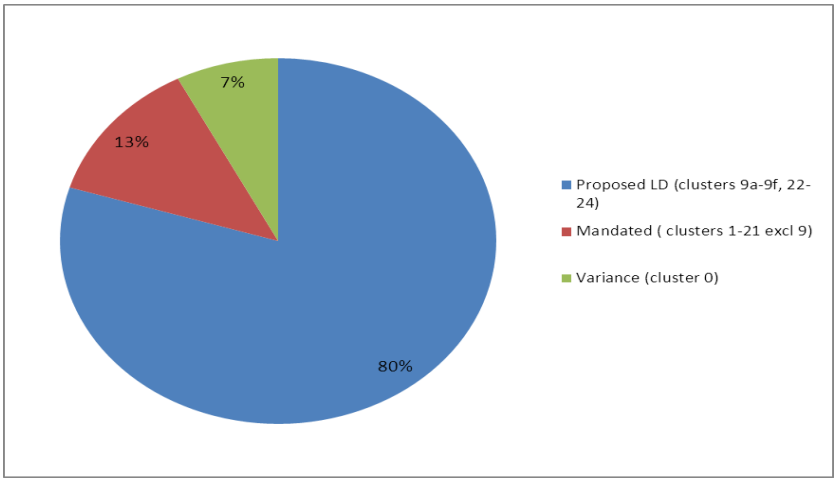
Following the final revision of the new proposed learning disability purchase units, the Trusts who were initially involved in the pilot were re-contacted. They were asked to use the proposed new system to re-allocate cases that had previously been rated using the tool (as well as other cases that had been allocated outside of submissions to the pilot project). A set of instructions and a spreadsheet were constructed to facilitate this (see Appendix 17). Clinicians were asked to use the MHLDCT to allocate service users to a purchase unit (including the mandated units) and rate how well that unit described the client's needs (from 1 to 5 – 5 being the best fit) Clinicians were also asked to make comments in relation to the allocated

unit regarding the language used in the unit title and other structured aspects of the unit description; likely diagnoses; unlikely diagnoses; impairment; risk; course; likely NICE guidance; and location of the units within the decision tree.

Requests for more general feedback on the new proposed units and their development was also sent out to other clinicians who had not submitted data for the pilot, but wished to contribute to the development process (see Appendix 18 for details).

In total, 829 cases were re-submitted by 11 of the 18 trusts involved in the initial pilot (see Appendix 18 for a list of Trusts). Figure 5 shows the distribution of cases across the new learning disabilities units, the mental health units and the variance unit (where another unit allocation was not possible).

Figure 5: Pies chart showing reallocation of cases to across learning disabilities and mental health units

