BMA Patient Liaison Group Symposium 2022

Achieving respectful, person-centred inpatient care for young people with severe and enduring mental illness

On Wednesday 27 April 2022, the BMA Patient liaison group (PLG) held a symposium attended by 76 delegates to discuss the needs of young people seeking and receiving care in inpatient settings. See Appendix 1 for a list of organisations that attended the symposium and Appendix 2 for the full programme.

Content warning: This post discusses suicidal feelings. Please note that the following report contains references and personal stories of self-harm and suicide, eating disorders and severe and enduring mental health problems that some readers may find triggering.

Summary

Christine Douglass, PLG chair opened the PLG 2022 symposium by noting PLG’s role as an internal reference group providing an independent patient and public perspective across BMA activities on matters of interest to the medical profession and to patients. Health equity, co-production and equality and inclusion are values at the core of PLG’s work. One of this year’s key priority areas for the group has been promoting the health and wellbeing of children and young people. The PLG was very pleased to make this the subject of their 2022 symposium and was privileged to work closely with young people with lived experience of severe and enduring mental illness and autism in planning and delivering the event.

The COVID-19 pandemic is set against a historic lack of parity between physical and mental health, and between children’s and adult health, with rising incidence of mental illness in children and young people who have been facing increased stigma, discrimination and marginalisation and whose needs have not been met. The pandemic has further added to the decline in mental health and mental health service provision for children and young people. The PLG was delighted four activists and lived experienced speakers Charli Clement, Stuart Dodzo, ZeZe Sohowan and Cara Lisette joined the symposium to discuss their experiences and reflections on building patient centred inpatient care. Two NHS doctors, Professor Bernadka Dubicka, a consultant child and adolescent psychiatrist for Greater Manchester Mental Health Trust and Dr Bola Owolabi, a GP and director health inequalities at NHS England and NHS Improvement also provided presentations on the current state of Child and Adolescent Mental Health Services (CAMHS) services and the mental health workforce, as well as how the NHS was addressing health inequities that young people faced. In addition, five themed breakout group discussions were supported by external facilitators including MIND, YoungMinds, Healthy Teen Minds, the Institute for Mental Health at University of Birmingham and the PLG.

As organisers, PLG aimed to provide an open and safe space for these complex discussions. PLG recognised that some of the discussions may be triggering for the delegates, and for the first time at the BMA, a free and confidential telephone support was available and trialled throughout the day to
provide participants with emotional support should they need it. This service was very positively received.

The following report represents a summary of the discussions on the day, as well as sharing some of the delegates perspectives on how to achieve respectful, person-centred inpatient care for young people with severe and enduring mental illness.

**Delivering person-centred inpatient care for young people with severe and enduring mental illness**

Professor Bernadka Dubicka noted the stark statistics that show the declining current situation of children and young people’s mental health. In 2020 one in six children aged between five to sixteen had a probable mental disorder; young women aged 17 - 22 had the highest probable mental disorder\(^1\). Moreover, in 2020 NHS Digital data reported admissions of self harm doubled over 10 years. The impact of COVID has been marked; from April-October 2022 there were 77.5% more referrals than April-October 2019 and emergency referrals from October 2019 - Oct 21 saw a 44% increase\(^2\). Moreover, while demand and supply for services and care has increased in the past years, there continues to be a high vacancy for full time CAMHS psychiatrists and psychologists as well as other healthcare and support workers such as nurses and therapists.

Professor Dubicka noted recommendations for reducing unnecessary admissions including improving resources and quality standards. Participation with children and young people, increasing co-production and advocacy i.e. a multidisciplinary competence framework would improve children’s mental health and inpatient mental healthcare. Community and crisis services also have important parts to play. Professor Dubicka strongly recommended a focus on interventions to prevent young people going into crisis in the first place.

**Protecting the human rights and dignity of young people with enduring mental illness and autism in inpatient settings**

Chari Clement discussed human rights and dignity of young people with enduring mental illness and autism in inpatient settings from her experiences as a young autistic person and activist. She noted most inpatients were not educated in their human rights, including the right to be free from torture and inhumane and degrading treatment. Restraint should only be applied when absolutely necessary. Charli noted that violations of restraint can and have led to a few deaths. Moreover, inpatients had the right to a private family life, despite inpatients often having restricted time to call their families and their calls not always being conducted in privacy. Although some young people may need supervised phone calls, this was often a normal procedure which needed reviewing. During her stay as an inpatient, Charli talked at length to staff, and a continuation of these conversations after discharge would have enabled greater learning and improved patient journey. Often when a patient was discharged communication with the staff ceased, which Charli felt was a missed opportunity. As part of her talk, Charli recommended focusing on the values of community,


autonomy and wellbeing, as these could lead to improved experiences for young people as inpatients.

