



Wiltshire and Swindon Users' Network



23rd Annual Report - July 2015

www.wsun.co.uk

Welcome to our 2014-2015 Annual Report

This has been a time to look back and reflect on both the challenges and successes the last year has brought. Following a reduction in our funding from Wiltshire Council and The Clinical Commissioning Group, some difficult decisions had to be made by the Management Committee. These included reducing the number of permanent staff and moving into smaller office accommodation at The Independent Living Centre. This was not an easy time for anyone, but with the support and dedication of the Staff Team and the commitment of our Head of Network Louise Rendle, these difficult times were overcome.



WSUN went on to tender for and be awarded a new contract with Wiltshire Council to look at services for adults with sensory loss, physical impairment or autism. This is a great opportunity for us to look at new and creative ways to engage with service users, so please let us know of any thoughts and ideas you may have that can help us achieve this.

Our World Mental Health Day was again a resounding success and was attended by over 120 WSUN members, members of the public and other organisations. Following the success of the memory groups at Royal Wootton Bassett and Calne another group opened its doors at Tisbury and continues to attract new members to its lively meetings. This report gives you the chance to hear from some of those people that have been involved with the Network in the past year.

Yes this has been a difficult year and I am sure the next will also be challenging with more changes to the way services may be delivered. However if we continue to work together, I am certain we can ensure the services continue to be responsive to all users needs.

Diane Gooch

Chair of Wiltshire and Swindon Users' Network

Management Committee 2014/15

**Diane Gooch (Chair), Martin Fortune (Vice Chair),
Mary Johns (Vice Chair) Paul Burgess, Gregory
Coombes, Tim French, Thomas Jeffery, Anne Keat, Jim
Law, Rosa Tran, Heather Tucker, Pat Donlon (Associate
Member), Alison Harland (Associate Member)**

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.
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Help to Live at Home Customer Reference Group (CRG)

The Customer Reference Group (CRG) has continued to do sterling work in monitoring all the H2LAH providers over the past year. This small group of volunteers, mostly older people, have given their time to telephone, meet with and interview customers to find out how happy they are with the service they receive. The CRG is now into its fourth year of operation and has been widely accepted by the providers and the commissioners as a valuable, independent and important monitoring tool of the H2LAH service.



“I wanted to be involved with ensuring customers were at the heart of services commissioned with and for them. I started out by being involved with the tendering process that the H2LAH providers went through, watching their presentations and providing an evaluation. The group were trained by WSUN and I remained to be one of the group monitoring the services by contacting the customers and listening to their views. The service providers were nervous of the CRG to begin with and the role we had but when they realised we weren't all about looking for negative comments they have responded well. I enjoy being a volunteer in the CRG and the work is expanding to look at provision for the future to support the public to live the life they want.” Linda Griffiths

The twelve members of the group are always busy, being called upon to visit the providers offices, spend hours calling customers, going to Sheltered Schemes, meeting customers and recently interviewing people on behalf of the council for future social care needs in Cricklade. The group have also been involved in facilitating workshops run by the Council in each of the Area Boards to try to find out older peoples priorities for future care needs in each area.

“ My reason for becoming a member of the CRG stemmed from my interest in the H2LAH project as an older person living in Sheltered Accommodation where the service provided has changed beyond all recognition in the past five years. I have an elderly mother living in private rented accommodation who has been accessing various aspects of care for the past 18 months. My hope has been that by gaining knowledge from the experiences of the variety of work of the CRG I could understand more, which would enable me to help my own community in Downton to access those providing the care resources available to them. Working in the CRG has been an interesting and enjoyable time from evaluating tenders, bedtime reading of draft proposals and visiting providers to monitor their services. Hopefully I have been able to bring a touch of reality (at least in my area) about what is happening with H2LAH. The continuing changes are a challenge to everyone. Hopefully the CRG will continue to be a voice in their delivery and I hope to continue to be a part of it.” Joyce England

Statistics for CRG

- **218 Monitoring telephone calls**
- **Cricklade Future of Adult Care Survey with Age UK Wiltshire - 105 interviews and questionnaires completed.**
- **Area Board Future Adult Care Workshops - 13 Area Board workshops facilitated.**

