

## **Identifying needs-based groupings among people accessing intellectual disability services**

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# **Identifying needs-based groupings among people accessing intellectual disability services.**

## **Abstract**

There is increasing emphasis on needs-led service-provision for people with intellectual disability (ID). This study outlines the statistical cluster analysis of clinical data from 1692 individuals accessing UK secondary care ID services. Using objective needs assessment data from a newly developed ID assessment tool, six clusters were identified. These had clinical face validity and were validated using six concurrently (but independently) rated tools. In keeping with previous studies, the clusters varied in terms of overall level of need as well as specific clinical features (autism spectrum disorder, mental health problems, challenging behaviors and physical health conditions). More work is now needed to further develop these clusters and explore their utility for planning, commissioning and optimizing needs-led services.

## **Keywords**

Need, classification, cluster analysis, LDNAT

## Introduction

In the field of specialist intellectual disability (ID) services, there has been a great deal of rhetoric concerning a shift towards needs-led service provision (Schalock & Luckasson, 2013). However, the plurality of ways that people with ID present to secondary healthcare ID services is diverse and hence, to design, deliver and optimize needs-led services it is necessary to have a way to both conceptualize and to organize these needs. Whilst Bradshaw's (1972) taxonomy includes four types of need, our focus is normative need. Bradshaw describes normative needs as a professional's assessment/judgement against a notional standard which, at an individual level, Marosszeky, Rix, and Owen (2006) suggest is typically aided by standardized assessment tools. For the needs assessment tool utilized in the current research, that notional standard can be thought of as an individual with no discernible healthcare needs (see fuller description of the measure below). Classification is an instinctive human activity (Clatworthy, Buick, Hankins, Weinman, & Horne, 2005) and a fundamental scientific approach (Speece, 1994) which aids our understanding of the world. It involves the division/organisation of heterogeneous groups into subsets that are similar in some way. The American Association of Intellectual and Developmental Disabilities (AAIDD), for example, published their first attempt to categorize ID into various subsets in 1910 and, since then, these have gone through a number of iterations in line with the evolving knowledge-base. The latest international ID taxonomy (DSM-5: American Psychiatric Association, 2013) includes four ID diagnostic categories (mild, moderate, severe, and profound), however these levels are not empirically derived (Shogren et al., 2017). Consequently, in the same year that DSM-5 was published, the case was also being made for fundamental alterations to ID classification such as the combining of severe and profound diagnoses in children with ID (Tassé, Luckasson, & Nygren, 2013). This suggests that the classification of ID remains a work in progress.

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The ongoing development of thinking about a social construct like intellectual disability is clearly appropriate, but does create practical problems for people with ID, such as poor access to appropriate, evidence-based healthcare (Salvador-Carulla et al., 2011). Additionally, service providers may feel they are constantly responding to a 'moving target'. Thus, these conceptual developments do not merely pose theoretical difficulties for researchers, academics, and clinicians.

Despite a range of proposed improvements to the current ID diagnostic categories (Salvador-Carulla et al., 2011; Tassé et al., 2013), diagnoses alone are poor predictors of service response (Mason & Goddard, 2009; The Sainsbury Centre for Mental Health, 2004). Also, the process of diagnosis is unlikely to improve an individual's functioning without an accompanying holistic assessment of need to inform interventions (Salvador-Carulla et al., 2011; Snell et al., 2009). Consequently, research into alternative/more multi-dimensional, data-driven approaches to classifying ID and associated needs have been advocated (Salvador-Carulla et al., 2011; Vieta & Phillips, 2007). In this regard, the methodology of cluster analysis has much to offer as it can yield empirically derived groups that help conceptualize the complexities of secondary healthcare for people with ID (Clatworthy et al., 2005).

Cluster analysis is an umbrella term for a group of descriptive statistical techniques which seek to divide heterogeneous groups into more homogenous subsets (Speece, 1994). It can provide a way to identify multivariate groupings of individuals that are relatively similar (Speece, 1994) without the need for completely discrete categories. With the shift towards needs-led service provision for people with ID, the ability to categorize individuals into relatively homogenous groups according to their needs (rather than diagnosis) has obvious utility for those designing, refining, delivering and commissioning such services.

In the field of intellectual and developmental disabilities, the majority of published accounts of empirical categorizations via cluster analysis have concerned children with autism (ASD). Whilst these studies have merit, they are predicated on the validity of diagnoses which are unlikely to fully capture the profile of needs for an individual (Beglinger & Smith, 2001). That said, Beglinger and Smith's (2001) review of 16 earlier studies of children with ASD and differing levels of ID, did find a level of consistency in research findings. Participants tended to be grouped according to either: social interaction/behavior; intellectual/adaptive functioning; medical condition, or some combination of these. Three or four subtypes of children with autism were typically identified and these could usually be readily distinguished from those with other/no diagnoses. There was an emergent view that subtyping autism by intellectual impairment could explain the majority of variance in presentation, and that a dimensional (rather than categorical) conceptualization of autism was preferable.

More recently, Witwer and Lecavalier (2008) examined the validity of ASD subtypes and concluded that the distinction between Autism and Asperger's syndrome was not supported by the 22 studies of children (with differing levels of ID) that they reviewed. Witwer and Lecavalier did however agree with the conclusions of the Beglinger and Smith (2001) review in that categorizing groups by cognitive ability produced the most salient inter-group differences and the plurality of methods, terms and tools made comparisons between studies challenging. Since the Witwer and Lecavalier (2008) review, Bitsika, Sharpley, and Orapeleng (2008) developed a three autism-cluster solution from data on 53 children, again with intellectual impairment found to be an important dimension. Finally Ji, Capone, and Kaufmann (2011) identified 4 autism subtypes in individuals from birth-21, this time differentiated by nature and level of behavior problems.

