# Service Evaluation Project: Evaluating and addressing staff training needs in relation to autism in an older adult mental health service.

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## Abstract

Autistic adults are at higher risk of experiencing mental health problems and commonly describe poor service experiences relating to a lack of understanding of autism by clinicians. Therefore, there is an increasing impetus in the National Health Service (NHS) for staff to receive autism training. However, there is a lack of understanding around training needs for older adult mental health teams. This service evaluation project used audit and survey methodologies to explore the autism training needs of an older adult mental health team. Whilst the audit identified that the team did see patients suspected to be on the autism spectrum, most patients did not have an official diagnosis. Most clinicians reported never having received any training in autism, and highlighted autism in older adults, and autism and mental health, as specific training priorities. A training programme based on these responses was developed, implemented, and evaluated using surveys. The training was rated as useful by attendees and resulted in non-statistically significant increases in self-rated knowledge. The findings of this study suggest that clinicians working in older adult mental health may particularly benefit from training specialised to their older adult context. Further research is required to better understand the area of older adulthood and autism, and to evaluate how to effectively enhance the capability of staff working in this area.

## Introduction

Autism is a neurodevelopmental condition characterized by “persistent difficulties with social communication and social interaction”, and “restricted and repetitive patterns of behaviours, activities or interests” (American Psychiatric Association, 2013). It is estimated that around 0.8 per centof adults in the UK meet diagnostic criteria for autism (McManus et al., 2016). 80 per cent of autistic adults will experience at least one mental health condition across their lifetime (Lever & Geurts, 2016). Autistic adults also report high levels of unmet healthcare needs (particularly relating to mental health) and low levels of satisfaction with service provision (Nicolaidis et al., 2013; Tint & Weiss, 2018).

Significantly, there appears to be a link between these poor healthcare experiences, and low clinician knowledge and confidence in working with autistic people (Maddox et al., 2020). A UK-based inquiry into healthcare access for autistic people identified that this population find it difficult to access services and feel that healthcare professionals do not understand autism or associated needs, particularly in relation to the overlap between autism and mental health (The Westminster Commission on Autism, 2016).

In this context, NHS trusts increasingly mandate that staff must attend autism training. However, the skills necessary for working with autistic people vary across healthcare settings, and generic autism training may not sufficiently meet the needs of clinicians working in more specialized areas (Dillenburger et al., 2016). To date, the needs of staff working in older adult mental health services in relation to autism, and how best these needs can be addressed, are under-explored.

This is reflective of a wider lack of research on autism in older adulthood. Older adults with mental health problems may experience specific needs that require treatment adaptations, and the needs of autistic people within this population are not fully understood (Bennett, 2016; Hand et al., 2020; Laidlaw & Kishita, 2015; Michael, 2016). For example, historical changes in diagnostic criteria may mean that older adults who meet modern criteria for autism do not have an official diagnosis (Bennett, 2016). This may influence how behaviours and difficulties experienced by older adults on the autism spectrum are understood, including a potential risk of misdiagnosis. The absence of a diagnosis may also mean that specific needs associated with autism are not considered when providing care for older adults: for example, whether difficulty experiencing transitions influences how autistic people experience moving into care homes. Finally, autistic older adults may also experience differing physical and cognitive needs associated with aging, including a higher risk of certain physical conditions (Tse et al., 2021).

In this context, the aim of this service evaluation project was to assess staff training needs in relation to autism in an older adult community mental health team, to implement a bespoke staff training event, and to explore the efficacy of this staff training. The project explored staff training needs in the context of the following questions:

* Is providing training necessary: do the staff see patients on the autism spectrum, and have staff already received training?
* What would staff want to be included in a further training program? Are there older adult specific elements?

The project took place in the South Bucks Older Adult Mental Health Team within Oxford Health NHS Foundation Trust. This is a multidisciplinary team (MDT) which provides care for older adults (typically aged 65 years and above) experiencing mental health problems, and additionally encompasses a memory clinic service for adults experiencing cognitive problems. The project was carried out by a trainee clinical psychologist on placement in the service and supervised by a team psychologist.

## Stage One: Audit

### Methods

All stages of this study received approval from the Oxford Health Clinical Audit team. The first stage used an audit to explore how often the CMHT were seeing patients either with a recorded diagnosis of autism, or where the possibility of autism or autistic traits had been mentioned in their notes. The audit was performed in November 2021 and covered a five year period (28th October 2016- 28th October 2021).

