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# Wiltshire and Swindon Users' Network





# 25<sup>th</sup> Annual Report July 2017









#### **Mission Statement**

'To promote the involvement of people and to disseminate examples of good practice in involvement in Health and Social Care purchasing, provision and evaluation'

This is done by:

- Supporting the empowerment of people.
- Enabling people to act as agents of change.
- Being proactive in facilitating learning amongst Community Care professionals, voluntary, statutory and private bodies both county-wide and nationally.
- Developing and managing projects.



#### Management Committee 2016/2017

Diane Gooch (Chair), Martin Fortune (Vice Chair), Mary Johns (Vice Chair) Gregory Coombes, Nick Crane, Anne Keat, Jim Law, Heather Tucker, Olga Tuffery, Pat Donlon (Associate Member), Alison Harland (Associate Member) Nicky Kinge (Associate Member) June Barnes (Associate Member)

# Welcome to our 2016-2017 Annual Report

## **Chairs Report**

As we come to the end of our 25th anniversary year I thought this would be a good opportunity to reflect back over the 25 years and think of some of our achievements, especially for those members who were not able to join us for our birthday celebration party.

As the first User Led Organisation in Wiltshire WSUN has been at the forefront of ensuring service users voices have been heard at all levels in the planning and development of services, to ensure they meet our needs. Many of you have been and still are actively participating in influencing and improving not only Health and Social Care services but others as well.



Claire Evans (founder of the Network) and Diane Gooch celebrating 25 years

How many members remember helping to co-produce WILF, the Wiltshire Independent Living Fund set up in 1993, or campaigning for an older persons nail cutting service despite health and safety concerns, hosting seminars called the 'Wiltshire Experience' for fellow groups of users across the country and also having a mayor involvement in influencing the 'Valuing People National Policy'

In recent years you, our members along with staff, have continued to be actively involved in promoting the service users' voice by being part of groups helping to feed back not only their concerns but also where they have received good practice. Some of these groups are, The Customer Reference Group who carry out independent monitoring of social care services in Wiltshire, Our Time to Talk a peer group for people with Mental Health experiences which aims to influence and improve service provision and the Safeguarding Reference Group where members bring issues from their communities and their own experiences to discuss and are taken back to the Wiltshire Safeguarding Adult Board (WSAB). Also Memory Clubs which reduce isolation for those with memory loss and their carers, The Wiltshire Independent Travel Service / Banes Travel Support, which was developed by service users to help address the barriers to transport for people with disabilities and Access Audits where members have advised on access to buildings for visitors with a variety of disabilities. Members also work with local colleges Social Work courses to share their experiences of living with a disability and more recently we offer Mental Health First Aid workshops to help people recognise their own mental health and that of others, so helping to raise awareness.

This is just a snap shot of some of the many achievements over the last 25 years. With your continued help and by feeding in your thoughts on issues important to you, we will embark on the next 25 years of speaking out together.

#### **Diane Gooch**

#### Chair of Wiltshire and Swindon Users' Network



How we engaged with our community in the last year

Our Members gave over 1700 volunteers hours

We worked with over 100 different Organisations in Wiltshire.

We visited 23 different Care Homes and Sheltered Housing Facilities

Our Outreach workers made over 180 separate visits to local groups & events in our community

812 service users gave their views on 10 different Wiltshire Council & Clinical Commissioning group strategic documents or consultations about local services, including Information and Advice, Sheltered Housing, Mental Health, Domiciliary Care, Autism and Wiltshire's Sustainability and Transformation Plan.

# Monitoring

# Help to Live at Home (H2LAH) Customer Reference Group (CRG)

The H2LAH Customer Reference Group (CRG) have been extremely busy this year interviewing people about their domiciliary care (care at home) and also visiting people who live in Sheltered Housing facilities across Wiltshire. This small group of volunteers, mostly older people, met with 184 residents of sheltered housing in 18 different facilities and the resulting report has been sent to Wiltshire Council to inform their future decision making. The CRG is recognised both locally and nationally by providers, commissioners, peer reviewers and other outside agencies as a valuable, independent and important monitoring tool.

