Improving Access to Psychological Therapies (IAPT) for BAME Communities

Workshop Report
28 March 2017
Contents

| Introduction and aims of the workshop |
| Understanding IAPT from a patient perspective |
| Understanding IAPT from a professional perspective |
| Understanding IAPT from BAME community perspective |
| Sharing good practice |
| Input from Survivors Manchester |
| Input from Lesbian, Gay, Bisexual and Transgender Foundation |
| Conclusions |
| Recommendations |
| Evaluation |

Listening and responding to service providers working with minority communities to gain insight into barriers and solutions to access and recovery rates for IAPT.
Introduction

Khadija Tily, Operations Manager of Kashmir Youth Project (KYP) welcomed everyone to Unity House and thanked everyone for taking time out from their busy schedules to come and participate in the Rochdale IAPT workshop. The 60 participants of the workshop were service providers of mental health services, community groups and voluntary sector organisation representatives.

Khadija welcomed and introduced the guest speakers including a patient of IAPT services Geeta Sarin, Frances Carbery and Maqsood Ahmad from the Greater Manchester & Eastern Cheshire Strategic Clinical Network, Dr Paul Campbell - IAPT Clinical Lead, Rossella Nicosia from LGBT Foundation and Duncan Craig from Survivors Manchester. KYP is delighted to work in collaboration with members of the Greater Manchester Health and Social Care Partnership to increase the awareness of IAPT services and engagement with BAME communities.

Khadija went through the programme and the aims of the workshop. She then introduced the first speaker Geeta Sarin who had travelled from York to attend the workshop. Geeta provided a very moving account of her
personal experience of accessing mental health services in Greater Manchester.

IAPT from a patient perspective

Geeta is aged 37 years, she previously lived in Whitefield, Manchester and got married last November and is currently living in York. She was a volunteer at BIG in Mental Health (Bury Involvement Group) a voluntary organisation in Bury providing a broad range of accessible and responsive user led support services for individuals experiencing mental health problems, such as depression, bipolar, schizophrenia, post-traumatic stress disorder (PTSD), etc. She also volunteered at Project 29, Samaritans, Creative Living Centre and the NSPCC. She was Bury Woman of the Year in 2012 and Volunteer of the Year 2016.
Geeta suffers with PTSD and depression, she takes four types of medication and has had electroconvulsive therapy (ECT) small electric currents are passed through the brain to stimulate chemicals, she said it worked.

At the age of 15 years, she was sexually abused for 2 years by a cousin who came from India to live with the family. She took him to court and he was given a jail term of 14 months and placed on the sex offenders register list for 10 years. At the age of 21 she became severely underweight, this led to anorexia and being on life support.

Her parents were unaware what this was, why was she like this, controlling food, because she had no control over the abuse. Aged 21 she was admitted to The Alexandra Hospital in Cheadle as she had heart problems.

Her parents were oblivious she had any other illness. Why, as there is no method out there to educate them, therefore no knowledge. All they knew, their daughter was restricting her food intake. She spent days crying, quiet, alone, no sleep, no food, not talking to anyone, her mum and dad had no idea what was going on and how it happened.

So, what is there out there? Geeta is an Asian (Hindu Punjabi), she is lucky that her parents were born in this country and therefore can speak and read English. But, are there any leaflets, telephone numbers or websites that people from the BME community can access, before illnesses reach a stage where they have to be hospitalised like she was.

Geeta has developed a leaflet of her own for children to educate them on child abuse and there is a contact number for the NSPCC which they can access in different languages. She has also developed a website for sexual abuse awareness, the link is: www.http://saa.me.uk/

Geeta went onto explain her experience of her treatment pathway:

ECT No warning given in enough detail about memory loss. Had 35 sessions within 1 year, fortnightly. Now suffers immense short term memory loss.

Medication Been on loads, all types of medication. Side effects, does anyone warn you or to find other options.

Psychotherapy Waiting list too long. Language barrier, I was lucky.

Family support At the beginning none – what is depression? You don’t have it?
Asked mum, she said never knew what it was until she sat down with doctor at all appointments. Would have understood it more if it was explained in own language and earlier. Just a word, no detail.

