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Current practice and adaptations being made for people with autism admitted to in-patient psychiatric services across the UK

Jones, K

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Current practice and adaptations being made for autistic people admitted to inpatient psychiatric services across the UK

Keir Jones¹, Satheesh Gangadharan¹, Philip Brigham², Edward Smith³, Rohit Shankar^{2,4}.

¹ Leicestershire Partnership NHS Trust, Leicester, UK

² Cornwall Intellectual Disability Epilepsy Research (CIDER) Cornwall Partnership NHS Foundation Trust Truro UK

³ Autistica UK

⁴ University of Plymouth Medical School, Truro, UK

Corresponding author –

Professor Rohit Shankar MBE

Telephone-+44-1872221553

Fax: - +44-1872 240765

Email: Rohit.shankar@nhs.net

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Author Contributions

All substantially contributed to the design, analysis and interpretation of the work, drafting and revision of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

The data that support the findings of this study are available from the corresponding author upon reasonable request.

For Peer Review

Abstract:Background:

A significant number of autistic people require inpatient psychiatric care. Although the requirement to adequately meet autistic people's needs in these settings is enshrined in UK law and supported by national guidelines, little information is available on current practice.

Aims:

Describe characteristics of UK inpatient psychiatric settings admitting autistic people. Examine psychiatric units for their suitability, and resultant impact on admission length and restrictive interventions.

Method:

Multiple-choice questions about inpatient settings and their ability to meet autistic people's needs and impact on their outcomes were developed as a cross-sectional study co-designed with a national autism charity. The survey was distributed nationally using exponential and non-discriminatory snowballing technique to inpatient unit clinicians to provide a current practice snapshot.

Results:

Eighty responses were analysed after excluding duplications, from across the UK. Significant variation between units across all inquired parameters exists. Lack of autism related training and skills across staff groups was identified becoming disproportionate when comparing intellectual disability units with general mental health particularly psychiatrists of each of those specialties (94% vs. 6%). Lack of holistic clinical pathway and over-representation of autistic people in delayed discharge (28%) and segregation (40%) compared to non-autistic peers was noted.

Conclusions:

There is no systematic approach in supporting autistic people admitted to inpatient psychiatric units. Significant concerns are highlighted of lack of professional training and skillsets resulting in nebulous clinical practice and care delivery underpinned by policy deficiency. This could account for the pronounced inpatient outcomes of longer stay and segregation suffered by autistic people.

Introduction:

Available evidence points to a significantly greater prevalence of autistic spectrum disorders in people admitted to inpatient mental health services when compared to the general population (1,2). A National Autistic Society report indicated a seven percent increase in autistic people admitted to hospital in England between March 2015 and October 2018 (3). This was despite the NHS England 'Transforming Care' programme which aimed to reduce avoidable admissions in this group. Meeting the needs of this group is particularly important within the intellectual disability (ID) population, as between 20-30% of people with an intellectual disability are estimated to have co-morbid autism (4). Historically, autistic people are more likely to have been supported within an ID setting for behavioural and mental health concerns. This is now changing with the current political focus on their behavioural and emotional needs being met by "main streaming" i.e. requiring mainstream services to make reasonable adjustments to meet the needs of their autistic patient group (5). There is significant over-representation of mental health needs in autistic people (6,7). This is highlighted by experiences of suicidal ideation, considered up to nine times more common than in the general population (8). This population therefore is at a higher risk of psychiatric admissions, both voluntary and involuntary. The specific challenges for autistic people in terms of their communication and cognitive profile, particularly if associated with an ID, could lead to difficulties in diagnosis and treatment of their mental health needs (7). This has the potential to leave them vulnerable to longer admissions and at risk of institutionalisation. The requirement to adequately meet the needs of autistic people is enshrined in UK law and in the associated statutory guidance to health and social care organisations in England (9,10). This places a legal obligation on Local Authorities and NHS Trusts to provide adequate training, specialist services and reasonable adjustments for autistic people. However, while this has been outlined in theory in various good practice guidance (7,10) there is little real world evidence of implementation of these measures across the different inpatient psychiatric settings in the UK which receive autistic people.

Admission to an inpatient psychiatric facility can be extremely unsettling and frightening for anyone. Many aspects of an admission may prove more distressing and/or disorientating for autistic people (7). Possible challenges include the sudden environmental and sensory changes, increased and unfamiliar social and communication demands and significant change of routines (11). In addition to this, there is a potential lack of access to usual safe spaces and coping mechanisms particularly needed for an autistic individual.

These additional challenges may explain growing evidence of increased length of stay, increased rates of distress and agitation, increased use of restrictive interventions such as “Long Term Segregation” (LTS) and seclusions in autistic people with concurrent mental illnesses (12,13). A recent UK study from secure care suggested that autistic individuals experienced both a higher number of episodes and duration of LTS than non- autistic individuals (14). A Finnish study informed that autistic people were significantly more likely to experience restraint (OR 4.5, 95%CI 2.0–9.9) (15).