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Beglinger and Smith (2001) suggested that, in addition to diagnostic challenges, the wide age range (and hence developmental stage) of child participants made comparisons between studies difficult. Soenen, Van Berckelaer-Onnes, and Scholte's (2009) 4-cluster solution mitigated these limitations to some degree by including a reasonably equal balance of children and adults as well as a wide range of diagnoses. However, the Soenen et al. study was a small scale pilot, limited to individuals assessed as having a mild cognitive impairment thus limiting the generalizability of the findings. In contrast, Shogren et al. (2017) have recently analyzed the support needs of over 2000 children (5-16yrs) with ASD and the full range of ID. Interestingly (given the different needs construct used) they also found 4 distinct clusters that varied both in terms of intensity and type of need.

Moving from ASD with a range of intellectual ability to focus exclusively on ID, Goldstein, Katz, Slomka, and Kelly (1993) derived three clusters from 102 sequential adult referrals for ID assessment/treatment (mean age 24.6 years). Referrals were all made for some form of employment support which, in conjunction with a mean IQ of 88 in the sample, again suggests relatively high functioning and a likely lack of generalizability. In contrast, Smith et al's. (1996) sample of 2202 adults (mean age 37.7) was drawn from a much broader spectrum of ID services but were, none-the-less, biased, this time towards severe and profound ID. Also, the Smith et al. (1996) cluster analysis was undertaken solely on ratings of behavior problems rather than the full spectrum of needs that people with ID experience, perhaps explaining why 54% of the sample fitted into one of their six clusters which exhibited very few behavior problems, autistic symptoms, and less severe intellectual impairment.

A similarly low needs or "quiet" group was identified by Crocker, Mercier, Allaire, and Roy (2007) whose statistical analysis of data from 296 adults (mean age 40.67) with mild-moderate ID detected 4 subtypes of aggression plus 34% of the sample who exhibited

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little/no aggression. Interestingly, whilst Crocker et al. presented information on the correlates of these aggressive behavior profiles, these data were not used to generate clusters, but rather to contextualize the results of the cluster analysis.

From this brief review of the literature it is clear that existing research supports the feasibility of empirically deriving homogenous groups from various samples of individuals with intellectual and developmental disabilities using a variety of dimensions. Prior to using cluster analysis, however, most researchers narrowed the range of participants (e.g., by diagnosis, IQ level) or the range of problems considered (e.g., focussing solely on aggression or other problem behavior(s)). Additionally, not all cluster analyses validated their models with independent data, as strongly advocated by Clatworthy, Buick, Hankins, Weinman and Horne (2005) .

Without such an empirically derived taxonomy, the development of Healthcare Related Groups (HRGs) and hence needs-led service provision for people with ID risks, at worst, being predicated on subjective judgement and, at best, on variable data-driven approaches. There are examples of countries or regions, including Australia, Canada, New Zealand and the Netherlands, where needs groupings inform service planning or provision (Mason & Goddard, 2009). However, as these groupings have not been derived empirically they tend to be subject to a disruptive annual cycle of refinement (Appleby, Harrieson, Hawkins, & Dixon, 2013). In the USA, a recent state by state survey of funding mechanisms for ID healthcare found a range of different needs assessment tools being utilized to inform resource allocation, including the Inventory for Client and Agency Planning (ICAP), the Developmental Disabilities Profile (DDP) and the Supports Intensity Scale. Most states had found it necessary to adapt, or augment these scales and almost half were so dissatisfied that they were planning to change tools completely (Engquist & Johnson, Courtland Johnson, 2012). Despite the reported difficulties with current needs assessments and their associated

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resource allocation groupings, we could find no existing study using cluster analysis to develop needs-based groupings of adults with ID across a wide spectrum of ability, and using a wide range of dimensions of normative needs.

Therefore, the main aim of the current study was to apply cluster analysis methods to identify normative needs-based groupings of adults with ID referred to ID services in the UK National Health Service (NHS) which, subject to replication, may be of use to those who commission services (strategically plan what services may be needed for a population), providers of services, and policy makers to inform future ID service provision at a local, regional, and national level. Although our focus was limited to adults, we assessed a wide range of needs to define our groupings.



## Method

### Participants

The normative needs of 1,692 individuals with ID were recorded by specialist ID professionals from a range of disciplines across six large, diverse and geographically disparate NHS healthcare provider organizations. 992 (54.5%) of these were male and their mean age was 41.7 years (range 18-90 years). Treatment setting information was available for 1,466 cases, of which 84 (5.7%) were being treated in specialist residential ID assessment and treatment units (ATUs) with the remainder being seen in the community. The ethnicity of 1631 individuals was recorded, 1540 (94.4%) of whom were White British. Accommodation status was recorded for 1170 (69.1%) of individuals. Of these, 231 (19.7%) were living independently in mainstream housing whilst 147 (12.6%) were living with family/friends. A further 491 (42.0%) were living in some form of supported accommodation (i.e. placements with varying levels of paid staff input). By virtue of acceptance into specialist ID services all individuals were deemed to have ID, however recording rates of ID diagnoses were generally low with just 595 (35.2%) receiving either a formal primary or secondary ID diagnosis. Of these diagnoses, 273 (45.8%) were for mild ID, 214 (36.0%) moderate, 78 (13.1%) severe and 30 (5.0%) profound. Individuals were referred into ID health services for a variety of primary reasons. Of the 696 cases where this information had been included in the dataset, the most frequent reasons for referral to health services were: 180 for challenging behavior; 110 for mental health problems; 67 for general vulnerability; 62 for ASD; 55 for mobility and posture, 34 for epilepsy; 30 for social emotional functioning issues; 26 for communication problems; 24 for offending behavior, and 23 for support in accessing mainstream primary care services.