Working with the Wiltshire Clinical Commissioning Group (CCG)

WSUN has worked in partnership with the CCG on a number of initiatives to ensure service users' voices are heard:

Care Coordination Evaluation – WSUN supported the CCG to develop Patient and Carer Questionnaires to ensure that they were in an accessible format. We gathered the results of the questionnaires and carried out telephone interviews with both Patients and Carers to obtain their views on the Care Coordination service. WSUN also held a workshop for Care Coordinators to share their views. The summary report produced by WSUN allowed the CCG to review and amend the service in line with the feedback received. This led to improvements to the support provided.

Facilitation of a Workshop – WSUN brought together a group of service users and facilitated a workshop on behalf of the CCG to discuss and obtain feedback about the outcomes patients expected of the new model of Integrated Teams. These teams are made up of nurses, physiotherapists, occupational therapists and support staff who work together to deliver integrated and consistent health care at home, or close to home, seven days a week. The findings from this workshop allowed the CCG to understand what service would be most effective for Wiltshire patients and used this information to form and commission services from its providers.

Facilitation of a meeting of rheumatology patients – WSUN organised a meeting with rheumatology patients from PsAZZ (a Psoriatic Arthritis Support Group made up largely of patients from the Royal National Hospital for Rheumatic Diseases, Bath) in order that the CCG could understand the quality of care currently in place in Wiltshire. The CCG was able to understand what worked well, what didn't currently work well and what would improve care for patients in the future. The CCG has used this feedback to develop patient passports which are soon to be piloted and to also consider other improvements to access to care.

'WSUN provide a route to access the unbiased views of the residents of Wiltshire on the health services commissioned by Wiltshire CCG. As a consequence these services can be shaped and developed to more closely match the needs of service users.'

Shelley Watson Service Redesign Lead (WWYKD)



PsAZZ Support Group

'Why joining up with WSUN is important...

Making a connection with WSUN and having their ongoing support has been invaluable to PsAZZ. Not only have they helped by sharing information or pointing us in the right direction, but by linking with them we have been able to take part in a rheumatology initiative led by Wiltshire CCG - something we feel was an important step in being able to share our patient voice and help form plans for the future.'

Mel Brooke PsAZZ Support Group

World Mental Health Day - Service User Perspectives

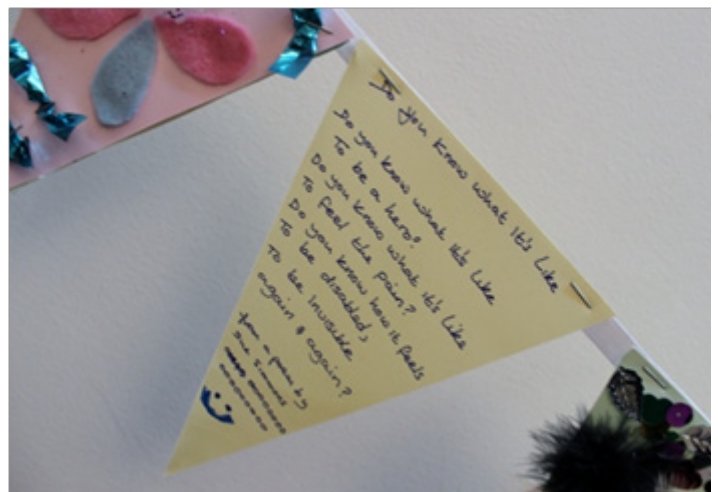
Following the event WSUN held in October to mark this important day we asked some people who use mental health services what they thought of the event.



'World Mental Health Day is a really valuable day. It is important that the event was open to people walking in off the street. Raising public awareness of mental health is so important. I attended as both a WSUN member and as a Friend of Wiltshire Mind volunteer. A number of people I spoke to did not know that MIND is there or how it can help.'