In the UK, people with known autism diagnosis presenting with mental health or behavioural concerns are admitted to specialised ID units although the role of local psychiatric units and other specialist facilities (forensic etc.) is increasing. However, there is little research on whether the needs specific to autistic people are being met irrespective of the setting.

Aims:

1. To explore the skills and adaptations current inpatient psychiatric services for people with ID have made to meet the needs of autistic people across the UK.
2. To explore inpatient clinicians’ views on current length of stay and use of restrictive interventions for autistic people in the UK based on their experience.

Method:

An online survey was developed in association with an UK autism charity between February and April 2020 and ran for four weeks in June / July 2020. The survey questionnaire can be found in supplementary information 1. The draft questionnaire was constructed by the authors based on a review of the literature. It was developed by peer consultation led by the authors. The survey was undertaken online using the google platform and set to approximately 5-10 minutes to complete. This was felt the optimum time to balance response engagement and gain the minimum required information to draw meaningful conclusions. The survey questionnaire had 16 questions that aimed to assess clinicians’ perceptions about and approach to, autistic individuals supported in psychiatric inpatient settings. The survey consisted of a mix of questions with predetermined answers, questions requiring the answer to be entered and questions that allowed for free text comments. We collected limited demographic details from the participants, though broadly, the survey was anonymous and all results anonymised. Box 1 provides the gist of the questionnaire themes.

Box 1: Principle Themes of Questionnaire

Demographics and area of work
Staff expertise
Assessments undertaken relating to autism
Adaptations, including environmental and communication tools
Use of long term segregation / seclusion
Care pathways
Other comments / feedback

It was circulated using an exponential and non-discriminatory snowballing technique, commencing with key personal contacts working in inpatient psychiatric settings. These contacts were then requested to forward the link within their own professional networks. The networks included consultant psychiatrists in ID/autism; higher specialty trainees in psychiatry of ID/autism; and ID/autism nursing networks. Other relevant networks such as forensic and general mental health were reached out to by personal contact of authors. This should be considered non-probability sampling, as it does not include complete coverage of services in the field and/or any particular sector. Analysis of data was performed using Microsoft Excel. Descriptive statistical analyses were carried out primarily to provide data on proportions using SPSS version 25 for windows. The survey had two sections. The first section looked primarily at collecting relevant demographic information and describing the availability of provisions in an area for people with ID/autism. The second section looked to ascertain the autism specific expertise, adaptations, processes and outcomes within that setting,

Ethics and participation consent

No ethical permission was required as this was a study to evaluate knowledge and attitudes as part of a service evaluation. Further, it was to a group of clinical practitioners where consent was implicit by participation. All participants were advised at the start of the study that participation was voluntary and their replies i.e.data would be anonymised and analysed. We also used the NHS Health research authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) which helped confirm that no ethics was needed for this project (supplementary information 2).

Results:

Overall, 90 responses were received from a varied geographical regions across the UK. On reviewing the data using the postcode provided, authors identified that there were multiple responses from the same postcode for some. Where there were multiple responses from the same postcode, response from the same postcode was counted only if it was for a different unit (an example is one response for assessment and treatment unit and another response for forensic unit). If there were multiple responses for the same unit, the response with most questions answered was chosen. Other same unit responses were used to examine the validity of principle responder. After eliminating duplication, we included 80 responses for further analyses.

Twenty-two responses were received from London and the South East England, eighteen responses from the North East England and Yorkshire, eight responses from the North West England, eight responses from the East of England, eight responses from the South West England and seven responses from the Midlands. There were also four responses from Wales and one from Scotland. Four responses could not be placed geographically but were otherwise valid responses and hence were included in the analysis. The clinicians responding were based in a variety of clinical settings (please see Table 1) with general adult mental health units being a quarter of respondents and ID specialist units being a fifth of respondents respectively. Although vast majority of responses were from the NHS (92.5%),