## Measures

In addition to the collection of routine demographic and other relevant clinical information, all individuals' health and social needs were rated using the Learning Disability Needs Assessment Tool (LDNAT) (Painter, Trevithick, Hastings, Ingham, & Roy, 2016). Note that the UK terminology of “Learning Disability” in the LDNAT's title is synonymous with the term Intellectual Disability used throughout this article. The LDNAT is a brief, but holistic normative needs assessment tool developed from the Health of the Nation Outcome Scales (HoNOS) (Wing et al 1993) and the Mental Health Clustering Tool (MHCT) (Self et al, 2008). The LDNAT consists of twenty three 0-4 scales. Whilst each has scale-specific anchor point descriptors, they all adhere to a common underlying set of response options (i.e. 0 (no problem); 1 (minor problem requiring no action) through to 4 (severe problem)), to capture the severity of each specific need. In this regard the LDNAT, like DSM-5, treats need as the inverse of the individual's limitations (Shogren et al., 2017). These needs include the 12 original HoNOS scales which are primarily (but not exclusively) associated with mental health, together with additional scales developed by multi-disciplinary groups of specialist ID clinicians.

The final list of needs was then reviewed by a large (n=75) group of ID practitioners to confirm the extended tool captured the full range of needs they encountered on a daily basis (see table 1 for a list of these scales and Painter et al., 2016). Developed and validated on data from 1,692 adults with a broad range of conditions, the LDNAT was found to have good internal consistency (Cronbach's alpha = 0.80), excellent test-retest reliability (ICC=0.91) and, (on a subset of 160 cases), clinically and statistically meaningful correlations with a number of validated independent measures of normative needs. In addition to an overall severity total score, principal component analysis identified three LDNAT components which provide sub-scores for the severity of: developmental needs (comprising 8 scales),

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challenging behavior (CB) (comprising 8 scales), and mental health and wellbeing (comprising 7 scales) (see Table 1 and Painter et al., 2016).

### **Table 1 location**

A subset of individuals from 4 of the services were also rated with six additional assessment tools each focusing on one of six domains (emboldened below) that both match the range of normative needs captured in the LDNAT and the reasons for referral to health services typical in the UK (see earlier). Data from these measures on a sub-set of the sample provided the opportunity to undertake preliminary validation of the clusters derived solely from LDNAT data. Candidate measures were identified from a brief literature review. The final choice for each domain was made by a multidisciplinary group of ID practitioners, based on criteria including brevity, simplicity, psychometric quality, and cost. The first two of these criteria were deemed particularly important given the tools would be completed independently by informants who would receive no training. The final choices were: the Waisman Activities of Daily Living Scale (W-ADL) (Maenner et al., 2013) - to assess general ability/severity of disability; the Threshold Assessment Grid (TAG) (Slade, Powell, Rosen, & Strathdee, 2000) - to provide an overall risk rating; the Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist (PAS-ADD checklist) (Moss et al., 1998) - to rate the overall severity of mental health problems; the Behavior Problems Inventory for Individuals with Intellectual Disabilities-Short Form (BPI-S) (Mascitelli et al., 2015; Rojahn et al., 2012a, 2012b) - to rate challenging behaviors; the Social Communication Questionnaire (SCQ), (Rutter, Bailey, & Lord, 2003) - to rate the severity of ASD symptoms; and a bespoke physical health questionnaire created by the authors, based on the POMONA study (Haverman et al., 2011) which, although yet to be fully validated, yielded acceptable internal consistency results in the present sample (Cronbach alpha = 0.73).

## **Procedure**

Six NHS services in England used the LDNAT to rate the normative needs of their service recipients following routine assessment. Qualified healthcare professionals from a range of disciplines attended a one-day training event before cascading training to other front-line qualified staff in their own organizations using standard training materials. These included case studies which allowed trainers to compare ratings to the 'correct' scores to help ensure competence. LDNAT ratings were then recorded as part of these healthcare professionals' routine assessments of referrals accepted between July 2014 and August 2015. The participating NHS services from across England sourced the required data from their individual service recipient record systems before submission via a standardized, encrypted dataset to the lead NHS service for collation and central analysis. This naturalistic study of routinely collected clinical data received governance approval for the purposes of NHS service evaluation.

In the four services that considered the nature of their services users in more detail the LDNAT assessor for each routine referral to these services was also asked to identify an independent rater who knew the person with ID well enough to complete the six additional measures (for preliminary validation of the clusters). These referrers (typically General Practitioners, family members or caregivers) were telephoned and asked to provide this more detailed level of referral information. Those that agreed were sent the six questionnaires for completion within 2 weeks. This resulted in 160 cases which had six independently rated questionnaires to complement their LDNAT ratings. This convenience sample did not significantly differ from the full dataset in terms of their demographics other than including a higher proportion of individuals treated in specialist ID residential assessment and treatment units (ATUs) (21% vs. 5.7% in the main dataset). These additional independent ratings were then included in the electronic datasets of the four services submitted to aid preliminary

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validation of the clusters derived from the LDNAT data.