'One barrier to people who use mental health service coming to events like this is transport. Even if you feel OK the day before you can wake up and not be able to face the journey. It's difficult for people in the villages. That is why WSUN is so good, but it shouldn't just be up to them'



'The people on the stands were very good listeners and were enthusiastic and well informed'

'Really useful for our group and getting information to give to our members but also for myself and the person I care for'

'Talking to people and getting contacts and leaflets for our peer support group was wonderful'

Aspergers – A Minority Report

WSUN has always been looking for new ways to engage with people across Wiltshire. It is part of our job to make sure that the thoughts, feelings, views and opinions of local service users are expressed to the people who provide those services. This year we worked with playwright and theatre-maker Richard Conlon to lift the lid on what it is like to live life on the autistic spectrum. Richard drew on the experiences of people with Aspergers in the south of Wiltshire and created a script for performance which was staged by Richard and two people on the Autistic spectrum. This pilot aimed to let people learn about the condition through wit and humour. It was taken to Corsham, Trowbridge and Salisbury and the feedback certainly indicated that there is appetite for more of this kind of project.



'An extremely powerful and insightful performance'

'Eye-opening, funny, honest'

'Needs to be shared as widely as possible so that everyone is aware'



Wiltshire Service User Safeguarding Reference Group

Wiltshire Service User Safeguarding Reference Group are hosted and facilitated by WSUN. We are made up of adult care service users with a range of perspectives -with physical and sensory impairment, mental health service users, older people and people with learning difficulties. WSUN supports people to attend the meetings including travel costs, transport and personal care.



We are now in our second year and meet regularly in between the Safeguarding Board Meetings. Margaret Sheather, Chair of the Safeguarding Board reports on items discussed at the main safe guarding meetings and service users have an opportunity to comment on any of the issues and raise concerns from their perspective.



The safeguarding board has appreciated and valued the input made by our group over the past year.

We would like to thank Margaret for her commitment to service user involvement during her term of office and we wish her well as she steps down. Members of the group have been involved in the recruitment of the new Chair of the Safeguarding board and look forward to working with that person to take the group forward.

"The work of the Wiltshire Safeguarding Adults Board (WSAB) has continued to be enlivened by the Service User Reference Group. They bring a fresh view to issues and their personal experiences help to keep us more fully in touch with the quality of our services. I'm very grateful to the Reference Group members for their time and enthusiasm and to WSUN for providing the facilitation and support. I'm very pleased to be able to hand on a successful group to my successor as WSAB Chair and hope the group's influence will grow steadily in the future."

Margaret Sheather - Chair Wiltshire Safeguarding Adults

Denise – Service User Representative

'I have been involved with mental health activities through WSUN for at least 12 years. Mainly this has been through "Our Time to Talk (OTTT)" which is a service user group for people who use mental health services in Wiltshire.

From 1978 to 2001 I worked for two major telecommunications companies. During this period I also became a Chartered Engineer. I was diagnosed as being bipolar during my time with the second company. This company was very supportive to me allowing me time to recover and take time off when I needed. My mental illness was relatively stable during my latter years at this company. Sadly I was made redundant due to prevailing economic conditions, ironically not my mental health.



Lack of meaningful work had a severe toll on my mental health. Also around the time of my redundancy my mother was diagnosed with dementia. I became a remote carer for her helping wherever I could and acting as her advocate especially when she was hospitalised for 19 months in 2006. My mother passed away in 2008.

One day a WSUN mental health outreach worker came to the Malmesbury Mind group, I decided to join and attend OTTT meetings in order to learn more about Wiltshire mental health services. This soon expanded into active participation commenting on these services and their future. I started attending consultations and workshops on Wiltshire mental health services. In particular I began to go to the Mental Health Commissioning Group involving service users supported by WSUN, Wiltshire NHS and Wiltshire County Council.

In 2009 I became a Service User Representative for OTTT. As well as chairing and supporting the OTTT meeting I attended a wider range of meetings discussing Wiltshire commissioning and operational issues. These meetings have involved AWP, NHS Wiltshire, Wiltshire County Council and other mental health service users.

In 2008 I was interviewed by the Bishop of Bristol for a Politics Show item on mental health and in 2013 I went on the BBC Wiltshire Mark O'Donnell Show for a special programme on bipolar disorder as part of a series on mental health.