four responses came from independent sector hospitals and two from units with mixed funding. Of the respondents 58.9% stated that there was access to a specialist assessment and treatment unit for people with ID/autism in the area. Nearly half (46.6%) stated that there was access to assessment and treatment within general adult mental health inpatient units. Only 11% had block commissioning of private sector beds and 22% had arrangement for spot purchase of assessment and treatment beds as required for people with ID/autism. The proportion of autistic people being admitted to respondent units varied from less than 10% (27 units) to 50% or over (18 units). Over half of the units reported that their patient group included more than 10% autistic people. Assessment and treatment and forensic units specifically catering for people with an ID/autism generally reported higher proportions of autistic people amongst their cohort. Of these 23 units, 11 of them reported that over 50% of their patient group had an autism diagnosis. Staff team specialist knowledge, training or skills with regards to autism was inquired about and results are presented in table 2. Across the MDT, the proportion of clinicians with specialist skillsets in autism ranged 46% to 60%. A comparison of the spread of professionals with autism expertise across the two main inpatient settings revealed ID/autism units being much better equipped than general settings (please see table 3) with striking discrepancies in skill sets across the professions starkest in psychiatrists of each setting respectively (94% vs. 6%). The survey also looked at assessments in place for inpatient services to support autistic people in a person centred manner as per current good practice (please see table 4). Ninety percent of units reported offering autism assessment, and just over 80% specific assessments on individual's "likes and dislikes" and coping strategies respectively. Care plans tailored to the autistic individual's needs were supported by 71%. However, only two third units provided communication passports and just over 60% a bespoke sensory assessment. The presence of a standardised protocol for autistic people was available only in a fifth of the respondent units. The range of communication support provided for autistic people was explored. Of all units 63% provided visual signage or orientation tools, 76% were able to provide visual timetables, 74% were able to provide visual help / cue cards and 60% were able to provide social stories. In terms of specific adaptations beyond communication support, one of seven units (15%) reported being unable to provide any extra adaptations for autistic people. Table 5 enumerates other autism relevant provisions made available by the respondents. Other adaptations mentioned in the free text included ear defenders, weighted blankets, stress ball and relaxing music. The experiences and outcomes for autistic people in inpatient settings from the perspective of the clinicians working there were solicited. Three proxy measures, which may reflect the patient experiences or outcomes, were inquired into (table 6). Two thirds of units responding felt that people with a diagnosis of autism were more frequently subject to delayed discharge. Nearly a third (28%) felt that autistic people were more likely to be secluded in their stay and 40% reported episodes of long term segregation for autistic people in the past year.

Discussion:

To our knowledge, this is the first such systematic survey undertaken in the UK examining the characteristics of available support for autistic people in psychiatric units where they get admitted. Data has been collected directly from various professionals to assess realistically how autistic people are supported. The survey provides a reflection of real-life practice, gathering the experience of "shop floor"

clinicians that can help focus further work to improve the inpatient experiences and management of autistic people. The survey successfully manages to bring opinions from across the UK to understand the challenges facing this vulnerable population with regard to inpatient support and care. Though the survey was UK wide majority of responses were from England thus more representative of the English nation than of the three devolved nations. However, the responses across England were across all geographical regions and proportionately well represented.

Limitations -

Firstly, it is difficult to envisage if the participants' responses suitably capture quantity and indeed the quality of the units under observation, which is a methodological limitation of survey approach. However, there appears to be face validity in the responses when the small samples of duplicate responses emerging from the same units were looked and compared. This gives confidence in the study results. Secondly, it is possible that more of those who are engaged or interested in the support of autistic people have responded to the online survey than those who are not. This may have introduced bias in the data. Thirdly, some questions might be perceived as ambiguous and there may be some overlap between questions. Relying on retrospective reports and answers are likely to lead to approximations. A further challenge is that different regions had different fill rates. **This obviously lends itself to the survey gaining a big picture as opposed to being definitive in its conclusions. The survey method, of exponential and non-discriminatory snowballing technique commencing with key personal contacts and them forwarding the link within their own professional networks, means that we cannot establish a response rate. Nor explore the characteristics of non-responders.** In spite of the limitations the survey has captured critical knowledge and evidence hitherto unavailable in scientific literature. It is interesting to note that all responding units had engagement with autistic people but numbers varied. The heterogeneous approach to facilities for assessment and treatment for autistic people in different regions stands out with approximately half of the respondents suggesting access to specialised ID/autism units while the other half to main stream mental health units. There appears to also be a lack of proactive procurement bed policy for this vulnerable group with only a minority of reporting areas having pre-emptive commissioning arrangements. Given the diverse nature of needs autistic people present with it is concerning to see that across the UK there is a significant gap in professional competencies in providing person centred input with only 40-60% of professionals, (depending on specialism), having relevant skillsets in inpatient settings suitable for supporting autistic people. This gap in skills across professions appears to be further magnified when the focus is on general mental health units. Compellingly, thematic analysis of the associated comments to this question confirmed that the respondents had insight and awareness of this lack in skills and associated training. Particularly of concern is the significant skew in staff skills and training in supporting autistic people to ID/autism units (65%- 94%) compared to general mental health units (6%-35%). In particular, the difference between the ID psychiatrist skills for autistic people (94%) to the general inpatient psychiatrist (6%) is very worrying indeed. The gap in skills between the two settings suggests that autistic people are likely to encounter a postcode lottery to where, how and quality they get their mental health and behavioural needs met. Even in ID units the individual professional skillsets are heterogeneous which undoubtedly will affect care delivery. In a similar vein the assessments, processes and interventions specific to autistic people offered in the respondent units are mixed and diverse. Majority offer an autism assessment and most units offer a