### **Statistical analysis**

All data were entered into SPSS version 22. The cleansing of these 2102 cases resulted in 36 cases being removed which were subsequent repeat assessments of an individual who had already been assessed, and 374 cases being removed where one or more LDNAT scale ratings was missing, or had been recorded as unknown. Therefore, hierarchical agglomerative cluster analysis was undertaken on the LDNAT ratings of the 1692 unique and sufficiently complete records (i.e. containing all 23 LDNAT scale ratings required for the cluster analysis).

The first step was the evaluation of a dendrogram showing squared Euclidean distances following cluster analysis using Ward's method. A range of cluster solutions were identified and subsequently examined using a series of k-means cluster analyses. K-means cluster analysis has the advantage of allowing some movement of cases between clusters whilst they are built to ensure groupings are generated which maximize within-cluster homogeneity and between-cluster heterogeneity.

For each candidate set of cluster solutions, data regarding a number of factors were reviewed by a small multi-disciplinary group of ID clinicians and academics. The cluster solution which, on balance, 'performed' most favorably across a range factors was then explored in more depth to better understand the nature of each identified group. From this, working titles were devised describing each cluster.

Analyses of variance (ANOVA) with post-hoc Tukey HSD tests were performed on LDNAT data (individual scales, components, and total scores) to explore variation between the clusters in the favored solution. A range of additional demographic and clinical data were also analyzed to highlight further cluster similarities/differences and hence resonance with

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the working titles. Finally, to validate the clusters, ANOVAs were performed on the scoring data from the 6 additional measures of normative needs that a subset of individuals had been rated with (see earlier).

## Results

### Initial generation of clusters

The dendrogram derived from Ward's method cluster analysis initially indicated that 4, 5, 6 and 7 cluster solutions were all potentially viable. Consequently, k-means cluster analysis solutions were produced for 4-7 clusters. The multi-disciplinary group of clinicians and academics reviewed each solution's 'performance' across a range of factors including: relative size of clusters; specificity of clusters versus parsimony in each solution; clinical face validity of clusters, based on relatively high and low scoring LDNAT scales (Figure 1). From this process the 6-cluster solution was favored and short working descriptions were produced for each grouping (see Table 2).

### Analysis of variance

For each cluster, the mean LDNAT scale scores were examined to confirm consistency with the working descriptions and to better understand the cluster differences. Primarily this was undertaken by considering the similarities, differences, general patterns and clinical implications of each cluster's scoring profile (as per Figure 1).

### **Figure 1 location**

One way ANOVAs with post hoc Tukey HSD tests were performed on the LDNAT subscales and total scoring data for the six clusters (Table 2). These analyses revealed that cluster E had consistently lower needs than the remaining clusters whilst cluster C had the highest total LDNAT score. The ranking of clusters (summarized in Table 2) varied somewhat, according to the subscale in question but continued to retain clinical face validity.

### **Table 2 location**

## **Associations with additional clinical and demographic variables**

The process of clinical 'sense checking' was continued with the introduction of a range of additional items from the data set (Table 3). Whilst completion rates varied notably, these data continued to support the emergent nature of, and relationship between the clusters. These data were presented descriptively purely to inform clinical understanding of the nature of each cluster grouping.

### **Table 3 location**

## **Cluster descriptions**

The results from the analyses thus far were synthesized to create a richer picture of the membership of each of the six clusters. These clinical characteristics are summarized below.

Cluster E, "low need requiring general support and monitoring" was the largest, constituting 27.9% of cases. It had the lowest proportion of males (48.7%) and of individuals treated in ATUs (0.0%) together with a high proportion of individuals with a diagnosis of mild ID (77.7%). The most common interventions being provided were physical health-related. Similarly, the most frequently prescribed medication was for physical health needs and the mean number of medications was 2.0. This cluster had the lowest LDNAT total score and subtotals. On average, 9 LDNAT individual scales scored significantly lower than the norm and there were no higher scoring scales. The clinicians' average ratings of normative needs were that there were 20 LDNAT scales with "no problems" and 3 with "minor problems that required no action".

Cluster F, "moderate need requiring sustained input" (18.3% of the sample) had more males (58.6%) and individuals in ATUs (4.0%) than cluster E. Most (79.3%) had a primary/secondary diagnosis of mild ID. 29.4% were receiving coping strategy enhancement



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interventions and 31.7% were primarily prescribed an antipsychotic. The mean total LDNAT score was the second lowest (20.1) and the mean LDNAT challenging behavior subtotal is notably higher than cluster E (9.1 vs 2.7). The majority of LDNAT individual scales mean scores were close to the sample norm whilst activities of daily living (ADL), and communication needs were less prominent. Only historical aggression and self-harm scored relatively highly. 15 of the average normative ratings were clinically rated as presenting "no problem", 6 as "minor problems but requiring no action" and just 2 rated as "mild but definitely present" (i.e. requiring low intensity, but focused intervention).

Cluster A, "moderate need requiring focused input including emphasis on ASD" comprised 19.4% of cases, making it the second largest grouping. It had one of the highest proportions of males (61.1%). 41.7% had a primary diagnosis of moderate ID and 16.9% had a co-morbid anxiety disorder. Over a quarter (27.4%) were primarily prescribed antipsychotics and 31.6% were receiving coping strategy enhancement interventions. The mean LDNAT total score was 23.0 (higher than clusters E and F but lower than B, C and D). The only outlying individual scale was 21 (social communication needs) which was relatively high compared to clusters E and F where it was relatively low. Here, on average 13 scales were rated by professionals as "no problem", 5 as a "minor, problem but requiring no action" and 5 as "mild but definitely present" (i.e. requiring low level, but focused intervention).