Reflecting on her experience as a young autistic person, Charli noted that CAMHS was not a suitable place where she could receive treatment, but there were no other services available. She described the significant impact the sensory environment can have on autistic people and that most wards were not set up to deal with this sensory impact. Urgent attention was needed to create appropriate sensory spaces in healthcare settings that focus on recovery.

Health inequities: severe and enduring mental illness

Dr Bola Owolabi provided a presentation on the health inequalities that young people face and explored good regional practice on how services were addressing that. The NHS was working towards improving and reducing inequities in healthcare by aiming to work with the communities and people it serves to advance equalities, deliver exceptional quality healthcare for all and achieve equitable access. Dr Owolabi noted the evidence to show that people who were most affected by the pandemic were already experiencing greater health inequalities and this included people with serious mental illness. Dr Owolabi also noted the work undertaken from a clinical perspective under Core20PLUS5, a national NHS England and NHS Improvement programme which defined key population groups and clinical focus areas for accelerated improvement in the reduction of health inequalities. ³The 2019 NHS Long Term Plan had also outlined why improvement in reducing health inequalities needed to be driven by mixed methods including a strength-based approach (identifying problems and building from strength), co-production (engaging with communities and co-designing, implementing measures with them), and a data driven approach. Dr Owolabi concluded that addressing social determinants of health across our systems and tackling disparities in healthcare provision was key to achieving this.

Building person centred inpatient care from lived experience

The experiential panel session explored priorities for building person centred inpatient care from lived experience. The panellists spoke very movingly and gave powerful insights into their inpatient care journey - the positive and the distressing practices they’ve experienced, as well as exploring ways in which care could be improved.

ZeZe recounted how she felt when first admitted to inpatient care: deliberated, trapped, confused. Being admitted to a psychiatric ward at the age of 14 and moving around eight units over a four-year period left her with systemic trauma. ZeZe stressed that a pivotal role in her recovery was when the health care workers moved away from focusing primarily on risk management to building relationships with her on a personal level. When the psychiatrist saw the person behind the illness and changed their communication style to a collaborative dialogue about de-escalating triggering situations, her care was transformed. Reflecting on her experience, to achieve respectful person-centred care, ZeZe stressed the importance of actively listening to patients to understand their experiences, collaborative two-way communication, and always involving patients in decision-making about their care.

Stuart’s experience of mental health started with a long-term physical illness which precipitated depression. This had a domino effect which resulted in him going back and forth between different services. It took a couple of years until Stuart’s diagnosis linked his physical and mental health. Stuart reflected on the difficulty of opening up to friends and family when coming from a background where mental health was not discussed openly. One of Stuart’s reflections and proposals to help reduce the stigma around mental health for young people was to create spaces where a patient’s family was brought in to discuss the issues openly. Stuart highlighted how mutual trust was central to achieving person centred care. In particular, how healthcare teams need to trust the patients to make informed decisions. Improved communication and coproducing expectations at the start of inpatient care should be seen as key factors in treatment plans.

Cara commented how young patients were often excluded from decision making processes e.g. care plans and important meetings with professionals. Recounting her experience in an inpatient setting for an eating disorder, she wasn’t asked for her viewpoint, and audit discussions about her life were taken without her being present or consulted. Cara noted how clinicians didn’t always know the young people they were treating. Sometimes a doctor might not have seen a patient for six months’ but they would still be the ones signing off big decisions. She described how knowing decisions were taken about you, without you was a scary feeling. As part of her talk, Cara questioned how joined up diagnosis and care was being provided and reflected on her experience when sometimes medical doctors don’t have enough experience of mental health and how eating disorders and physical health are intertwined. Cara stated young people become disconnected from the outside world while in hospital/ inpatient settings and school life becomes impacted as a result. Ultimately, Cara proposed that greater resources are needed for transitional services nationwide.

Delegates’ perspectives

Attendees discussed the following topics in the five breakout groups:

1. How to maintain person-centred care in extreme suicidal crisis in CAMHS inpatient settings
2. Co-designing with young people suicide prevention resources to facilitate help-seeking pathways
3. Improving transitions from CAMHS to adult mental health services
4. Co-production with young people at risk of marginalisation
5. Creating a space for recovery: How creating safe spaces can improve autism and mental healthcare

Key recommendations for achieving person-centred inpatient care

It is vital that we address the worsening mental health of children and young people and the workforce crisis in the NHS. The following recommendations were put forward by the symposium:

- Children and young people should be at the centre of all policy making, care and treatment decisions. This involves power sharing, authentic co-production and co-learning from the start. Core components include:
The promotion of human rights, dignity, and trust
Inclusive communication using accessible, non-judgemental and non-stigmatising language
Active listening to understand, not just to hear
Empowering young people to speak up
Co-producing clear expectations

Health equity focus
Intersectionality is key
Training in understanding diversity and inclusion
Diverse, representative healthcare teams
Improving access to and quality of care for marginalised groups