range of autism specific interventions. There is a lack of consistency on what is on offer and likewise the evidence base for those offerings. Very few units told of full proactive care pathways for autistic people. This is major failing towards autistic people. A further concern is the small but significant minority of units unable to offer any autism specific adaptations. This further establishes that autistic people remain vulnerable to the vagaries of local commissioning. Given the above situation it is not surprising that autistic people are more likely to be delayed in discharge and more prone to segregation. This is a vicious circle as it further perpetuates institutionalization and increases community breakdown. It is imperative that issues such as delayed discharge and segregation be seen in continuum with the unit type, staff skill set and mix and available processes for supporting autistic people. This survey highlights multiple issues on clinical, training, policy and research matters.

Implications for the patient

Our co-author, representing a national charity, who helped design the study, shares his perspective in response to the results of this study.

Autistic people have the right to mental health care that meets their needs. These findings illustrate what many in the autism community suspected: that inpatient services lack clear guidance on how to best support autistic people in their care. To enable that guidance to be developed, the Government and NHS needs to direct resources towards closing fundamental gaps in the evidence base. These findings highlight just how little clarity there is on the effectiveness and safety of different approaches to providing inpatient care for autistic people. The initial insights from this study – on differences in environmental adaptations, staffing and intervention models – provide possible starting points for further exploration. Reliably testing which of those interventions and adaptations are effective, and under what circumstance, would help the NHS take a solid step towards developing evidenced clinical pathways from admission through to discharge.

Implications for clinical practice –

There is an urgent need to establish and incorporate an evidence based clinical pathway from admission to discharge for autistic people across all psychiatric settings which admit autistic people. The pathway needs to include all essential elements from a bio-psycho-social perspective to support the assessment and treatment of the emotional and behavioural needs of autistic people. Suitable workable and valid clinical outcome measures can help compare and improve clinical delivery.

Implications for training –

Focus has to be on ensuring the care of autistic people is led by a well-trained and informed staff team irrespective of their individual clinical discipline. Every unit open to admitting autistic people needs to meet high levels of formal training standards on autism care. A minimum standard training framework co-produced with service user would be an important step forward. Using experts by experience in training of staff would be novel, empathetic and deliver better outcomes. It is expected that there will be basic autism training and more skilled professional autism competencies. Recognition of a suitable blend of the two is

needed and implemented.

Implications for policy –

The current identified levels of ambiguity, heterogeneity and differential attainment of different units is very concerning. In addition the significant gap in support of autistic people between ID specialised units versus general units needs addressing through suitable policy measures. The improvements outlined for clinical practice and training need to be encapsulated into suitable policy initiatives. There needs to be an open dialogue on how to ensure proactive commissioning to facilitate seamless inpatient assessment and treatment to prevent distress and trauma when admissions are needed. **It is also important to explore how support for autistic people from health care, social care and voluntary sector in the community can be enhanced to minimise admission and facilitate early discharge. Joint commissioning that focuses on the timely and individualised support for autistic people may be a way of achieving this.**

Implications for research -

The lack of research has prevented the suitable quality evidence to generate for understanding best treatments and experiences of autistic people in inpatient settings. A larger national study proactively looking to capture clinical outcomes and the conjoined patient experience could lead to improved understanding and current issues and concerns.

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Table 1- Nature of Inpatient Unit

	Frequency	Percent	Valid Percent	Cumulative %
CAMHS	2	2.5	2.5	2.5
Forensic LD Unit	10	12.5	12.5	15
Forensic Unit non-LD	8	10	10	25
General Adult MH Unit	21	26.3	26.3	51.2
LD	17	21.3	21.3	72.5
Mental Health hospital	2	2.5	2.5	75
Mixed	12	15	15	90
Perinatal	2	2.5	2.5	92.5
Rehabilitation	3	3.8	3.8	96.3
Specialist Autism Unit	3	3.8	3.8	100
Total	80	100	100	

Table 2: Staff Expertise

Profession	Percentage with specialist skills related to autism
Psychiatrist	46%
Speech and Language Therapists	57%
Occupational Therapists	60%
Nurses	55%
Psychologist	58%

Table 3: Comparison of expertise between intellectual disability specific assessment and treatment units and general adult mental health units

Professionals with expertise in autism	ID units	General adult mental health units
Psychiatrists	94%	6%
Speech and Language therapists	88%	35%
Occupational Therapists	94%	18%
Nurses	65%	35%
Psychologists	82%	35%

Table 4: Additional assessments provided for autistic patients

Specific support for autistic people	Proportion of units providing this
Assessment of autism	90%
Care plans based on individual needs specific to people with ASD	71%
Sensory assessment	62%
Assessment of likes and dislikes	81%
Assessment of coping strategies	82%
Communication passports	66%
Specific protocol for admission, assessment and management of people with ASD	21%

Table 5: Additional provisions / adaptations provided for autistic people

Type of provision	Proportion of units providing this
Open access low stimulus area	52%
On request low stimulus area	42%
Scheduled access low stimulus area	15%
Lighting adaptations	23%
Ability to adapt meal plans to sensory requirements	51%
Noise adaptations	14%
Other adaptations	4%
No adaptations provided	15%

Table 6: Reported outcomes for autistic patients admitted to inpatient units.