### Results

Over this time 3185 patients were referred to the CMHT. Five of these patients (0.16 per cent) had an autism diagnosis. A further 36 patients (1.13 per cent) had an autism spectrum condition query recorded in their notes. Therefore, a total of 41 patients (1.29 per cent) over the past five years had either an autism diagnosis, or query autism raised in their notes. Demographic and referral data for the sample are summarised in Table One.

*Table One: Summary of demographic and referral data for the audit sample.*

|  |  |  |
| --- | --- | --- |
|  | Autism Spectrum Sample (*n*= 41; mean (*SD*)) | Non Queried Sample (*n*= 3,144; mean (*SD*)) |
| Age (years) | 76.41 (8.12) | 84.34 (9.45) |
| Gender | 27 (65.86 per cent) male14 (34.14 per cent) female | 1243 (39.53 per cent) male1900 (60.43 per cent) female1 (0.03 per cent) not recorded |
| Ethnicity | 18 (43.90 per cent) White British23 (56.10 per cent) not recorded/ unknown | 1137 (36.16 per cent) White British78 (2.48 per cent) Other White Background19 (0.60 per cent) Black/ Black British54 (1.72 per cent) Asian/ Asian British5 (0.20 per cent) Mixed Background11 (0.34 per cent) Other Ethnic Group1840 (58.52 per cent) not recorded/ unknown |
| Number of referrals over five year period | 1.73 (0.96) | 1.40 (0.7 per cent) |
| Referral Length (days) | 158.47 (139.62) | 121.89 (169.16) |

Table Two summarises the diagnoses recorded for the patients in the autism spectrum group.

*Table Two: Recorded diagnoses for diagnosed autism or query autism patients.*

|  |  |
| --- | --- |
|  | Autism Spectrum Sample Diagnoses (*n*= 41) |
| Autism | 5 (12.20 per cent) |
| Depression | 15 (36.59 per cent) |
| Psychotic condition (schizophrenia, schizoaffective disorder, psychotic symptoms, delusional disorder, paranoia) | 11 (26.83 per cent) |
| Memory disorders | 11 (26.83 per cent) |
| Anxiety | 5 (12.20 per cent) |
| Personality disorder | 5 (12.20 per cent) |
| Bipolar disorder | 1 (2.43 per cent) |
| Adjustment disorder | 1 (2.43 per cent) |
| Unspecified developmental disorder | 1 (2.43 per cent) |

## Stage Two: Needs Survey

### Methods

An online survey was used to evaluate whether staff subjectively reported seeing patients on the autism spectrum, whether they had previously received training, and what they would like to be included in a training programme (Appendix One). Clinicians were also asked to self-rate their knowledge of autism in general, autism in older adults, and treatment adaptations for autism, on a scale of 0 (no knowledge) to 100 (very knowledgeable). The survey was sent to 45 clinicians across the CMHT.

### Results

23 clinicians completed the survey (51 per cent response rate). On average clinicians had worked for the CMHT for 2.98 (*SD*= 4.70) years, and over that time self-reported seeing 2.18 (*SD*= 7.19) patients with diagnosed autism, and 9.04 (*SD*= 35.09) patients where they queried autism. Only one clinician (0.04 per cent) had previously received autism training. On average clinicians rated their knowledge of autism in older adults (*M*= 35.57, *SD*= 22.58) and treatment adaptations (*M*= 30.04, *SD*= 22.55) lower compared to their overall knowledge of autism (*M*= 52.43 (*SD*= 20.04).

Table Three summarises what staff wanted to see included in a training programme.

*Table Three: Staff requests for what they would want to be included in a training session on autism (participants were allowed to request multiple topics).*

|  |  |
| --- | --- |
| Topic | Frequency of requests |
| Autism in older adults | 20 |
| Autism and mental health | 17 |
| I think a patient might be on the spectrum but undiagnosed: what next?  | 14 |
| Treatment adaptations | 14 |
| Recognising autistic traits | 12 |
| Autism diagnostic process | 12 |
| Autism and communication | 11 |
| Autism and sensory processing | 11 |
| Overlaps between autism and other conditions | 10 |
| Basic introduction to autism | 9 |
| Working with families and carers | 9 |
| Autism and physical health | 8 |
| Autism and routine/ repetition | 8 |

## Stage Three: Training and Evaluation

### Methods

Invitations were sent to 19 clinicians. The training lasted an hour and was designed and delivered by EK. The content was based on a combination of the findings of the needs survey, and consultation from two autistic adults. The training covered the topics of introducing autism, autism in older adults, autism and mental health, and treatment adaptations. The section on autism in older adults included reflections on difficulties diagnosing autism in this population. Attendees were asked to self-rate their knowledge of these four areas pre and post training using an online survey (Appendix One). These ratings were compared using paired t-tests.