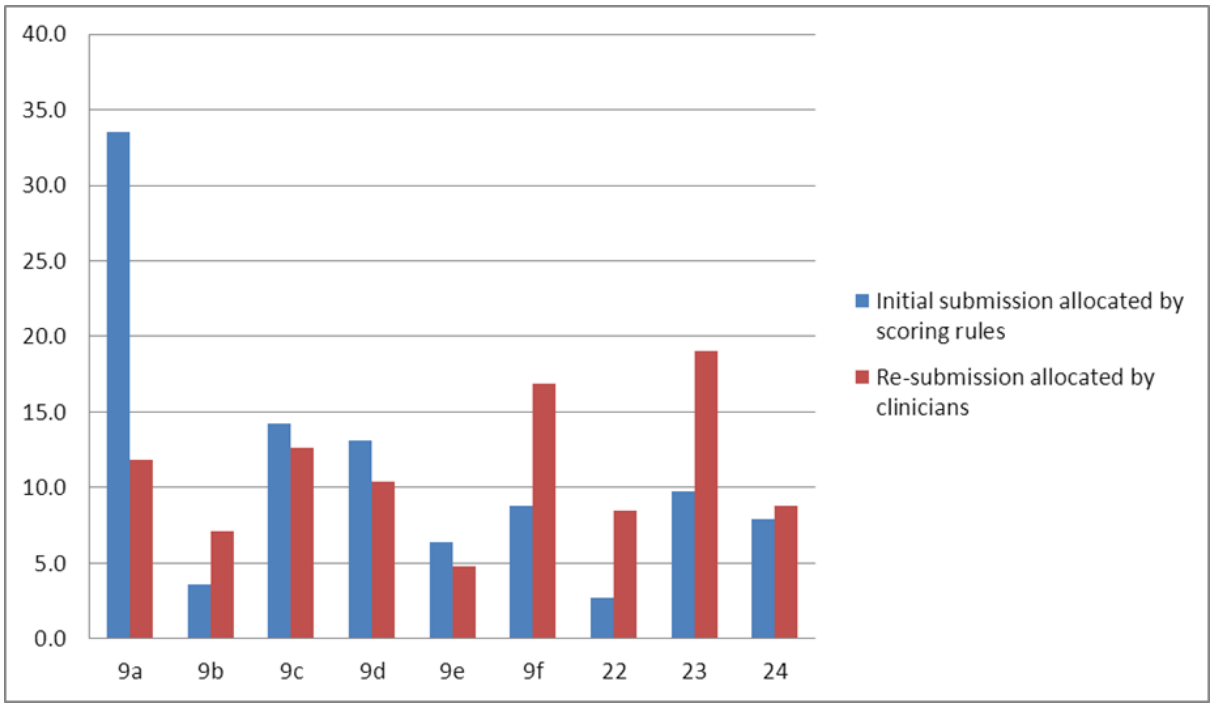


There was a shift in the proportions allocated to mental health and learning disabilities units from the initial data collection with more cases being allocated to the learning disabilities units. This may have been due to the new units providing a more comprehensive coverage of the needs of people with learning disabilities. However, it should be noted that there was no additional training provided in this reallocation task so this shift could be due to an over inclusive approach to using the new learning disabilities units. Nonetheless, there remained a significant proportion allocated to the mental health units and use of variance unit remained at a similar rate.

Clinicians rated the acceptability of reallocated units as a good fit with the relevant cases with a mean rating of 3.85 and modal rating of 4 (where 1=poor fit; 5=good fit). Appendix 18 shows this in more detail.

Figure 6 shows the percentage of cases (from those allocated to the learning disabilities units in the initial data collection) allocated to each of the new units. This is shown for cases that were submitted in the initial pilot and allocated to the proposed units based on rules for allocation and not clinical decisions (shown by blue bars) and those that have been re-submitted and allocated to the proposed units by clinicians (red bars). This showed a more even spread of allocation across the learning disabilities units by clinicians in the reallocation task.

Figure 6: Bar chart comparing proportion of units allocated by rules for allocation and clinical decisions



The analysis also included an exploration of the extent to which the clinician allocation matched with the scoring profiles within the Integrated MHLD Tool (see Appendix 18 for an example). There was a 53% match for those individuals allocated to the learning disabilities units and a 57% match for those allocated to the mental health units. This suggests that the learning disabilities units profiles function in a broadly similar way to the mental health units in terms of agreement between

scoring profiles and clinician allocation. As with the early mental health work this highlights the need for a more robust training process going forwards.

Clinicians' descriptive feedback on allocation process

Clinician responses to the pilot learning disability allocation process were sought throughout the process. An initial survey was completed which helped shape subsequent developments and the full report on this can be found in the Appendix 19. These clinicians were drawn from a variety of professions across different settings from a number of different NHS Trusts participating in the pilot data collection with the learning disability allocation process. Overall, clinicians felt that they had an understanding of the tool and the allocation process through using it to assess a number of clients and use the tool and units to allocate clients according to their needs. They also felt that the scales within the tool represented differentiation of needs which suggested that the tool had some face validity in terms potential to allocate according to need. At an early stage, clinicians also reported a number of themes around barriers, boosters and gaps within the tool and the wider allocation process. In particular, there were concerns that the tool was not able to fully capture the complexity of need of their client group. Table 3 below highlights some of the themes identified by clinicians. It also gives an account of how the development of the final set of units has addressed those themes.

Table 3: Gaps originally identified by clinicians and developments within new learning disabilities units to match these

Clinician feedback themes:	**Matching elements within learning disabilities units:**
General concern that complex multiple needs not fully captured	*Additional scales were developed in concordance with existing scales to capture the additional needs identified by clinicians.* *Broadening of complex needs across intensity of need within units*
Complexity related to broader mental health and risk related needs not captured	*Use of mandated units for people with learning disability. The development of forensic units in a separate work stream should capture offending behaviour.* *Risk features across unit sub-levels*
Developmental disabilities related complexity not covered	*Social Communication & Interaction difficulties are a key part of a number of units*
Range of physical health needs not captured	*Generic learning disability physical health units developed*
Need for more differentiation to capture the ranging severity of needs	*Continuum of severity developed across units*
Tool more specific to LD is needed Sensitivity/Specificity issues Better descriptions needed Uncertainties on how to rate impact of support	*Coverage improved and no other LD specific needs identified within MDT workshops.* *Profiles developed* *Additional Guidance document has been reviewed and clarified*
Service related issues Failing to reflect work done e.g. capacity and cognitive assessment and health access teams Consideration of multiagency working (e.g. joint services)	*Service related issues* The assessment tariff model could be used to consider broader aspects of work undertaken by learning disabilities services Wider engagement of stakeholders and consideration of casemix is required going

Burden of allocation on workload	forward.