'What is so important as a member of the CRG, is that we can meet up with those people who either live in sheltered accommodation or in their own homes to find out how well (or not) their care packages and support is working.

As WSUN is an independent organisation asking questions on behalf of Wiltshire Council, service users can be open and honest with us about what works well and what needs looking into and improved.' **June Barnes Member of the CRG** 

# **Consultation and Service User Engagement**

## **Information and Advice Consultation**

WSUN were asked to engage with people as part of Wiltshire Council's program of work around the review, design and recommissioning of the information and advice service for Wiltshire.

The questionnaire used was designed by WSUN to be as clear and as easily accessible as possible. It was used either as a stand alone questionnaire which people could complete independently or by the Outreach Workers for semi-structured interviews.

105 people took part in the consultation and the results will be used to shape the future provision of services.

A copy of the report is available from WSUN or can be found on our website.

#### Service user perspectives

#### John

John attended the Mental Health and Wellbeing Needs Assessment Café event which was one of two events held in April and May, he said he felt welcomed but also that community venues can sometimes be difficult. John also recently joined the Mental Health and Wellbeing board as one of the service user / customer representatives.

He likes to attend Avon and Wiltshire Partnership events and says, 'They have helped me give back and contribute to local services and give feedback on policies and procedures. I have written a book in the past and different communication styles can help people feel included and listened to'

'It's good to volunteer and enjoy everyone's feedback and support and give each other confidence that offers respect privacy camaraderie and the chance to fit in'

Equality and diversity is very important and peer support for each other and attending events like the Care Forums and Mental Health and Wellbeing event really help you feel included

Johns message for all is 'Don't be afraid to come along to meetings, your contribution might help to empower yourself and others! '

#### **Debbie – Wiltshire and Swindon Users' Network**

Debbie joined the Wiltshire and Swindon Users' Network fourteen years ago, her partner was a member and he introduced Debbie to some of the support that helped his health and well-being, he sadly passed away and Debbie felt she wanted to continue to share and gain support from forums and meeting other service users. She has been a member of the Management Committee twice.

'Peer support to me means many things; Friendship and communication and being able to share and discuss with other members of WSUN, things that others understand and may have experienced.

The recent Public Health Consultation around the Mental Health and Wellbeing Needs Assessment allowed me to feedback how I feel about local mental health support in Wiltshire. The Mental Health Café style event was fun and useful at the same time. The event gave all of us the chance to discuss what real peer support means and how it can affect health, communication and community support for each other.

Different accommodation options too, such as supported housing where I live and the Help to Live at Home service can also help people have choice about the support they need.

These things can help sustain a person's wellbeing and recovery and because they never judge or give up helping someone it helps them to feel well, safe secure, and valued.'

## Samiha

I became involved with mental health services through my own lived experience of being a service user. In 2009, I was elected as one of two WSUN Service User Representatives. I have been closely working with them ever since.

At first, my involvement gave me a sense of purpose while I was still recovering and very fragile. I was in a fog, and uncertain about the value of my contribution, but gradually I gained skills, knowledge and confidence. Working with WSUN was key in my recovery, to regaining my selfesteem, and in helping me, eventually, to return to the world of work.

As part of my work with WSUN, I've been involved with Avon and Wiltshire Partnership Trust, speaking up on behalf of service users. I've attended meetings and given input on commissioning, design of services, promotion, communication, ethics and safeguarding. I've witnessed, and been affected by, the Health and Social Care Act reforms; an important part of our work has been to support service users through this challenging time.

I have regularly attended the Trust-wide Service User meeting; as well as the Wiltshire Care Forum which deals with operational matters within the Trust, and builds partnerships with other local service providers. All this work has enabled me to gain in-depth knowledge of how local services work, how they interact with each other, and how best to ensure service users are involved at every level.