I have done my best to represent WSUN and the OTTT community at meetings such as the current Wiltshire Care Forum and the AWP Service User Group. This voluntary work has also increased my self worth and improved certain aspects of my mental health. I also very much enjoy my involvement with WSUN and OTTT.'

Samiha - Service User Representative

'My journey for Mental Health was arduous. It took me many years to get a diagnosis, accept my illness, and to work with doctors on finding the right treatment. I found out how isolating and debilitating mental illness can be.



Along my path, I met amazing people: doctors, nurses, support workers and above all, other service users. I discovered a tremendous community with a unique ability to support one another: solidarity, an absence of judgment....and also many tears and laughs. Creativity and travel were an essential part of my journey to recovery, as was the support of my loved ones; in this I feel very lucky.

Though I am now stable, I have to monitor my wellbeing, and still have some scary moments. I take medication every day. I'm acutely aware that a trigger could tip me back into illness. This gives me a vivid sense of how precious health is, and how easily lost – as a result I have a greater sense of responsibility to look after it and encourage others to do likewise.

As a result of my struggles with mental health, I've become less judgmental, more open, and keen to help others and to give something back to the community which has been so supportive over the years.

My involvement with WSUN began when a staff-member visited the Wiltshire Mind group; he was looking for attendees for a county-wide day event organised by WSUN. On the day, I was encouraged by friends to put myself up as a candidate and was elected as Shadow SU Rep.

My involvement has given me a sense of purpose. At first 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 self-esteem, and in helping me, eventually, to return to the world of work as a film-maker.

I would encourage anyone else to be involved. WSUN are great at reaching and supporting people, and do everything they can to help with access.

As part of my work with WSUN, I've been involved with Avon and Wiltshire Partnership for about seven years now, speaking up on behalf of service users. 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. Currently I regularly attend the Trust-wide Service User meeting and the Wiltshire Care Forum.

I co-chair the Our Time To Talk meetings with Denise, enabling WSUN members to speak out on issues they face. We regularly invite speakers to these meetings, where they also respond to members' questions on a wide range of subjects from crisis care to benefits, public health and prevention to advocacy. The OTTT meetings are definitely one of the most rewarding aspects of my work with WSUN.

The Mental Health priority for me is parity of esteem. I'm outraged that mental health is still not taken as seriously as physical health, that people are turned away from emergency care when this would never even be contemplated with a physical emergency. There needs to be more awareness that mental illness can be life-threatening. This is a national problem with local implications, and Denise and I work hard to ensure that the issue is kept on top of the agenda at all times. I would like to see a national strategy for balance between community care and hospital beds. I also think a lot of work still remains to be done on fighting stigma, particularly discrimination in the work-place; and on suicide prevention I would like to see tailored (rather than generic) access to psychological treatments; as well as Mental Health First Aid training to become more accessible and widely available.

For the last 2 years, WSUN have been organising very successful events for World Mental Health Day, which Denise and I have helped to organise by giving feedback on the plans; we have also facilitated a "Question Time" on mental health services for attendees.

WSUN are planning another event for this October and the theme will be "dignity". My personal message is that dignity will be achieved when everyone has access to good quality mental health-care and support based on need; and when we see an end to discrimination and stigmatisation. In many aspects, society has moved forward in leaps and bounds on these issues; in others it has moved backwards. There is still a long way to go.'

Tisbury Memory Group (TMG)

TMG has been going for a year. In fact it celebrated its first birthday on the 13th May. In that short space of time the membership has grown substantially with an average attendance of between fifteen and twenty people coming to each fortnightly meeting. People with memory loss, or who care for those with memory loss, are able to meet in a social environment to help remove the isolation of memory loss and perhaps stimulate and promote memory.



The members who attend have been involved with a whole range of activities and visits including a drumming session, pottery making, visiting someone who keeps alpacas, doing origami or just sitting in welcoming and safe surroundings having a cup of tea, a piece of cake and a chat.

WSUN supports this group and was instrumental in its establishment. We are part of the Steering Group and whenever we can we have an outreach worker attending the sessions. The real driving force behind the TMG and the person who must take a lion's share of the credit for making this group an important part of the Tisbury Community is its local organiser Anne Marie Dean, who with a small group of local volunteers ensure that the sessions are a success and meet the needs of those who attend.