Cluster B, "high need requiring sustained and focused input with an emphasis on physical health" was one of three that were labeled as high need in some way. Containing 12.9% of the sample, half (50.2%) were male and just 3% were being treated in ATUs, it was also the oldest group (mean age 46.6 years). In total 36.8% were diagnosed as moderate/severe ID and 39.1% had a secondary ICD-10 diagnosis of G00-G99 (diseases of the nervous system). Almost half (48.7%) were primarily prescribed anticonvulsants and over a third (34.5%) a second medication for a physical health condition. On average, they

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were prescribed 4.6 different medications (higher than E, F and A, but similar to C and D). Their mean LDNAT total score is 23.0 (akin to cluster A) but the developmental needs subtotal was much higher whilst the challenging behavior total was markedly lower. LDNAT individual aggression scales were relatively low whilst others, including cognitive problems, communication problems, vulnerability and physical health problems (including those concerned with eating and drinking) were all significantly higher than the other clusters. Although on average 15 scales still rated as "no problem", 3 were deemed to be "minor problems, requiring no action" and 1 as "mild but definitely present"; importantly 4 were now termed as being "moderately problematic" (i.e. requiring a higher intensity of focused intervention).

Cluster C, "high need requiring sustained and focused intervention with an emphasis on challenging behaviors and ASD", with 10.5% of the sample was the smallest group. It was also the youngest (mean age 36.9 years) and, similar to cluster A, it contained a high proportion of males (61.2%). A third (32.5%) had a primary diagnosis of severe ID and 27.3% a secondary ICD-10 diagnosis of G00-G99 (diseases of the nervous system). On average, they were prescribed 4.91 different medications and, for 35.4% this was primarily an antipsychotic. The most common interventions were coping strategy enhancement and physical health-related (both 30.8%). This cluster had the highest mean LDNAT total score (37.4) and the second highest challenging behavior subscale score (13.8). The developmental needs subtotal was marginally lower than cluster B (19.4). No individual LDNAT scale scored significantly lower than the norm but 12 of the 23 scored relatively high. These included the cognitive impairment, relationships and ADL scales as well as historical aggression, engagement, vulnerability and social communication needs. In cluster C on average, 8 scales were clinically rated as "no problem", 6 as being "minor problems requiring

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no action". However, 3 scales presented "mild problems" and 6 were "moderately problematic" (i.e. requiring lower / higher intensities of focused intervention respectively).

Cluster D, "high need requiring sustained and focused interventions with emphasis on mental health", was again relatively small (10.9% of the sample), relatively young (mean age 37.9 years) and had a fairly even gender split (49.2% male). In total, 56.6% of the group had a primary or secondary diagnosis of mild ID and 27% were treated in ATUs (by far the highest proportion of the 6 clusters). Individuals in this cluster were prescribed more medications than any other (mean 5.07). In 30.7% of cases the primary drug's action was antipsychotic and in 22.2% of cases a secondary anti-depressant was included. This group had the second highest mean LDNAT total score (36.0) and by far the highest mental health and wellbeing component score (11.1). The mean challenging behavior component score was also the highest (14.7) though the difference between clusters D and C was less pronounced. As with cluster C, there were no unusually low scoring scales but a large number (13) of relatively high scoring scales, all of which were from the original mental health version of the LDNAT (Self et al., 2008). In this final cluster the mean normative ratings for 5 scales were "no problem", for 10 scales were "minor but requiring no action" and 8 were "mild" (i.e. requiring low level but focused interventions).

## **Preliminary cluster validation**

The mean scores for each of the independently-rated questionnaires were generated for all cases where these data were available (Table 4). These scores were compared across the six clusters using a series of one-way ANOVAs. These confirmed the clusters to be statistically different across nine of the 11 measures' total/subscales, together with a marginal group difference for BPI-S self-injury scores ( $p = .08$ ). There were no significant cluster differences overall for the PAS-ADD checklist scores. Finally, the post hoc Tukey HSD tests were reviewed to clarify how the clusters differed from one another when an overall

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difference between the clusters was apparent from the ANOVA. Upon review, this detailed statistical exploration again yielded results that had clinical face validity. The clusters were therefore deemed to be measurably different not only in the severity but also the nature of needs. These preliminary validation results are also summarized in Table 4.

### **Table 4 location**

## Discussion

Triggered by a pressing need for more cost-effective services, this study stemmed from a desire by specialist ID clinicians across a number of NHS healthcare provider organizations to better understand the type and level of demand for their services prior to planning service improvements.

There has been a marked shift towards needs-led services internationally. However, there is an ongoing state of flux surrounding the classification of people with ID and significant dissatisfaction with current approaches to Healthcare Related Groupings (HRGs)/needs-led resource allocation. Against this backdrop, the application of statistical cluster analysis techniques to data from a newly developed tool (the LDNAT) provided an exciting opportunity to explore and conceptualize the normative needs of a significant number of people accessing a diverse range of secondary care ID services across the UK. The fact that the LDNAT measures normative need rather than directly assessing support needs may seem counter-intuitive. However, two of the most popular measures used in the USA to inform resource allocation (the ICAP and the DDP) have a similar focus and, parallel work in the UK's mainstream mental health services (see Trevithick, Painter, & Keown, 2015) has found considerable utility from this approach. Additionally, our multi-site project would have almost certainly encountered the geographical variation in current service provision that may lead to distorted clinician-ratings of support needs (Acheson, 1978).