Nature of outcome	Proportion of units with the outcome
Autistic patients likely to have discharge delays	66%
Autistic patients more likely or significantly more likely to be secluded during their inpatient stay	28%
Autistic patients subjected to long term segregation in the last 12 months	40%

For Peer Review

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Keir Jones¹, Satheesh Gangadharan¹, Philip Brigham², Edward Smith³, Rohit Shankar^{2,4}.

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³ Autistica UK

⁴ University of Plymouth Medical School, Truro, UK

Corresponding author –

Professor Rohit Shankar MBE

Telephone-+44-1872221553

Fax: - +44-1872 240765

Email: Rohit.shankar@nhs.net

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Author Contributions

All substantially contributed to the design, analysis and interpretation of the work, drafting and revision of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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There is no systematic approach in supporting autistic people admitted to inpatient psychiatric units. Significant concerns are highlighted of lack of professional training and skillsets resulting in nebulous clinical practice and care delivery underpinned by policy deficiency. This could account for the pronounced inpatient outcomes of longer stay and segregation suffered by autistic people.

Introduction:

Available evidence points to a significantly greater prevalence of autistic spectrum disorders in people admitted to inpatient mental health services when compared to the general population (1,2). A National Autistic Society report indicated a seven percent increase in autistic people admitted to hospital in England between March 2015 and October 2018 (3). This was despite the NHS England 'Transforming Care' programme which aimed to reduce avoidable admissions in this group. Meeting the needs of this group is particularly important within the intellectual disability (ID) population, as between 20-30% of people with an intellectual disability are estimated to have co-morbid autism (4). Historically, autistic people are more likely to have been supported within an ID setting for behavioural and mental health concerns. This is now changing with the current political focus on their behavioural and emotional needs being met by "main streaming" i.e. requiring mainstream services to make reasonable adjustments to meet the needs of their autistic patient group (5). There is significant over-representation of mental health needs in autistic people (6,7). This is highlighted by experiences of suicidal ideation, considered up to nine times more common than in the general population (8). This population therefore is at a higher risk of psychiatric admissions, both voluntary and involuntary. The specific challenges for autistic people in terms of their communication and cognitive profile, particularly if associated with an ID, could lead to difficulties in diagnosis and treatment of their mental health needs (7). This has the potential to leave them vulnerable to longer admissions and at risk of institutionalisation. The requirement to adequately meet the needs of autistic people is enshrined in UK law and in the associated statutory guidance to health and social care organisations in England (9,10). This places a legal obligation on Local Authorities and NHS Trusts to provide adequate training, specialist services and reasonable adjustments for autistic people. However, while this has been outlined in theory in various good practice guidance (7,10) there is little real world evidence of implementation of these measures across the different inpatient psychiatric settings in the UK which receive autistic people.

Admission to an inpatient psychiatric facility can be extremely unsettling and frightening for anyone. Many aspects of an admission may prove more distressing and/or disorientating for autistic people (7). Possible challenges include the sudden environmental and sensory changes, increased and unfamiliar social and communication demands and significant change of routines (11). In addition to this, there is a potential lack of access to usual safe spaces and coping mechanisms particularly needed for an autistic individual.

These additional challenges may explain growing evidence of increased length of stay, increased rates of distress and agitation, increased use of restrictive interventions such as “Long Term Segregation” (LTS) and seclusions in autistic people with concurrent mental illnesses (12,13). A recent UK study from secure care suggested that autistic individuals experienced both a higher number of episodes and duration of LTS than non- autistic individuals (14). A Finnish study informed that autistic people were significantly more likely to experience restraint (OR 4.5, 95%CI 2.0–9.9) (15).

In the UK, people with known autism diagnosis presenting with mental health or behavioural concerns are admitted to specialised ID units although the role of local psychiatric units and other specialist facilities (forensic etc.) is increasing. However, there is little research on whether the needs specific to autistic people are being met irrespective of the setting.

Aims:

1. To explore the skills and adaptations current inpatient psychiatric services for people with ID have made to meet the needs of autistic people across the UK.
2. To explore inpatient clinicians’ views on current length of stay and use of restrictive interventions for autistic people in the UK based on their experience.