Nurses All English, no Asian so didn’t understand cultural barriers and language barriers. If I had an Asian nurse could understand better e.g. when a patient came in and I was asked to translate, I was too ill myself. Somebody should be there, as a nurse to explain to patient and family when they visit if need be.

Food Unhealthy, I put on a lot of weight, requested salad.

Gym Never used, pool table.

Staff Assigned time with nurse not always given, too busy writing notes or doing something else.

Therapy room Limited use.

Occupational Therapy Do occupational therapy activities for BME communities

Geeta highlighted some of the key issues that BAME communities face when accessing psychological therapies. She feels that we need to educate the BME community and make them more aware of mental illnesses before they reach a stage where they need to be hospitalised. Prevention is better than cure.

Some of her solutions were:

- Groups such as BIG in Mental Health for people of diverse backgrounds to attend
- Websites to educate
- Doctor’s to give talks
- Leaflets - use more pictures to explain things

Geeta finished off her presentation by sharing the speedy recovery progress in York, where she had access to a mental health nurse, psychiatrist, social worker and perinatal counselling. Compared to Whitefield, where she had 3 social workers who changed within 3 months.

Khadija thanked Geeta for sharing her personal experience of using IAPT services in Greater Manchester and then went on to introducing the next
guest speaker Dr Paul Campbell, Consultant Clinical Psychologist and IAPT Clinical Lead to outline IAPT and what is meant by access and recovery.

IAPT from a professional perspective

Dr Campbell started his presentation by explaining the IAPT acronym. He went onto say that the IAPT programme began in 2008 and IAPT services provide evidence based treatments for people with anxiety and depression (implementing NICE guidelines). A priority for service development is to expand services so that at least 1.5m adults access care each year by 2020/21. This means that the prevalence target nationally will move from seeing around 15% of all people with anxiety and depression each year to 25%, and all areas will have more IAPT services.

The principles of IAPT are:

- Improving access
  - moving away from GP to self-referrals
- Improving quality
  - only NICE guideline therapies are provided
- Demonstrating effectiveness
  - outcome measurement at every session

The targets for IAPT are:

- 15% prevalence
- 50% recovery rate
- 75% of referrals into treatment within 6 weeks
- 95% of referrals into treatment within 18 weeks

Regarding recovery rates, Dr Campbell indicated that 50% of IAPT patients should be free of clinical symptoms such as depression and anxiety by their final session, regardless of how severe the patient’s symptoms were at the beginning. The current national average recovery rate stands at 48.9%.

One of the other targets of the IAPT programme is new referrals. 75% enter treatment within 6 weeks and 95% within 18 weeks. These are based on the waiting time between the referral date and the first attended treatment appointment, it cannot be assessment it has to be treatment.

Dr Campbell discussed in detail the 10 common mental health disorders that are defined as a range of depression and anxiety disorders that can be treated. This included conditions such as depression, generalised anxiety disorder through to social phobia and mixed anxiety and depressive disorder.

These conditions are treated using the following stepped care model:
How effective is the IAPT programme in relation to treating people from BAME communities? Dr Campbell stated with regards to ethnicity it was very difficult to obtain local IAPT data. However, he was able to get some national data which indicated that the lowest group for recovery rates were people of Pakistani, Bangladeshi, mixed white and Caribbean heritage.

IAPT services are not doing enough to find out who is accessing the service. Some IAPT services are very good in engagement and there are those who are not so good.
Dr Campbell finished off his presentation by talking through the next steps for organisations or groups wanting to implement IAPT services:

- to approach local IAPT providers about
  - improving access and recovery rates for BAME communities
  - building partnerships to act as a conduit between the BAME communities and local providers
- collaboration with local CCGs to ensure a strategic alliance that includes the needs of BAME communities, taking into account extended family members who are carers of patients.

It was noted that there was no representation from the local CCG at the workshop to discuss how engagement with local groups and organisations could take place.