There are no definitive guidelines regarding the specific method of cluster analysis to employ in any given field of study, nor exactly how to apply them in any set of given circumstances (Speece, 1994). Cluster analysis will, by its very nature almost always produce groupings. However, these groupings will not always be meaningful/ valuable to the field of study. As a result caution must be exercised, with cluster analysis viewed as an

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exploratory technique, rather than an approach with which to ‘force’ an answer from the data (Clatworthy et al., 2005; Speece, 1994).

The clusters identified through this analysis had significantly different LDNAT total scores which logically increased in terms of overall intensity of normative need as follows: low - cluster E (minor needs requiring general support and monitoring); moderate - clusters A and F (requiring focused interventions with more or less emphasis on ASD respectively) and high - clusters B, D and C (requiring sustained, intensive interventions focusing on physical health/ mental health / challenging behaviors and ASD respectively). At a macro level, information about HRGs (i.e. groups of individuals with similar intensities of healthcare needs) provide the means to objectively compare case mixes and hence could be used by commissioners/strategic planners when distributing ID healthcare budgets across multiple providers. Additionally commissioners could more confidently make the case for redirecting funds into more tailored primary care interventions (e.g. coping skills enhancement), for the significant number of individuals with generally low needs (cluster E) currently receiving secondary ID services in the UK NHS.

At a more granular level, each of the three LDNAT subscales provided a slightly different ranking of need but the nature of these patterns of normative needs continued to resonate with clinical experience and correlated well with other assessment tools concurrently (but independently) rated. Cluster E, for example scored lowest on the LDNAT developmental needs subscale as well as being the lowest need group according to the WADL, the TAG needs and disabilities subscale and the SCQ. Logically, therefore, this cluster will require relatively little active involvement from professionals. Conversely, cluster C scored highest on these three tools as well as the BPI stereotyped behavior subscale suggesting a much higher level of support will be required. As the LDNAT developmental needs subscale included a number of physical health-related items, it was unsurprising that

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cluster B also ranking highly, as well as on the WADL and the bespoke physical health tool. For service providers, this highlights the need for integrated (physical and psychological) services.

Turning to the LDNAT challenging behaviors subscale, cluster E was again the lowest need, contrasted by clusters C and D which were the highest. This clinical 'picture' corresponded well with the BPI aggression subscale and the TAG total and subscale scores. Lastly, the LDNAT's mental health and wellbeing subscale logically placed cluster D as the highest need and cluster E as the lowest. Interestingly, there were no statistically significant differences between these clusters on the PASS-ADD checklist, none-the-less this again highlights the need for joined-up services (on this occasion ID and mental health). This richer picture, created by understanding the type, as well as the intensity of need could then be of value to service providers seeking to match supply with demand; developing services/service pathways to more efficiently and effectively meet the needs of their service users. It could also highlight the proportion of individuals accessing their services that exhibit challenging behavior, mental health problems and/or ASD. With UK clinical guidance for these problems now available (e.g. NICE, 2012, 2015, 2016), these data would allow staff training programmes to be developed, ensuring the knowledge and skills of ID staff match the type and level of demand for their services in NHS contexts.

At the most detailed, individual level (and if repeated periodically), the standardized assessment of need could be used by ID clinicians to gauge the success of their care/treatment plans as good outcomes would be indicated by reductions in objective need over time and, potentially, allocation to a less resource intense cluster. This could helpfully augment ID diagnoses which tend to be more static and have other known limitations in this field. Finally, moving from providers to the recipients of services, if resource utilization for each

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cluster showed sufficient homogeneity it would also be possible to create 'menus' of service entitlements that would provide more informed choices for people with ID.

The findings of this study add to the existing evidence base regarding ID subgroups as our project focused on adults rather than children and included a broader range of presenting needs than most previously published accounts of cluster analysis in the field of ID.

Additionally, as well as covering the full breadth of normative needs identified by a large multi-disciplinary group of specialist ID professionals, the LDNAT is quick and easy to use, meaning the required data could be realistically produced as part of routine practice rather than requiring 'gold standard' research conditions (an important consideration for service providers).

The characteristics of the six clusters generated by this project (derived from LDNAT and with preliminary validation by other measures) still resonated with previous research findings in that social interaction/behavior, intellectual/adaptive functioning and medical conditions (physical health and disability needs) were all found to be key dimensions. More specifically, severity of ASD differentiated between otherwise similar levels of overall need (e.g. clusters F and A) and this supported the findings of previous research (Beglinger & Smith, 2001). Conversely, ASD could be subdivided by intellectual impairment and/or level of challenging behavior (e.g. clusters F, A and C), again confirming previous research (e.g. Bitsika et al., 2008; Ji et al., 2011; Witwer & Lecavalier, 2008). Finally, cluster E (low need) accounted for 28% of the cases. This is lower than the 34-54% of 'quiet' cases found in previous studies who required a service none-the-less (Crocker et al., 2007; Smith et al., 1996) but is likely to be the result of the current study's participants' broader range of presenting need. Again, in the current economic climate, the identification of a sizeable proportion of people with low needs being treated in specialist ID services has significant implications for future service re-design.