Additional clinician feedback was gained at the unit reallocation stage. The feedback is summarised in Table 4 below which also notes sections of the unit development process relevant to these themes and where they may be considered in recommended next steps following this report.

Table 4: Clinician feedback following the unit reallocation process and ways in which these areas may have been addressed

Clinician feedback themes:	**How addressed within the unit development process:**
Units did not cover the whole range of interventions currently undertaken by staff.	*As noted above, 93% of cases are covered within the units so there may be a small number of interventions not directly covered.*
Further subdivisions to units could be beneficial (e.g. including an additional physical health unit that emphasised the impact of epilepsy/seizures).	*This had been considered but no other clear units emerged from the data.*
The scoring profiles did not always allow patients to fit into the most appropriate unit and the inclusion of autism spectrum disorder (ASD) in unit titles could lead to individuals without a formal ASD diagnosis being excluded.	*As noted earlier, the red rule adherence for the new learning disabilities units is similar to the mental health units suggesting that there is not a specific problem with the learning disabilities units' scoring profiles; however, comprehensive staff training in use of units alongside testing of functionality and casemix of units is an important part of next steps.*
Concerns raised about the integration of the units within the decision tree (e.g. concerns about the labelling system of 9A-9F and confusion this may cause alongside wider concerns about integrating the learning disabilities units within the broader mental health framework).	*The new learning disabilities units were integrated within the broader framework in order to avoid difficulties with recreating silo working and uncertain boundaries between services.*
Clinicians expressed concern about the problem focussed nature of the wording within some unit profiles.	*Further consultation with user/families to be part of next steps to consider this (e.g. develop a balance between technical accuracy and acceptability potentially through the user friendly/easy read versions of the unit descriptions).*
The new learning disabilities units were an	*This will be assessed further in testing functionality*

improvement from the initial data collection stage	*through the recommended next steps.*

Gathering of user & carer views

At an early stage in the process a series of workshops were held in order to consult with service users and their families / carers. The aim was to gain views on the nature of the allocation process and, in particular, the grouping of individuals according to similar needs. Inclusion North were commissioned to undertake the units and they facilitated by Scott Cunningham (Project Officer, Inclusion North). The following is a summary of their report (see Appendix 20 for full account). In order that the workshops could give the opportunity to have their say then the following was areas were focussed upon:

- Understanding the nature of the allocation process and how it works;
- Saying whether they thought there are any opportunities from the allocation process;
- Saying if there is anything people are worried about.

Four workshops were held (two in Middlesbrough; one in Sheffield; and one in Newcastle) which were aimed at people with learning disabilities with direct experience of specialist services including family members and carers of people with learning disabilities using specialist health services. Other people joined in the workshops including staff who worked in health, social care, commissioning and the voluntary sector. In total there were 24 people with learning disabilities; eight family members and family carers; 20 staff members.

The workshops started with an introduction to specialist learning disabilities healthcare services as some people did not know what specialist services were. This was useful as some people were using specialist services but did not know they were.

- What did people say?

There were similar key themes emerging across all the workshops.

Lots of the things that people said were ‘ideas’ about what the allocation process might look like or what it might do in the future. Some of the things people said were more about people ‘getting their head around’ what this really means and might not be how the allocation process works at all. These areas were included to help 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 outcomes of the workshops were compiled by Inclusion and themes that emerged were framed as questions. These questions could be split in to two broad areas. Firstly, questions about the ways in which the allocation process and payment system could help services for people with learning disabilities:

- Might this work in a similar way to self-directed support?
- Will this mean we can use the money in the best way?
- Can we use the allocation process to make sure we use the skills of staff in the best way possible?
- Could the allocation process help us plan and buy the right kinds of services for people?
- Will this help us work more closely with social care?
- Is this a chance to get what people really need?
- Could this show good ways of preventing people becoming unsafe or unwell?

Secondly, a set of questions also emerged which focussed more around worries about the nature and potential impact of the allocation process:

- Is the tool too big?
- Will the tool allow person centred care for people who have needs that fit in different boxes?
- Can the tool be more positive?
- What if staff don’t have the skills needed to do the allocation process well?
- Will everybody understand what is being talked about?

  - Does the allocation process need to work more with other people who plan and buy services (e.g. commissioners; social workers)?

Inclusion North thought that there were two main messages emerging from the workshops.