IAPT from a community perspective

Khadija thanked Dr Campbell for his insightful presentation before introducing Maqsood Ahmad from the Greater Manchester & Eastern Cheshire Strategic Clinical Network to lead on the interactive table discussions. Maqsood presented a number of questions to the participants to discuss and then asked for one person to feedback from the respective tables.
Questions discussed:

**Identify the issues affecting the BAME communities in relation to IAPT services?**

The following issues were highlighted as barriers to accessing IAPT services:

- Lack of awareness of services for community, professionals, GP/ poor communication
- Confidence to ask for help
- Stigma, cultural shame (shame on the family) – treating you with contempt
- Professionals block referrals
- Funding
- Language barriers – lack of language
- Training opportunities to enter career
- Lack of cultural awareness
- Not aware of condition/ physical
- Faith/ will
Fear
Understanding of illness and lack of understanding of mental health
Lack of knowledge and education around emotional distress
Exclusion criteria for groups
Time for assessment
Age
Awareness, communication
Tolerance
Education
Lack of awareness/ communication around individual organisations
Forms
Lack of understanding – professionals
Staff training
Referral system
Lack of education – unaware of support services that exist
Awareness about self-referral
Training to identify early problems - groups, teachers, work
Staff representing community
Referral process – I.T./ On-line/ GP Referral/ Literacy skills
Cultural influences – prevents people seeking help
Distrust of the NHS – confidentiality
No support - no network around you
GP’s – will GP’s refer to services
Less hate
Environment
Ego – young people – men
Use of interpreters
Access to transport
Childcare – prevention
Increase partnership working
Staff training
Single point
Not making use of BME staff within IAPT to share knowledge with other staff
Youth Representative
Deprivation and unemployment
Gender bias
Community links
Abuse
Institutional racist behaviour
Culture and religion – service level
Structure of IAPT service – origin/ develop
No diversity target and so no push to do it
Educating people to believe they can knock on doors
- No awareness of opportunities and lack of awareness of services available
- Some opportunities are too limited
- Funding – capacity/ demand and money for services
- Innovation
- Limited risk taking
- “Them and Us”
- Not engaging at grass roots
- Data! = Knowledge!
- Postcode Lottery
- Location
- IAPT staff retention issues
- Mental Health “topic”
- Family and community influence – engaging family and community
- Translators training of working in a psychotherapeutic setting (lack of...negative)

**Identify the solutions to increase access for BAME communities to IAPT services?**

- Train therapists with translation qualifications
- Deliver training/ awareness on mental health in community centres
- Local community centres – involvement
- Confidentiality issues to be discussed
- Materials available in different formats – audio, written
- Treat each person as an individual instead of placing them in a box
- Community events – make services and support more accessible
- Change approach – simplify language
- Monitor audience
- Services more community based
- SPOC (single point of contact) with language
- Free cultural training (NHS and CCG). Cultural awareness within services.
- Simplify clinical service language
- Referral forms more simple/ different language
- Research and development funding
- Workforce development strategy – clinical staff representing populations they serve
- Health roadshows
- Wider literature availability
- Schools
- Targeting specific subgroups – age/ sex/ occupation
- Acknowledging mental health
- Samaritans
- Increase of cultural awareness
- Accessibility – weekends
Training community leaders
Training the workforce around cultural issues
Increase in accountability to commissioners
Identifying specific issues and setting group targets, not just individuals (e.g. specific risks, specific ethnicities)
Responding/ recognising differences between BME communities. Not lumped under same label.
Regular forms for feedback/ information
BME – specific Healthwatch – monitored groups
More flexibility on venues, times (weekend appointments), sending letters (or not), etc.
Mental health ambassadors within communities who can speak the language
Going into ESOL classes/ Talk English volunteers
Interpreters to have wide range of languages, including dialects to reflect the communities – Rochdale/ Oldham
Educating communities groups at grass roots level
Open door access
Using various social media to raise awareness
Multi agency working
Partnerships
Training for translators/ for therapists on use of IAPT forms
Awareness sessions for the community – delivered by professionals
Networking between local organisations – skills sharing
Education – CYP on mental health, CYP will educate the adults
Local directory of services
Mental health first aid training
Assess needs of IAPT services
Get rid of silo working by joined up/ creative working – create pathways
Publications of diversity data – readily available
Setting of diversity targets
Training and retention of diverse staff
More training for staff on working with interpreters, ethnic minorities etc.
More accessible materials/ toolkits
Key points raised were:

- There was a huge lack of understanding of the system and IAPT services within local voluntary, community and faith organisations. This was the first IAPT awareness session in Rochdale targeting BAME communities to learn and collate information about their individual needs. More sessions of this kind are needed at a local level to meaningfully engage with BAME communities and tailor services appropriately, including by varying methods of delivery to ensure they are accessible.