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The size, diversity and naturalistic nature of this study make these findings noteworthy. Inevitably, however, some potential limitations need to be born in mind. For example, the delivery of the standard training materials may have varied between organizations; also staff will subsequently have had different levels of opportunity to use the tool, both leading to potential data quality issues. Additionally there were relatively low levels of data completeness for some contextual data items, and the proportion of individuals with ID being treated in ATUs varied between the whole sample and the subset with ratings for the six additional measures. All participants had been referred for support to adult NHS services, thus the cluster groupings may not apply to people with ID with primarily social care needs, to children and young people, and to adults with ID who rarely come into contact with services. Finally, although data were gathered from a diverse range of secondary care healthcare providers it is possible that our sample was not representative of all users of such services.

That said, the increasing emphasis on needs-led (and mainstream service provision, for people with ID in the UK at least), means these clusters (representing different severities and profiles of need) may have utility in the transformation of both mainstream mental health, and specialist ID services. Understanding service demand using this needs-led taxonomy could also have other tangible benefits for practice. As a result, this cluster analysis project now requires replication and extension to confirm these groupings and understand more about the typical services received by each cluster group (a recommendation also made by Shogren et al., 2017). From this it will be possible to more fully evaluate the utility of the groupings in helping to plan and deliver services for individuals with ID that are optimally responsive to their needs.

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**Table 1: LDNAT Scales and subscales.**

LDNAT Scale Titles		LDNAT subscale
1	Overactive, aggressive, disruptive or agitated behavior	Challenging behaviors
2	Non-accidental self-injury	Challenging behaviors
3	Problem drinking or drug taking	None
4	Cognitive problems	Developmental needs
5	Physical illness or disability problems	Developmental needs
6	Hallucinations or delusions	Mental health & wellbeing
7	Depressed mood	Mental health & wellbeing
8	Other mental and behavioral problems (Choose from: A phobic; B anxiety; C obsessive-compulsive; D mental strain/tension; E dissociative; F somatoform; G eating; H sleep; I sexual; J other).	Challenging behaviors and Mental health & wellbeing
9	Relationships	Mental health & wellbeing
10	Activities of daily living (ADLs)	Developmental needs
11	Living conditions	Mental health & wellbeing
12	Occupation and activities	Mental health & wellbeing
13	Strong unreasonable beliefs	Mental health & wellbeing
14	Non-accidental self-injury (associated with cognitive impairment)	Challenging behaviors
15	Physical problems with eating and drinking	Developmental needs
16	Agitated behavior/expansive mood	Challenging behaviors
17	Repeat Self-Harm	Challenging behaviors
18	Safeguarding other children & vulnerable dependent adults	Challenging behaviors
19	Engagement	Challenging behaviors
20	Vulnerability	Developmental needs
21	Social communication difficulties	Developmental needs
22	Communication problems	Developmental needs
23	Seizures	Developmental needs



**Table 2: Cluster sizes, LDNAT characteristics and working titles.**

	Cluster						Statistically significant scoring differences between clusters based on one-way ANOVA and post-hoc Tukey HSD tests
	E	F	A	B	C	D	
<b>Cluster Working title</b>	Low need requiring general support and monitoring	Moderate need requiring sustained input	Moderate need requiring focused input including emphasis on ASD	High need requiring sustained and focused input with an emphasis on physical health	High need requiring sustained and focused intervention with an emphasis on challenging behaviors and ASD	High need requiring sustained and focused interventions with emphasis on mental health	
<b>Membership</b>	N=472 (27.9%)	N=309 (18.3%)	N=329 (19.4%)	N=219 (12.9%)	N=178 (10.5%)	N=185 (10.9%)	
<b>Mean LDNAT developmental needs component score (S.D.)</b>	6.7 (3.0)	7.6 (6.1)	12.1 (2.9)	20.2 (4.5)	19.4 (3.4)	11.8 (3.9)	E,F<A,D<B,C
<b>Mean LDNAT challenging behavior component score (S.D.)</b>	2.7 (2.2)	9.1 (3.1)	7.1 (2.7)	3.3 (2.9)	13.8 (4.3)	14.7 (4.3)	E<B<A<F<C<D
<b>Mean LDNAT mental health &amp; wellbeing component score (S.D.)</b>	2.5 (2.3)	3.9 (2.5)	5.2 (2.8)	27 (2.7)	5.9 (3.5)	11.01 (2.9)	E<B<F<A<C<D
<b>Mean LDNAT total score (S.D.)</b>	11.5 (4.6)	20.1 (4.9)	23.0 (4.3)	25.7 (6.5)	37.4 (7.0)	36.0 (7.4)	E<F<A<B<D<C

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<b>Relatively low needs*</b>	1,4,9,10, 16,19,20, 21,22	10,21,22		1,8,16			
<b>Relatively high needs*</b>		16,17	21	4,5,10, 15,20,2 2,23	1,4,8,9,10, 14,16,18,1 9,20,21,22	1,2,6,7,8,9,11, 12,13,16,17,18 ,19	
*(>1 S.D. from the mean)							