- Firstly, people thought that that is was important to have a balance between using the money in the best way whilst still treating people as citizens with a right to a good service.
- Secondly, that it was a good idea to be able to say how much it would cost to meet peoples' needs and that people should get access to good quality specialist health services if they need it.

It was felt that these messages endorsed that assessing and understanding need (through the allocation process) in determining allocation of resources for services for people with learning disabilities was important.

Conclusions

The development of a payment system in learning disabilities needs to support the implementation of national policy and guidance which takes account of the range of stakeholders involved (including service users, families / carers, local authority, multi-disciplinary clinicians). Within this, there are important principles, such as inclusion, integration and personalisation, to consider in order to deliver evidence based, individualised care in a fair and efficient manner whilst increasing use of local community services and reducing the need for out-of-area inpatient care. This is a complex and challenging context for the development of a payment system. Members of the CPPP Consortium believe that the concept of a payment system within the field of learning disabilities, though contentious, can support joint commissioning based on clinical need. This project set out to determine the viability of taking a similar approach to that adopted by mainstream mental health services particularly exploring whether existing needs-based purchase units could be extended to capture the needs of people with learning disabilities whilst also meeting the wider contextual needs described above.

This pilot project established that:

- It is possible to extend the scope of the mental health payment system through the addition of relevant scales to describe the needs of people accessing specialist health funded learning disabilities services.
- The additional new learning disabilities units have been informed by the same statistical techniques that were used to derive the mandated mental health units. The outcomes from these statistical techniques were then shaped by groups of clinicians from 18 organisations using a variety of workshop exercises, small group work and email feedback.
- In the data collection exercise the needs of a significant number of people accessing learning disabilities services could be captured with the mental health units. Of the remainder 85% were allocated to one of the additional

learning disabilities units (with 7% being allocated to the variance unit). This is in keeping with the original mental health development work.

- This project demonstrates the potential for a universal means of classifying service users with learning disabilities according to need which can then link to delivery of effective and efficient healthcare and meaningful outcome measurement. If used properly by commissioners together these initiatives could meet the demands of stakeholders in the wider learning disabilities context (e.g. inclusion, personalisation and the challenges set following the Winterbourne View abuse scandal). It would also direct effective, individualised interventions and care pathways.
- This also starts to better define spending on the healthcare component of care on the needs of people with learning disabilities. As noted earlier in this report, there is an overlap within these needs between health and social care and this work will help to describe the overall spend on people with learning disabilities, in particular how this spend could be better used to achieve personalisation.

Recommendations

The following recommendations are put forward from the project findings:

- For this report to be considered by Department of Health colleagues in the context of:
    - Extending the scope of the developing work of a payment system for healthcare to include services for people with learning disabilities.
    - Learning Disabilities Policy context (eg Transforming Care & Valuing People).
- Wider scale use and evaluation of the proposed learning disabilities purchase units in clinical practice as building blocks for development a payment system and that this be appropriately commissioned with supporting governance

arrangements (through NHS England, Monitor and Local Authority where appropriate).

- Explore how lead commissioning responsibilities within Local Authority can support the development of a common currency model for learning disabilities specialist health in order to facilitate joint commissioning.
- Explore how the learning disabilities units can form the basis of high quality, comparable packages of care monitored through a robust outcomes framework.
- An exploration of costing for the proposed new units.
- Longitudinal analysis and exploration of movement between the new learning disabilities units.
- Integration of the key data fields into the forthcoming Mental Health Learning Disabilities Data Set (MHLDDS) to support national flows of data for analysis.
- Further investigation of the differences in presentation and potential treatment packages delivered to patients allocated to the mandated mental health units.
- Wider consultation and engagement with key stakeholders e.g. Local Authority colleagues, service user and family/carer groups to understand:
    - How the approach might meet their needs and support the work they are trying to achieve.
    - Any implementation issues that may arise at the interface with care provision for the vast majority of people with Learning Disabilities who do not also have specialist healthcare needs.
- Further analysis of the overlap between scoring profiles of the existing mental health and proposed learning disabilities units
- Ensure a clear interface between learning disabilities units and emerging units for children and adolescents as well as forensic units.

- Explore how a payment system might fit with the wider spend on healthcare for people with learning disabilities (e.g. Continuing Healthcare Funding).
- Develop care packages that are directed by the new purchase units and test out ways in which these could integrate with personal social care budgets to develop individualised care that meets an individual's needs.

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Appendices

1. Additional items added to the MHT to form the integrated MHLD integrated allocation tool
2. Testing of the preliminary version of the MHLD 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 on the allocation process full report
20. Inclusion North service user & carer views full report