Method:

An online survey was developed in association with an UK autism charity between February and April 2020 and ran for four weeks in June / July 2020. The survey questionnaire can be found in supplementary information 1. The draft questionnaire was constructed by the authors based on a review of the literature. It was developed by peer consultation led by the authors. The survey was undertaken online using the google platform and set to approximately 5-10 minutes to complete. This was felt the optimum time to balance response engagement and gain the minimum required information to draw meaningful conclusions. The survey questionnaire had 16 questions that aimed to assess clinicians’ perceptions about and approach to, autistic individuals supported in psychiatric inpatient settings. The survey consisted of a mix of questions with predetermined answers, questions requiring the answer to be entered and questions that allowed for free text comments. We collected limited demographic details from the participants, though broadly, the survey was anonymous and all results anonymised. Box 1 provides the gist of the questionnaire themes.

Box 1: Principle Themes of Questionnaire

Demographics and area of work
Staff expertise
Assessments undertaken relating to autism
Adaptations, including environmental and communication tools
Use of long term segregation / seclusion
Care pathways
Other comments / feedback

It was circulated using an exponential and non-discriminatory snowballing technique, commencing with key personal contacts working in inpatient psychiatric settings. These contacts were then requested to forward the link within their own professional networks. The networks included consultant psychiatrists in ID/autism; higher specialty trainees in psychiatry of ID/autism; and ID/autism nursing networks. Other relevant networks such as forensic and general mental health were reached out to by personal contact of authors. This should be considered non-probability sampling, as it does not include complete coverage of services in the field and/or any particular sector. Analysis of data was performed using Microsoft Excel. Descriptive statistical analyses were carried out primarily to provide data on proportions using SPSS version 25 for windows. The survey had two sections. The first section looked primarily at collecting relevant demographic information and describing the availability of provisions in an area for people with ID/autism. The second section looked to ascertain the autism specific expertise, adaptations, processes and outcomes within that setting,

Ethics and participation consent

No ethical permission was required as this was a study to evaluate knowledge and attitudes as part of a service evaluation. Further, it was to a group of clinical practitioners where consent was implicit by participation. All participants were advised at the start of the study that participation was voluntary and their replies i.e.data would be anonymised and analysed. We also used the NHS Health research authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) which helped confirm that no ethics was needed for this project (supplementary information 2).

Results:

Overall, 90 responses were received from a varied geographical regions across the UK. On reviewing the data using the postcode provided, authors identified that there were multiple responses from the same postcode for some. Where there were multiple responses from the same postcode, response from the same postcode was counted only if it was for a different unit (an example is one response for assessment and treatment unit and another response for forensic unit). If there were multiple responses for the same unit, the response with most questions answered was chosen. Other same unit responses were used to examine the validity of principle responder. After eliminating duplication, we included 80 responses for further analyses.

Twenty-two responses were received from London and the South East England, eighteen responses from the North East England and Yorkshire, eight responses from the North West England, eight responses from the East of England, eight responses from the South West England and seven responses from the Midlands. There were also four responses from Wales and one from Scotland. Four responses could not be placed geographically but were otherwise valid responses and hence were included in the analysis. The clinicians responding were based in a variety of clinical settings (please see Table 1) with general adult mental health units being a quarter of respondents and ID specialist units being a fifth of respondents respectively. Although vast majority of responses were from the NHS (92.5%),

four responses came from independent sector hospitals and two from units with mixed funding. Of the respondents 58.9% stated that there was access to a specialist assessment and treatment unit for people with ID/autism in the area. Nearly half (46.6%) stated that there was access to assessment and treatment within general adult mental health inpatient units. Only 11% had block commissioning of private sector beds and 22% had arrangement for spot purchase of assessment and treatment beds as required for people with ID/autism. The proportion of autistic people being admitted to respondent units varied from less than 10% (27 units) to 50% or over (18 units). Over half of the units reported that their patient group included more than 10% autistic people. Assessment and treatment and forensic units specifically catering for people with an ID/autism generally reported higher proportions of autistic people amongst their cohort. Of these 23 units, 11 of them reported that over 50% of their patient group had an autism diagnosis. Staff team specialist knowledge, training or skills with regards to autism was inquired about and results are presented in table 2. Across the MDT, the proportion of clinicians with specialist skillsets in autism ranged 46% to 60%. A comparison of the spread of professionals with autism expertise across the two main inpatient settings revealed ID/autism units being much better equipped than general settings (please see table 3) with striking discrepancies in skill sets across the professions starkest in psychiatrists of each setting respectively (94% vs. 6%). The survey also looked at assessments in place for inpatient services to support autistic people in a person centred manner as per current good practice (please see table 4). Ninety percent of units reported offering autism assessment, and just over 80% specific assessments on individual's "likes and dislikes" and coping strategies respectively. Care plans tailored to the autistic individual's needs were supported by 71%. However, only two third units provided communication passports and just over 60% a bespoke sensory assessment. The presence of a standardised protocol for autistic people was available only in a fifth of the respondent units. The range of communication support provided for autistic people was explored. Of all units 63% provided visual signage or orientation tools, 76% were able to provide visual timetables, 74% were able to provide visual help / cue cards and 60% were able to provide social stories. In terms of specific adaptations beyond communication support, one of seven units (15%) reported being unable to provide any extra adaptations for autistic people. Table 5 enumerates other autism relevant provisions made available by the respondents. Other adaptations mentioned in the free text included ear defenders, weighted blankets, stress ball and relaxing music. The experiences and outcomes for autistic people in inpatient settings from the perspective of the clinicians working there were solicited. Three proxy measures, which may reflect the patient experiences or outcomes, were inquired into (table 6). Two thirds of units responding felt that people with a diagnosis of autism were more frequently subject to delayed discharge. Nearly a third (28%) felt that autistic people were more likely to be secluded in their stay and 40% reported episodes of long term segregation for autistic people in the past year.