Tisbury Parish Council has also expressed its support for the group and has made two substantial donations to assist with the provision of activities.

As the group now begins its second year of activities those who attend can have a whole host of activities to look forward to including a day trip to the seaside in July.

'One of the needs identified in the Tisbury rural area was a lack of activities for people with short term memory loss.

Why do they have a need? The reason being that many are embarrassed by their condition especially those with dementia or who have had strokes find that they are not accepted in regular groups or day centres making them even more aware that they are 'different' so they remain at home becoming isolated.

To me the most important part of our group is that we are non judgemental everyone is accepted for what they are and there is a true sense of belonging. In 12 months we have become an integral part of the community, and have been able to add value in an informally structured way. As an example, Mary(93) arrived as a member of our group after much persuasion. Her daughter was embarrassed at the possible behaviour which could be exhibited by her mother. We took her on our first outing a few weeks ago and she was so animated that I was able to have my first lucid conversation with her. Her daughter has already booked up for our barge trip in September.

I love the atmosphere of our group, the camaraderie, chatting, laughter, total relaxation and no-one rushes to leave.

What a difference a year can make!' Anne Marie Dean



The memory groups in Royal Wootton Bassett and Calne continue to thrive thanks to their very committed volunteers.

Swindon Mobility Club

The Swindon Mobility Club is made up of people who have mobility issues, their carers' and anyone who has an interest in the group. New members are often introduced by word of mouth.

We meet every 3 months at the Civic Offices, Euclid Street, Swindon.

It's a very informal group where members have the opportunity to have a chat and socialise over coffee and biscuits.

The discussions are predominantly around mobility, however, if anyone has any other information or ideas they wish to share, these are always welcomed!

'A great opportunity to get together socially'

'Share useful information'

'WSUN has the knowledge to help put our ideas and issues forward to the relevant professionals/authorities'

'A good place for us to discuss mobility issues'

'WSUN are able to help us get our issues to the right place'

'WSUN will always try to get some answers for us'



There has been an increase in members over the months, however new members are always welcome!

Meet Liam, Wiltshire Independent Travel Support (WITS) Service User

'When I started the travel training with the WITS Travel Trainer, I was very anxious and nervous and did not know what to expect, as I had never gone anywhere independently, let alone travelled independently before. My mum was just as nervous as me, if not more, and she came with me and the travel trainer on the first journey. My travel trainer helped me with learning the route to college. As well as teaching me the way to college, she increased my confidence to the point where I could do bits of the journey on my own. I was very proud of myself at each step. I was taught timings for leaving my house, and have now learnt to get myself up without any prompting from my parents, so that I am at college on time.

My travel trainer also helped me to learn what to do when things go wrong, and we went through lots of scenarios. This helped me to use my own initiative, and sometimes now, if the bus to college is full, I have actually walked to college by myself, using the route of the bus. This has amazed my mum. In the summer, when the weather is nice, I sometimes get off at an earlier stop, and walk the rest of the way home, to enjoy the sunshine and have a walk. WITS has given me the confidence to do this.

I am starting a course at main stream college in September, and it is very scary, but I am not as scared as I would have been, because I know that I can do the journey to college by myself. I would like to do more travel training with WITS in the future, so that I can attend job interviews and hopefully get a job somewhere after college.

I was also taught by WITS to do a journey to visit my Nan and Grandad in Wroughton. This was great, as I had somewhere to go during the college holidays, and spend time with my family.

My mum has recently started a new job, and for the past few months, I have travelled to meet her from work, using the bus networks that I have been taught, and walking.

I am now able to go to the travel shop and get new timetables for the buses that I need, and I can plan my journeys on the computer as well.

WITS were brilliant, and the travel trainer was very kind, and very patient with me. I really enjoyed the travel training and I am now able to go to lots of different places. I would never have been able to do all this without WITS, and my mum would not have had the freedom to work the hours she does now, if I had not gained the confidence, independence and freedom that I have now, thanks to WITS.'



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