**Table 3: Cluster demographics, and association with clinical variables.**

Characteristic		Cluster					
Description	Recording rate for sample	E (n=472)	F (n=309)	A (n=329)	B (n=219)	C (n=178)	D (n=185)
Cluster Working title	N/A	Low need requiring general support and monitoring	Moderate need requiring sustained input	Moderate need requiring focused input including emphasis on ASD	High need requiring sustained and focused input with an emphasis on physical health	High need requiring sustained and focused intervention with an emphasis on challenging behaviors and ASD	High need requiring sustained and focused interventions with emphasis on mental health
Mean age in years (S.D)	100%	44.0 (16.5)	42.0 (15.4)	39.8 (16.4)	46.6 (15.8)	36.9 (15.0)	37.9 (14.4)
% Males	100%	48.7%	58.6%	61.1%	50.2%	61.2%	49.2%
% ATUs	86.6%	0.0%	4.0%	2.9%	2.6%	12.1%	26.9%
Most common primary diagnosis (% of those recorded)	40.4%	Mild ID (44.4%)	Mild ID (48.4%)	Mod ID (41.7%)	Mod ID (18.4%) Severe ID (18.4%)	Severe ID (32.5%)	Mild ID (35.5%)
Most common secondary diagnosis (% of those recorded)	26.8%	Mild ID (33.3%)	Mild ID (30.9)	Anxiety (16.9)	Diseases of nervous 39.1%)	Diseases of nervous system (27.3%)	Mild ID (21.1%)
Most common primary medication type (% of those recorded)	36.1%	Physical health med (27.6%)	Antipsychotic (31.7%)	Antipsychotic (27.4%)	Anticonvulsant (48.7%)	Antipsychotic (35.4%)	Antipsychotic (30.7%)
Most common secondary medication type (% of those recorded)	31.3%	None (55.4%)	None (41.1%)	None (41.3%)	Physical health med (34.5%)	None (27.8%)	Antidepressant (22.2%) None (22.2%)
Mean total no of meds (S.D.)	31.2%	2.0 (2.5)	2.8 (2.9)	2.9 (3.3)	4.6 (3.3)	4.9 (4.4)	5.1 (4.4)

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Most frequent intervention	31.8%	Physical health (23.9%)	Coping strategies (29.4%)	Coping strategies (31.6%)	Physical health (43.7%)	Coping strategies (30.8%) physical health (30.8%)	Coping strategies (32.2%)
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**Table 4: Cluster scoring profiles for each of the six independently-rated questionnaires used for preliminary cluster validation.**

		Cluster						
		E	F	A	B	C	D	
<b>Cluster description/ Measure</b>		Low need requiring general support and monitoring	Moderate need requiring sustained input	Moderate need requiring focused input including emphasis on ASD	High need requiring sustained and focused input with an emphasis on physical health	High need requiring sustained and focused intervention with an emphasis on challenging behaviors and ASD	High need requiring sustained and focused interventions with emphasis on mental health	<b>Significant scoring differences between clusters based on one-way ANOVA and post-hoc Tukey HSD tests</b>
<b>WADL total</b>	Mean (S.D.)	20.6 (7.4)	24.8 (5.0)	17.9 (5.7)	9.2 (7.8)	11.3 (6.3)	21.0 (5.3)	B,C<,E,F,A,D
	n	21	28	26	12	26	25	
<b>Physical health tool total</b>	Mean (S.D.)	2.4 (2.4)	1.7 (1.5)	2.3 (1.9)	5.6 (2.4)	4.2 (2.7)	1.1 (1.5)	F,A,D<E,C<B
	n	11	15	20	10	19	14	
<b>PAS-ADD total</b>	Mean (S.D.)	4.0 (6.8)	4.8 (8.0)	4.9 (7.0)	3.7 (6.0)	4.4 (6.1)	3.3 (6.1)	None
	n	19	25	22	10	22	26	
<b>SCQ total</b>	Mean (S.D.)	11.3 (3.6)	13.4 (4.3)	15.6 (4.8)	16.0 (5.8)	17.9 (6.1)	15.3 (4.5)	E,F<A,C
	n	20	28	29	12	26	26	
<b>BPI SIB subscale total</b>	Mean (S.D.)	3.0 (12.1)	9.8 (29.1)	3.2 (4.9)	1.7 (3.8)	15.0 (19.0)	5.2 (8.6)	None
	n	20	24	27	10	22	25	
<b>BPI aggression subscale total</b>	Mean (S.D.)	6.1 (12.1)	5.6 (6.5)	10.2 (18.7)	4.9 (8.8)	35.3 (48.0)	22.2 (24.6)	E,F,A,B<C
	n	14	18	20	11	19	21	

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<b>BPI stereotyped subscale total</b>	Mean (S.D.)	2.2 (4.1)	6.2 (10.9)	10.1 (11.8)	6.4 (7.0)	20.4 (17.1)	8.1 (9.9)	E,F,A,B,D<C
	n	20	26	26	12	24	28	
<b>Mean TAG safety subscale total</b>	Mean (S.D.)	0.6 (0.7)	1.0 (1.5)	1.2 (1.3)	0.6 (1.0)	2.2 (1.7)	1.6 (1.5)	E,F,B<C
	n	21	28	30	12	26	27	
<b>TAG risk subscale total</b>	Mean (S.D.)	1.2 (1.0)	2.1 (1.7)	1.9 (1.6)	1.0 (1.3)	2.8 (1.7)	2.8 (1.6)	E,B<C,D
	n	20	28	29	12	27	27	
<b>TAG needs &amp; disabilities subscale total</b>	Mean (S.D.)	2.2 (1.8)	3.1 (2.1)	4.3 (2.2)	3.1 (2.9)	5.3 (3.0)	5.1 (2.3)	E,F<A,C,D
	n	22	28	30	11	25	27	
<b>TAG total</b>	Mean (S.D.)	4.0 (2.7)	6.3 (4.1)	7.4 (4.0)	4.8 (4.5)	10.7 (5.7)	9.6 (4.5)	E,F,B<C,D
	n	20	28	29	11	25	27	

**Figure 1: Example graphical comparison of mean LDNAT scoring profiles for clusters.**