I have co-chaired the Our Time To Talk meetings, which enable WSUN members to speak out on issues they face. We have regularly invited speakers to these meetings, where they respond to members' questions on a wide range of subjects from crisis care to benefits, public health and prevention to advocacy. Those experiences have definitely been one of the most rewarding aspects of my work with WSUN, as well as giving me precious experience of chairing and facilitating service user-led meetings.

As well as my work with WSUN, I am regularly invited by the AWP Trust to be a member of interview panels, and thus have been actively involved in the recruitment of consultants and nurses, bringing a service user perspective to the process. In 2015, I was a member of the Wiltshire Council panel tasked with allocating the tender for specialist mental health advocacy services in the county.

I have learned a tremendous amount from WSUN and from my other service user representation work, about reaching and supporting people. I'm passionate about the involvement and empowerment of people, and about everyone being given a say in the way their services are run. This year, and with the support of WSUN, I was lucky enough to be offered a part time job with renowned mental health charity Together For Mental Wellbeing, working in their new residential service in Swindon.

#### http://www.together-uk.org/projects/swindon-carfas/

I have been in my new role of Peer Supporter Coordinator since April, and am hugely enjoying the experience. Peer Supporters have the unique ability to empathise with, and thus effectively assist people who are experiencing mental distress. Being supported by WSUN, becoming a service user representative and speaking up for others, have all given me the immense satisfaction of helping to give others a voice, as well as being instrumental in my own recovery...and now in my career. The new job is a natural continuation of the work I have been doing so far, with many further challenges and opportunities to learn.

#### Wiltshire Adult Mental Health and Emotional Wellbeing Needs Assessment

'We were very pleased that WSUN were able to work with us to help ensure that the views of local mental health service users and carers were fully represented in the Wiltshire Adult Mental Health and Emotional Wellbeing Needs Assessment we are producing. Their help in piloting and distributing questionnaires, and also in managing and facilitating our two World Café engagement events, was invaluable. WSUN's professionalism, attention to detail and willingness to go the extra mile to ensure the events were a success was admirable. With WSUN's help and support we heard from over 100 local mental health service users and carers and were able to ensure that their voice was heard and their perspectives used to inform the needs assessment.' Dr Charlotte Bigland, Public Health Specialty Registrar

#### Wiltshire Autism Forum (WAF)

The forum was set up to give people with an Autism Spectrum Condition a voice about things in the community that affect them. The forum meets regularly and feeds service user views and issues back to the main Autism Board which include a group of people from various organisations including Wiltshire Council; these are the people who shape the services we receive in Wiltshire



Autism Criminal Justice System Conference

As we enter our 2nd year of hosting the forum, we have had busy, but productive year. People either participate by attending the meetings in person or through feeding in their views via email or the telephone.

On the 29th November last year, over 100 people attended a Conference on the Criminal Justice System. The aim of this conference was to inform people who work in the criminal justice system and the wider area how someone with Autism may feel and react in this situation.



Autism Criminal Justice System Conference

'The relationship between people on the autistic spectrum and the Criminal Justice System isn't one that is as comfortable as it should be. I was pleased to be invited by WSUN and Wiltshire Council to prepare a short piece of performance which lifted the lid on the autistic perspective and how everyone from the police to court officials might hope to deal better with this section of their community. I was able to include people's real experiences of how things had gone wrong in the past into a script which was delivered by three adults on the spectrum; the piece also made suggestion as to how the two worlds might work better together in the future. We couldn't solve a complex issue in such a short time but we were able to promote and provoke debate in the hope that dialogue will continue.' Richard Conlon, Playwright 'Those of us with an Autism Spectrum Condition live in a neurotypical world. This can be tiring, as every day involves navigating our way around unspoken communication and unwritten social conventions we find hard to understand.