- Terminology, language and access to interpreters for those who cannot speak English as their first language is essential to meet the needs of BAME communities and new emerging communities. If an interpreter is used for an IAPT therapy session, then enough time should be allocated for it to be effective. The vast majority of time was taken up in translation and not therapy. The interpreters must have an appropriate command of the spoken language including dialects and cultural knowledge. Clinicians need to be sensitive to the possibility of...
the interpreter being from the same community and if there are gender issues for the patient.

- It was evident that there is a lack of cultural awareness amongst professionals who deliver IAPT services. For BAME patients, faith plays an important part in their recovery process. Professionals have very little knowledge of faith and they are therefore unable to connect with patients from diverse cultures. There is a genuine need for IAPT services to be more culturally appropriate and to engage more with their local community to find out what the needs of their local BAME communities are in relation to IAPT talking therapies.

- Stigma and cultural shame was identified as a paramount issue for BAME communities in accessing IAPT services. Offence words such as “pagal” are used to describe the word “mental” within Pakistani communities. People are reluctant to access services for fear of being labelled as being “mad” by the wider community and how their children will be perceived. There is a need to increase awareness and education amongst BAME communities to gain a better understanding of mental wellbeing and the IAPT programme.

- It was clear that a huge amount of work is already taking place in the community by the local voluntary, community and faith groups to help those with mental health issues. Many of the participants shared examples of the work they are doing and it was recognised as Step 1 and 2 provision, but there was no investment in resources. Local commissioners need to actively work with the voluntary sector to adopt best practice and allow for a commissioning model which encourages innovation and understands the needs of the local community.

- It is essential for IAPT services to have diversity targets and to radically rethink how they deliver services for BAME communities. A suggestion was made to have a workforce development strategy that looks at IAPT staff retention and recruitment of clinical staff which represent the communities they serve. The IAPT therapy session should be designed around the individual needs of the patient and not targets.
Sharing Good Practice: Survivors Manchester

Khadija went on to introduce Duncan Craig, Chief Executive Officer of Survivors Manchester who shared his journey of becoming an IAPT compliant organisation. Duncan’s presentation was based on the challenges and opportunities of IAPT for the Third Sector.
After providing a brief background to Survivors Manchester, a survivor led, third sector organisation for male survivors of sexual abuse, rape and sexual exploitation in Greater Manchester. Duncan explained the reason why the organisation became IAPT compliant. The organisation was already delivering a three step approach to healing which models the ‘recovery process’.

When Duncan consulted a service user about Survivors Manchester becoming IAPT compliant he was taken back by his response, this still resonates with him till today:

“"But why wouldn’t you want to improve the access for us clients to get the right counselling?"”

“Luke” (Aged 38)
From the start of the journey, Survivors Manchester was not going to become another NHS primary care mental health service. The organisation was created to provide specialist support to boys and men, affected by sexual abuse, rape and sexual exploitation in Greater Manchester, based on an identified need. From opening the doors they have been fighting to be heard and be open. Initial conversations with commissioners, and colleagues in other voluntary sector organisations, felt like we were engaging in a familiar fight.

“Improving Access to Psychological Therapies is an NHS programme rolling out services across England offering interventions approved by the National Institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders”

Duncan went on to share some of the challenges he faced when setting up Survivors Manchester:

- the importance of funding, continuous knocking on doors to get the funds needed to support his client groups.
- conversations with various stakeholders such as the CCG, Third Sector, commissioners, board of trustees, staff, clients and some difficult discussion with himself too.

He stated that the “devil is in the detail” when applying to become IAPT compliant and for a small third sector organisation, this is a huge task. From start to finish, it took Survivors Manchester 15 months to:

- Undertake a review of our service pathways
- Complete a workforce skills audit and generate a workforce development plan
- Systematically review all the organisations policies and procedures
- Document the ‘current’ Survivors Manchester datasets, match against the IAPT minimum datasets, then create a workplan on the introduction of new data collection types; and
- Review the ‘current’ outcome data reporting mechanisms and develop the new transmission pathways that would include the need to transfer data, using new technology.