Greater emphasis on prevention and earlier access to care
Increased resources to support engagement with families, friends, and communities
Peer support - those with lived experience can offer support to those still in recovery and doing so can also aid their ongoing recovery

Improved focus on transitions in care
Young people need to be better informed and prepared before transitioning to adult services
Care must be needs based, not age based and flexible
More resources for CAMHS and AMHS staff to support transitions
Personal navigators
Better communication - greater collaboration and integration, listening to feedback from young people and service users

Continuity of care
Low retention of staff, using agency staff and the transition from paediatric to adult services needs to be addressed

Autism
60% of CAMHS inpatients are autistic and their discrete needs are often not catered for in inpatient settings
At a systems and individual level, the assessment and provision of services that cater for sensory needs is essential
Individual sensory needs must be assessed in inpatient settings and be designed around recovery, not for preventing ‘incidents’
- Staff trained in inclusive communication for autistic people and those with learning disabilities

The BMA Patient liaison group (PLG) would like to extend their gratitude to all those who took part in the symposium and helped to make it a successful and productive event, including all the speakers, third sector organisations and delegates.

Appendices 1 and 2 listing all the organisations who were represented at the symposium, and the agenda respectively follow.
Appendix 1

Attendees at the symposium represented the following organisations:

1. Association of Child and Adolescent Mental Health (ACAMH)
2. BMA Board of Science
3. BMA Co-chief Executive Officer
4. BMA Consultants Committee
5. BMA International Committee
6. BMA Junior Doctors Committee
7. BMA Medical Academic Staff Committee
8. BMA Medical Academic Staff Committee (MASC) Women in Academic Medicine Group
9. BMA Medical Students Committee
10. BMA Staff, Associate Specialists and Specialty Doctors Committee
11. British and Irish group for the study in Personality Disorder
12. Child and Adolescent Mental Health
13. Cornerstone
14. Great Ormond Street Hospital
15. Greater Manchester Mental Health Trust
16. Healthwatch
17. International Association for Youth Mental Health
18. Me First
19. Mind
20. Mirada Medical
21. National Children’s Bureau
22. NHS England
23. NHS Improvement
24. Patients Association
25. Pennine Care Foundation Trust
26. Point of Care Foundation
27. Royal College of Emergency Medicine
28. Royal College of Psychiatrists
29. South London and Maudsley NHS Foundation Trust
30. University of Birmingham
31. University of Lancaster
32. University of Manchester
33. University of Nottingham
34. Young Minds
Appendix 2

Patient Liaison Group Symposium 2022
Achieving respectful, person-centred inpatient care for young people with severe and enduring mental illness

Wednesday 27 April 2022
Online event

Programme

9.30 – 9.35am  Welcome and introduction
Christine Douglass, BMA Patient Liaison Group (PLG) chair

9.35 – 9.55am  Delivering person-centred inpatient care for young people with severe and enduring mental illness
Professor Bernadka Dubicka, consultant child and adolescent psychiatrist, Greater Manchester Mental Health Trust

9.55 – 10.05am Questions and answers

10.05 – 10.25am Protecting the human rights and dignity of young people with enduring mental illness and autism in inpatient settings
Charli Clement, activist and lived experience expert

10.25 – 10.35am Questions and answers

10.35 – 10.45am Break

10.45 – 11.30am Panel discussion: Building person centred in-patient care from lived experience
Moderator: Emma Beeden, BMA PLG member
Panellists to include:
- Cara Lisette, mental health campaigner and author
- Zeze Sohawon, award-winning lived experience practitioner, mental health speaker, author and executive
- Stuart Dodzo, Co-production and people co-ordinator, Healthy Teen Minds

11.30 – 11.50am Health inequities: severe and enduring mental illness
Dr Bola Owolabi, GP and director health inequalities, NHS England and NHS Improvement
11.50am – 12pm Questions and answers

12 – 12.10pm Break

12.10 – 12.45pm Breakout sessions

- How to maintain person-centred care in extreme suicidal crisis in CAMHS inpatient settings
  - Facilitator: Zeze Sohawon, Award-winning lived experience practitioner, mental health speaker, author and executive
- Co-designing with young people suicide prevention resources to facilitate help-seeking pathways
  - Facilitator: Dr Maria Michail, associate professor, Institute for Mental Health, University of Birmingham
- Improving transitions from CAMHS to adult mental health services
  - Facilitators Gemma Byrne, senior policy and campaigns manager, MIND and Cara Lisette, Mental health campaigner and author
- Co-production with young people at risk of marginalisation
  - Facilitators: Fiona Lacey, Senior manager for service design, Young Minds and Jess Leigh, Consultant at Young Minds
- Creating a space for recovery: How creating safe spaces can improve autism and mental health care
  - Facilitators: Charli Clement, Activist and lived experience expert, and Emma Beeden, PLG Member

12.45 – 1.10pm Feedback from breakout groups

1.10 – 1.15pm Closing remarks