The Autism Forum provides a unique opportunity for us to have our voices heard in a safe environment where - for once - WE are the majority. Although my work commitments mean I am not able to attend very often, I am able to convey my views via email, meaning that my own voice is added to the wider conversation.' **Jane Harber, Social Worker** 

'Three WAP members gave feedback on the Autism Strategy, two of these members comments have been quoted in the strategy and many of the comments suggested by them resulted in a change to the wording of the strategy. Their feedback is invaluable in supporting us to make sure we give the right message. Case studies from WSUN on our assessment process continues to evidence gaps in our pathway for autistic customers without a learning disability.' Victoria Bayley Joint Commissioner – Autism, PI & SI

# Wiltshire Service User Safeguarding

# **Reference Group**

Since our last annual report the Safeguarding Service User Reference Group has flagged up a number of issues though their meetings. These have included; Dealing with self-neglect and anti-social behaviours, provision of replacement batteries in specialist fire



alarms, access to the internet and the need to broaden ways of engaging with service-users and respecting and protecting privacy to name but a few.

Through the group, issues about how safeguarding concerns are dealt with by social care call handlers were also highlighted and feedback was passed directly to the safeguarding adults team.

The group has also worked with the (WSAB) Wiltshire Safeguarding Adults Board in giving feedback and suggestions during the development of the WSAB staff guidance and the Boards strategic plan.

'The group is well attended by service-users who have substantial experience of how local systems are working from a care / users perspective through their own experience and through the networks they have developed. WSUN facilitate the group meetings and have worked effectively to ensure the Board is working, not just for, but with the people it seeks to support.' Emily Kavanagh – Safeguarding Adults Board Manager

This is just a brief overview of the important work the group carries out. Please contact WSUN to find out more. There is also a new website with lots of useful information www.wiltshiresab.org.uk

# **Outreach, Signposting and Peer Support**

## **Our Time to Talk**

The Our Time To Talk mental health group continues to grow and has enjoyed a very busy and productive year. Among other work we have contributed to the Wiltshire Police Crime Plan consultation, Wiltshire Council Peer Review and the Avon and Wiltshire Partnership Place of Safety consultation. We continue in our aim to influence mental health services and engage actively with providers to do this. We have said a warm farewell to Samiha who has done so much for the group over the years. She is now working in mental health peer support and is keeping in touch with us still.



Possibly the biggest achievement of the past year has been the creation of a beautiful booklet featuring creative writing, crafts, photography, and the stories of Our Time To Talk members. It's themed around wellbeing and really has something for everyone. Copies can be bought from WSUN.

Most important of all is the support Our Time To Talk members give each other and the chance to come together in a safe and supportive group, to share their experiences and support each other.

We asked what was good about the meetings and here are some of the responses; 'open discussion and support' 'contributing ideas' 'hearing from others in the group' 'working on the booklet' 'hearing about future events' 'being listened to'

We welcome new members so if you are interested in joining us do call the WSUN office for more information.

## 25th Birthday Celebrations Wellbeing Event

Over 150 people, including 23 stand holders, attended the event at the Corn Exchange and helped us to celebrate 25 years of supporting people to speak out.

# 'Brilliant day meeting everyone old and new. Thank you all at WSUN for all your hard work and making the event such a success



'The event was really good, a diverse range of workshops which were enjoyed by everyone. A lot of interaction and ideas exchanged. Thank you, keep up the good work for the next 25 years'

'Fantastic day lots of laughter and fun. '



'A lovely joyful day. Plenty of interaction, I enjoyed the Reiki and mindfulness'

'A great event. Very well attended by a selection of services. Great networking opportunity. Keep up the good work!' Rehabilitation worker for visual impairment Wiltshire Council hearing & vision team



'Just wanted to say a big thank you for inviting me to contribute to the event... was a great opportunity to connect and reconnect with some truly inspiring people and the dance session at the end left me buzzing all the way home! 'Malcolm Burgin Regional Manager Alive



'The smiling welcome as I walked through the door really made me feel good'

## From Alpacas to Zinnias – memories matter

The past year has been another busy and successful one for the three memory groups WSUN supports. All three (3M's Lyneham area, Calne and Tisbury) have grown and continue to thrive, offering their members a diverse range of activities and opportunities. From visits to Alpacas, singing, dancing, classic cars, and curling matches through to wheelbarrow planting there is never a dull moment. Equally important as the different activities is the support and friendships which come from within the group.