He mentioned data reporting has significantly changed and that data collection gives the organisation a better insight into their clients, their
engagement with the service and the effectiveness of their input in their lives. Duncan finished off by sharing what lessons they learned:

- Urgent need for NHS and National IAPT programme board to engage with the third sector and understand its needs.
- Third sector needs to pull down the barriers and look properly at making a transition to being IAPT-compliant,
- Commissioners need to fully embrace the importance of the Third Sector and see us as part of the solution
- Support and investment has got to happen to make any meaningful transition.
- It is time for the third sector to stand up and be counted
- It is time for the NHS to truly recognise that for many clients, the third sector is the first port of call.
- Open the borders and join forces to work together to improve the access to psychological therapies for all of us.
Sharing Good Practice: LGBT Foundation

After the networking lunch, Khadija introduced the final speaker of the day, Rossella Nicosia, Mental Health Lead at LGBT Foundation. Rossella’s presentation was based on delivering an effective IAPT service.

Rossella provided an overview of LGTB Foundation’s values which are based on equality, wellbeing and safety. These principles are incorporated in delivering IAPT services to their clients.

Workplace

Of LGB people in Greater Manchester:

- 44% Experienced verbal bullying
- 15% Experienced physical bullying
- 46% Been treated in a negative way
- 15% Felt that this had negatively affected their ability to perform at work

Over half of transgender people have struggled with employment due to their trans status

She highlighted that mental health of LGBT people in Greater Manchester was worse than the general population. Only 8% of LGBT people stated that they never had mental health problems compared to 1 in 4 of the general population. Their experience of mental health had a negative impact on their ability to perform at work or find work, participate in the community and access public services. Rossella shared some statistics and indicated that “minority stress” based on discrimination and exclusion of minority groups plays an important part in psychological distress.
She then talked about developing an effective IAPT service, by focusing on the following areas:

- Core values and principles
- Embedding IAPT
- Infrastructure
- Recruitment
- Part of a wider network

Rossella then went on to explain how LGBT Foundation turned the barriers they faced into opportunities.

- Infrastructure – shared tools with other providers
- Recruitment – specialist roles took 3 months to get the right personnel
- Cultural Competence – training swaps (free offer of LGBT training)
- Language Barriers – partnership working, identified a budget for interpreters
- Nature of the service – being honest of what you can and cannot deliver, therapy ready (Step 2 and 3)
- Location – community setting, telephone sessions, on-line

Rossella discussed the Talking Therapies Programme Referral Pathway and what IAPT services provision there is on offer at LGBT Foundation. She finished off her presentation by outlining a case study and shared some service user experience.

“"You can be open and honest without fear of being judged. My life has changed completely during the time between my first and last sessions. Thanks to the service I have found so much confidence in myself and know that I can move on with my life and be happy in my own skin.""
Conclusion

Khadija closed the workshop by once again thanking everyone for their attendance and input. It was noted that this was a great example of the Greater Manchester & Eastern Cheshire Strategic Clinical Network team working with KYP at a local level to engage BAME communities affected by mental health.

In terms of next steps a series of focus groups will be organised with local people and service users to gain an insight into barriers and solutions for accessing IAPT services. The findings will be collated from all four localities where workshops have taken place and findings will be reported and shared at a learning lessons seminar in mid-May.

Recommendations

- Professionals with appropriate community languages should be recruited from diverse communities. Investment in training for staff and the development of a workforce strategy for retention of IAPT staff
- There is a need for ongoing mental health awareness and engagement workshop sessions for BAME communities. The sessions need to be held locally and organised in partnership with local communities and voluntary sector organisations.

- Time allocation for IAPT therapy sessions to take into consideration the need for translation for BAME patients.

- Local commissioners and mental health providers to have a better appreciation of the services being offered and delivered by community and voluntary sector organisations.

- More investment from local commissioners to support the excellent work being done by community groups and voluntary sector organisations to deliver IAPT compliant services locally.