Discussion:

To our knowledge, this is the first such systematic survey undertaken in the UK examining the characteristics of available support for autistic people in psychiatric units where they get admitted. Data has been collected directly from various professionals to assess realistically how autistic people are supported. The survey provides a reflection of real-life practice, gathering the experience of "shop floor"

clinicians that can help focus further work to improve the inpatient experiences and management of autistic people. The survey successfully manages to bring opinions from across the UK to understand the challenges facing this vulnerable population with regard to inpatient support and care. Though the survey was UK wide majority of responses were from England thus more representative of the English nation than of the three devolved nations. However, the responses across England were across all geographical regions and proportionately well represented.

Limitations -

Firstly, it is difficult to envisage if the participants' responses suitably capture quantity and indeed the quality of the units under observation, which is a methodological limitation of survey approach. However, there appears to be face validity in the responses when the small samples of duplicate responses emerging from the same units were looked and compared. This gives confidence in the study results. Secondly, it is possible that more of those who are engaged or interested in the support of autistic people have responded to the online survey than those who are not. This may have introduced bias in the data. Thirdly, some questions might be perceived as ambiguous and there may be some overlap between questions. Relying on retrospective reports and answers are likely to lead to approximations. A further challenge is that different regions had different fill rates. This obviously lends itself to the survey gaining a big picture as opposed to being definitive in its conclusions. The survey method, of exponential and non-discriminatory snowballing technique commencing with key personal contacts and them forwarding the link within their own professional networks, means that we cannot establish a response rate. Nor explore the characteristics of non-responders. In spite of the limitations the survey has captured critical knowledge and evidence hitherto unavailable in scientific literature. It is interesting to note that all responding units had engagement with autistic people but numbers varied. The heterogeneous approach to facilities for assessment and treatment for autistic people in different regions stands out with approximately half of the respondents suggesting access to specialised ID/autism units while the other half to main stream mental health units. There appears to also be a lack of proactive procurement bed policy for this vulnerable group with only a minority of reporting areas having pre-emptive commissioning arrangements. Given the diverse nature of needs autistic people present with it is concerning to see that across the UK there is a significant gap in professional competencies in providing person centred input with only 40-60% of professionals, (depending on specialism), having relevant skillsets in inpatient settings suitable for supporting autistic people. This gap in skills across professions appears to be further magnified when the focus is on general mental health units. Compellingly, thematic analysis of the associated comments to this question confirmed that the respondents had insight and awareness of this lack in skills and associated training. Particularly of concern is the significant skew in staff skills and training in supporting autistic people to ID/autism units (65%- 94%) compared to general mental health units (6%-35%). In particular, the difference between the ID psychiatrist skills for autistic people (94%) to the general inpatient psychiatrist (6%) is very worrying indeed. The gap in skills between the two settings suggests that autistic people are likely to encounter a postcode lottery to where, how and quality they get their mental health and behavioural needs met. Even in ID units the individual professional skillsets are heterogeneous which undoubtedly will affect care delivery. In a similar vein the assessments, processes and interventions specific to autistic people offered in the respondent units are mixed and diverse. Majority offer an autism assessment and most units offer a

range of autism specific interventions. There is a lack of consistency on what is on offer and likewise the evidence base for those offerings. Very few units told of full proactive care pathways for autistic people. This is major failing towards autistic people. A further concern is the small but significant minority of units unable to offer any autism specific adaptations. This further establishes that autistic people remain vulnerable to the vagaries of local commissioning. Given the above situation it is not surprising that autistic people are more likely to be delayed in discharge and more prone to segregation. This is a vicious circle as it further perpetuates institutionalization and increases community breakdown. It is imperative that issues such as delayed discharge and segregation be seen in continuum with the unit type, staff skill set and mix and available processes for supporting autistic people. This survey highlights multiple issues on clinical, training, policy and research matters.