Wheelbarrow planting

'we are all living longer and families living further away, so groups like this are so important'

The groups also afford the opportunity to share information with members, whether about the Safe and Well checks from the fire service which a number of members have used, or signposting to benefits and finance advice. It is very apparent that many carers are struggling to navigate a complex system so the support and knowledge of the memory groups and WSUN is invaluable.

We asked members, carers and volunteers to sum up what they value about the groups.

'The boundaries of life have changed – more to do and talk about'

'I hope the people who come to the group have got as much out of it as I have. They have made such an impression on me, especially the carers'

'The stimulation from the group leaves our residents in a calm and content mood leading to a good sense of wellbeing'

'Memory club is a big part of our lives and we love being part of the family'

'I look forard now'



3M's group enjoying curling



Crafts by Amesbury Mental Health Group

 $There is an evaluation report of the clubs available from WSUN. \ Please call if you would like a copy.$ 

#### Hate Crime Focus Group



In February, WSUN facilitated a workshop aimed at understanding the impact of hate crime on members of vulnerable communities in Wiltshire and Swindon. The event was used to inform those who attended about the difference between a hate crime and a hate incident and how to report them. The focus group was organised in response to the need for further information around Disability Hate Crime and the results were used to inform the Wiltshire's Hate Crime Multi Agency Group (of which WSUN is a member). The event provided an invaluable insight into the level of understanding of what hate crime is and how service users could and would consider reporting it. It highlighted areas in which support agencies could focus and improve. Examples included the lack of access to the internet or difficulties in using the internet as a means of third party reporting, which was reported back to the Wiltshire and Swindon Hate Crime Group.

This has led to the promotion of a Hate Crime Conference in October 2017 which will seek to promote a series of seminars set up by the group aimed at educating support workers and other agencies. The focus group provided an enhanced level of engagement with members of the community who were able to speak directly to Police Officers. This develops a reassurance that not only the Police but all partner agencies took hate crime seriously and wanted them to report any form of hate crime or incident so that together something could be done to stop it.

Detective Sergeant Tamara Campe, Equality and Diversity Wiltshire Police

#### Working with others - Doorway

WSUN have been attending Doorway on a regular basis for the last 18 months.

This provides an opportunity for us to



meet with the Doorway guests and the team of staff and volunteers within the community. WSUN are able to support them in their remit of empowering guests by assisting with signposting in an easy to understand and factual way.

Doorway helps people to help themselves, a philosophy very much in the spirit of the Wiltshire and Swindon Users' Network.

WSUN has encouraged information sharing and meeting opportunities that help individuals to access support in order to give feedback and try to get the best for themselves.

Doorway staff encourage attendees to speak with the us when they need help or advice in connection with benefits, support groups, feedback in consultations and directly to service providers.

We have informed people about the 'Our Time to Talk' meetings, the Ruth Underwood Mental Health Support Group and the book that the group produced dedicated to people that have lost the battle against mental illness.

We regularly pass on feedback from the Avon and Wiltshire Partnership Care Forum and Service User Engagement forum and have brought questionnaires and leaflets clarifying the new community services, information on how to access them and the plans for the Devizes Place of Safety beds. Many of the guests fed into the Mental Health Needs assessment consultation too.

Our interactions at Doorway vary from a laugh and a joke over breakfast, or one of the fantastic healthy and tasty lunches, and hearing guests discussing what is going on locally or in the newspapers.

We have over 650 members but it is at Doorway that we meet the people without a letterbox or phone or diary, those who might not know or remember their next appointment or even their last.