### Results

A total of 11 people attended the training (attendance rate 57.89 per cent). Eight people completed both pre and post questionnaires (response rate 72.73 per cent). Whilst mean knowledge scores increased post training, this did not reach a statistically significant threshold (Table Four).

*Table Four: Mean pre and post training knowledge ratings, and statistical comparisons.*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Pre-training (*n*= 8)Mean (Standard deviation) | Post-training (*n*= 8)Mean (Standard deviation) | T-test results |
| Knowledge of autism | 50.63 (17.82) | 59.38 (10.84) | *t*(7)= -1.62, *p*= 0.15, CI [-21.54, 4.04] |
| Knowledge of autistic traits in older adults | 41.25 (17.27) | 53.75 (20.66) | *t*(7)= -1.72, *p*= 0.13, CI [-29.66, 4.66] |
| Knowledge of mental health and autism | 38.75 (19.59) | 55.00 (12.25) | *t*(7)= -2.17, *p*= 0.06, CI [-33.95, 1.45] |
| Knowledge of adapting care for patients on the autism spectrum | 30 (18.52) | 51.25 (19.60) | *t*(7)= -1.97, *p*= 0.09, CI [-46.70, 4.20] |

## Discussion

Both the findings from the clinical audit, and the subjective reports of clinicians in the needs survey, suggest that this team see patients on the autism spectrum. However, very few patients identified in the audit had an official diagnosis. The finding that just 0.16 per cent of the CMHT patients over the past five years had an official autism diagnosis is far lower compared to the estimated 0.8 per cent prevalence rate in adults in the UK (McManus et al., 2016). This is consistent with previous speculation in the research literature that due to historical changes in the diagnostic criteria, and difficulties in diagnosing autism in adulthood due to the need for developmental information, older adults are less likely to be diagnosed as autistic (Bennett, 2016). The findings of this audit suggest that the prevalence of autism in older adulthood populations, and what proportion of these cases are undiagnosed, requires further research.

Furthermore, whilst an additional 1.13 per cent of patients had query autism recorded in their notes, the finding that a total of 1.29 per cent of patients in the CMHT presented with either confirmed or suspected autistic traits is again lower compared to estimates that 4.8 per cent of patients in adult mental health services in the UK meet criteria for autism (Brugha et al., 2020). It is possible that the low number of query autism cases could reflect a lack of clinician awareness of the possibility of autism in this population, or that due to the service context behaviour may be interpreted through a lens of mental health or memory problems, rather than neurodevelopmental differences (van Niekerk et al., 2011).The overlap between autism and mental health problems, including dual or differential diagnosis and implications for presentation, is an ongoing area of discussion in the research literature, but to date there is very little information on the overlap between autism and symptoms of memory problems (Lai et al., 2019; Shulman et al., 2020). Overall, the findings of the current study emphasise the need for further research on providing care and enhancing wellbeing in autistic older adults with mental health needs.

Finally, the findings of this study have implications for the provision of training programmes in this field. NHS policies and NICE guidelines clearly state that autistic people with mental health difficulties should be provided with adapted care by trained staff (Department of Health, 2015; NHS Improvement, 2018; NICE, 2016). This project identified that despite seeing patients on the autism spectrum, the team had not been offered these training opportunities. It should be noted that the provision of autism training is an ongoing area of development across the NHS, and shortly following this survey the NHS trust introduced mandatory autism training for clinicians. However, the findings of this project suggest that for clinicians working in more specialised areas, including older adult services, generic training may not fully meet their training needs (Dillenburger et al., 2016). In the needs survey clinicians rated their generic understanding of autism more highly compared to their knowledge of autism in older adults, and highlighted autism in older adults as their strongest training need.