Implications for the patient

Our co-author, representing a national charity, who helped design the study, shares his perspective in response to the results of this study.

Autistic people have the right to mental health care that meets their needs. These findings illustrate what many in the autism community suspected: that inpatient services lack clear guidance on how to best support autistic people in their care. To enable that guidance to be developed, the Government and NHS needs to direct resources towards closing fundamental gaps in the evidence base. These findings highlight just how little clarity there is on the effectiveness and safety of different approaches to providing inpatient care for autistic people. The initial insights from this study – on differences in environmental adaptations, staffing and intervention models – provide possible starting points for further exploration. Reliably testing which of those interventions and adaptations are effective, and under what circumstance, would help the NHS take a solid step towards developing evidenced clinical pathways from admission through to discharge.

Implications for clinical practice –

There is an urgent need to establish and incorporate an evidence based clinical pathway from admission to discharge for autistic people across all psychiatric settings which admit autistic people. The pathway needs to include all essential elements from a bio-psycho-social perspective to support the assessment and treatment of the emotional and behavioural needs of autistic people. Suitable workable and valid clinical outcome measures can help compare and improve clinical delivery.

Implications for training –

Focus has to be on ensuring the care of autistic people is led by a well-trained and informed staff team irrespective of their individual clinical discipline. Every unit open to admitting autistic people needs to meet high levels of formal training standards on autism care. A minimum standard training framework co-produced with service user would be an important step forward. Using experts by experience in training of staff would be novel, empathetic and deliver better outcomes. It is expected that there will be basic autism training and more skilled professional autism competencies. Recognition of a suitable blend of the two is

needed and implemented.

Implications for policy –

The current identified levels of ambiguity, heterogeneity and differential attainment of different units is very concerning. In addition the significant gap in support of autistic people between ID specialised units versus general units needs addressing through suitable policy measures. The improvements outlined for clinical practice and training need to be encapsulated into suitable policy initiatives. There needs to be an open dialogue on how to ensure proactive commissioning to facilitate seamless inpatient assessment and treatment to prevent distress and trauma when admissions are needed. It is also important to explore how support for autistic people from health care, social care and voluntary sector in the community can be enhanced to minimise admission and facilitate early discharge. Joint commissioning that focuses on the timely and individualised support for autistic people may be a way of achieving this.

Implications for research -

The lack of research has prevented the suitable quality evidence to generate for understanding best treatments and experiences of autistic people in inpatient settings. A larger national study proactively looking to capture clinical outcomes and the conjoined patient experience could lead to improved understanding and current issues and concerns.

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Table 1- Nature of Inpatient Unit

	Frequency	Percent	Valid Percent	Cumulative %
CAMHS	2	2.5	2.5	2.5
Forensic LD Unit	10	12.5	12.5	15
Forensic Unit non-LD	8	10	10	25
General Adult MH Unit	21	26.3	26.3	51.2
LD	17	21.3	21.3	72.5
Mental Health hospital	2	2.5	2.5	75
Mixed	12	15	15	90
Perinatal	2	2.5	2.5	92.5
Rehabilitation	3	3.8	3.8	96.3
Specialist Autism Unit	3	3.8	3.8	100
Total	80	100	100	

Table 2: Staff Expertise

Profession	Percentage with specialist skills related to autism
Psychiatrist	46%
Speech and Language Therapists	57%
Occupational Therapists	60%
Nurses	55%
Psychologist	58%

Table 3: Comparison of expertise between intellectual disability specific assessment and treatment units and general adult mental health units

Professionals with expertise in autism	ID units	General adult mental health units
Psychiatrists	94%	6%
Speech and Language therapists	88%	35%
Occupational Therapists	94%	18%
Nurses	65%	35%
Psychologists	82%	35%

Table 4: Additional assessments provided for autistic patients

Specific support for autistic people	Proportion of units providing this
Assessment of autism	90%
Care plans based on individual needs specific to people with ASD	71%
Sensory assessment	62%
Assessment of likes and dislikes	81%
Assessment of coping strategies	82%
Communication passports	66%
Specific protocol for admission, assessment and management of people with ASD	21%

Table 5: Additional provisions / adaptations provided for autistic people

Type of provision	Proportion of units providing this
Open access low stimulus area	52%
On request low stimulus area	42%
Scheduled access low stimulus area	15%
Lighting adaptations	23%
Ability to adapt meal plans to sensory requirements	51%
Noise adaptations	14%
Other adaptations	4%
No adaptations provided	15%

Table 6: Reported outcomes for autistic patients admitted to inpatient units.

Nature of outcome	Proportion of units with the outcome
Autistic patients likely to have discharge delays	66%
Autistic patients more likely or significantly more likely to be secluded during their inpatient stay	28%
Autistic patients subjected to long term segregation in the last 12 months	40%

For Peer Review

For Peer Review

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