'The establishment of strong effective working partnerships with local organisations is at the heart of Doorway's success. Networking with agencies, within the safe environment of the drop-in, enables our guests to learn to trust other people and engage with their services. WSUN's remit mirrors a very important part of our work in which people who marginalised are enabled to have a voice in the provision of statutory services relating to health and wellbeing, and we are very grateful for the opportunity of having WSUN visit the sessions.' Lisa Lewis, Chief Executive of Doorway,

# Training

## Younger People's Mental Health

We are very pleased to report that our training programme has gone from strength to strength since it began in April 2016.

Award winning Psychotherapist and approved mental health instructor Daran Bailey has been busy delivery a range of courses which include Mental Health First Aid, Mindfulness, Emotional Resilience, coping with Stress and Anxiety as well as working closely with other organisations to deliver courses designed to meet their identified needs.

This year we have been working with schools throughout Wiltshire and Somerset and have delivered training to approximately four hundred Students.

'Self-Harm has been a big part of my life for the last year, Daran's training course was brilliant! it helped me understand the anxiety I have been suffering with and that I can do something about it, thank you' **Student at Saint Gregory's** 

In addition to working with young people, we have also been delivering courses and developing close links with organisations that meet young people, Bath Mind, School Teachers, Wiltshire College, Carers Support Wiltshire and many other organisations like Green Square Group, Aster and Cross point.

This year approximately 600 students, teachers and staff have dramatically increased their knowledge of mental health through the training we have delivered with demand continuing to increase.





'The best Young Adult Carers Mental Health workshop that we have run so far' Young Adult Carers

'Fantastic training and trainer, learnt so much, I particularly enjoyed the panic attack skills which I have already used to support a student' Teacher, Wiltshire College

'Everyone should do this course' Manager Aster Group

#### Wiltshire Independent Travel Support (WITS) & Banes Travel Support

There have been some real changes and challenges for our service since the last report. After funding was removed by Wiltshire Council in March 2016, we continued to train the remaining service users on our Wiltshire list, completing our final one in February this year.

Our Bath & North East Somerset Travel Support contract, which offers travel support for young people with learning difficulties or other complex needs in schools, goes from strength to strength and we have exceeded the numbers required by our contract.

In our first year we completed 27 Annual Meetings (these are meetings with students, parents and teachers, to introduce the idea of independent travel) and successfully trained 6 students who are now travelling independently to school or college.

'JL has really enjoyed the travel training and is now confident to get the bus from school to home. He has relished the step towards independent travelling, it means he does not have to rely on anyone picking him up. He was proud to have passed his final assessment and showed me the route he needs to take. The pace of the training was good, he managed to deal with the unexpected too, such as when he forgot his bus pass and house key, good came out of both incidences and he will be more careful in the future. So, a great service and hopefully Banes Travel Support will be able to work with him again when he starts college.' **Parent of a student who completed Travel training** 

'The training was really good and now I can get the bus home by myself. Marie was really understanding and helped me.' Georgia who is now travelling independently 'Georgia has really gained independence through the travel training.' **Georgia's Mum** 

'At Bath and North East Somerset Council, we believe that independent travel is a valuable skill which can give young people with special needs the confidence not only to travel independently, but to develop transferable skills such as using money, reading timetables, communication skills, journey and time planning. Working towards travel training can therefore develop confidence to open up a whole new independent way of life for young people. BANES have been offering this service since April 2016 to BANES schools, using the highly reputable service called BANES Travel Support (WSUN), who use proven and effective travel training techniques. This service has proved popular with young people and parents and is going from strength to strength in our area.' Kate Potter, Placements & Budgets Officer, Education Inclusion Officer Wiltshire & Swindon Users' Network Independent Living Centre St. George's Road Semington BA14 6JQ Tel: 01380 871800 Email: info.wsun@btconnect.com Website: www.wsun.co.uk





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