A training programme specifically addressing the area of autism and older adulthood did result in an increase in self-rated knowledge of these areas for attendees (although not statistically significant), and the staff rated the training as useful. It is possible that the non-significance reflects the small sample size: whilst 19 people were invited to the training, just over half attended and not all attendees completed pre and post surveys. There was also a low response rate to qualitative survey questions exploring what was helpful about the training and what could be improved in future, which made it difficult to do a richer analysis around how staff experienced the training. The low attendance rate likely reflects high time pressure on the staff team and highlights that upskilling staff using training as an intervention may be of limited effect in teams where staff do not have sufficient time to attend and engage in sessions. Ensuring that clinicians receive ongoing adequate training in this area, as mandated by the NHS, balanced with service pressures is an ongoing area for discussion.

### Limitations

To date this is the first study exploring the prevalence of autism in older adults in a mental health setting. However, a significant limitation of the current study’s audit approach is that it relies on clinical notes, and therefore likely underestimates the true prevalence of autistic patients seen by the CMHT. This area could benefit from further research exploring what proportion of older adults in mental health teams meet criteria for autism using validated diagnostic tools.

Furthermore, the conclusions drawn around the efficacy of the training are speculative and require further empirical investigation. Firstly, the low sample size made it difficult to quantitatively evaluate whether training was successful in increasing staff capability. Secondly, it was not possible using the current design to evaluate where providing staff with training will result in long-term behavioural change and service improvements relating to the provision of care for autistic patients.

Thirdly, this paper has wondered if staff working in older adult teams could benefit from training specifically on older adulthood and autism, rather than generic autism training. This is speculative, and the most effective way of delivering autism training (for example, the outcomes of generic training compared to more specific training for different teams) requires further empirical investigation to understand the best way to increase staff capability in this area.

Finally, this project evaluated the implementation of a one-off training programme and did not assess whether this resulted in long-term improvements in knowledge. Whilst it raises several ideas in relation to what staff might find helpful from training that could be beneficial to the design of future interventions, there is a risk that the current intervention will not result in long-term team upskilling. As meeting the needs of autistic service users continues to be a priority within the NHS, further work is required to explore the best ways to increase staff capability over the long term.

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**Appendix 1: Survey Questions**

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| --- |
| *Table 1: Training needs Survey* |
| What is your role? |  |
| How long have you worked with this team (in years)? |  |
| How many clients have you seen whilst working with the OA CMHT who have a diagnosis of autism? |  |
| How many clients have you seen whilst working with the OA CMHT who did not have a diagnosis, but you thought might have autistic traits/ had a query autism raised? |  |
| Have you completed any autism training whilst working with the OA CMHT? |  |
| On a scale of 0 (no knowledge) -100 (very knowledgeable), where would you rate your knowledge of autism? |  |
| On a scale of 0-100 (no knowledge/ very knowledgable), where would you rate your knowledge of adapting standard care for patients on the autism spectrum? |  |
| On a scale of 0 (no knowledge) -100 (very knowledgeable), where would you rate your knowledge of autism in older adults? |  |
| What would you like to see included in a training session on autism in older adulthood? (You can circle/tick multiple options). | Basic introduction to autismAutism and communicationAutism and sensory processingAutism and routine/ repetitionRecognising autistic traitsI think a patient might be on the spectrum but undiagnosed: what next?Treatment adaptationsAutism and mental healthAutism and physical healthAutism in older adultsAutism diagnostic processOverlaps between autism and other conditionsWorking with families and carersOther: |

|  |
| --- |
| *Table 2: Pre/Post Training Surveys* |
| **Question** | **Asked pre training, post training, or both** |
| What is your job role?  | Both |
| How long have you worked with this team (in years)? | Both |
| On a scale of 0 (no knowledge)- 100 (very knowledgeable, where would you rate your knowledge of autism?  | Both |
| On a scale of 0 (no knowledge)- 100 (very knowledgeable, where would you rate your knowledge of autistic traits in older adults? | Both |
| On a scale of 0 (no knowledge)- 100 (very knowledgeable, where would you rate your knowledge of mental health and autism? | Both |
| On a scale of 0 (no knowledge)- 100 (very knowledgeable, where would you rate your knowledge of adapting standard care for patients on the autism spectrum?  | Both |
| How would you rate the usefulness of today’s training on a scale of 1 (not useful) to 10 (very useful)?  | Post only |
| What did you find helpful about today’s training?  | Post only |
| What could we do to improve today’s training?  | Post only |