



An Involvement Event for 18-25 year olds
Leeds Personality Disorder Clinical Network
with
Leeds Survivor-Led Crisis Service

Background

Leeds PDMCN has a rich history of service user involvement. However, the service has struggled to engage younger service users (18-25 year olds) in the range of involvement activities available. This has been particularly concerning given that the average age of service users in the Network has dramatically decreased over recent years. Indeed, the age of service users accessing care coordination in 2017-2018 was a mean average of 21 years (median age of 18.5 years) – this reflects a significant decrease over the last 10 years – the average age of service users accessing care coordination in 2009-2010 was 33 (median 30). There has also been a smaller but noticeable decrease in average ages of service users attending the group programs (DBT and Journey).

YOUNG
PEOPLE



At the **'Reimagining Involvement'** in November 2016, a small group of staff and service users met together to discuss the challenges and opportunities around engaging younger people.

Challenges included the potential impact of diagnosis and stigma for young people, and the difficulties that some young people may encounter in sharing their experiences with adults with whom they do not particularly identify.

Opportunities included the potential benefits of participation for young people, such as providing hope, supporting the development of young people's self-determination and identity, breaking down barriers and supporting the management of transitions. There are also opportunities to learn from those involved with other services for young people, who may prefer to engage elsewhere rather than with mental health services. Developing links between services may be important.

It was acknowledged that it may be necessary to develop forums/involvement strategies/activities specifically targeted at young people, in order to engage them in proactive and creative ways with their own peer group. As a result, an event specifically for younger adults who are using or who have used the Personality Disorder Network was planned.

Overview of the day

'**Your Voice**' was held on Thursday 14th June at the West Yorkshire Playhouse to explore young adult's experience of using the Network and how they might prefer to 'get involved'. 90 current and recently discharged service users were sent a postal invitation, designed by a former service user.

The event was co-designed and co-facilitated by James Smith (service user), Liz Smith (LSLCS) and Ruth Sutherland (Clinical Psychologist/Network Involvement Lead). Sharon Prince (Network Clinical Lead) opened the event.

The event included a range of creative opportunities to give feedback about service user experience of the network, including group discussions, emoji rating scales, drawing and writing, and online feedback (Padlet and Twitter #YourVoice)

Three young people attended the event, all of whom were previous attendees at Network Group programs (DBT or Journey). Additionally another service user gave some feedback over the telephone, as she was not able to attend in person.

Feedback

Your Experience of using the Network

A group discussion took place about what has worked well, what has not worked so well, and how this might connect to the particular needs of young people.

Issues Specific to 18–25 Year Olds:

All groups
<ul style="list-style-type: none">• Money and benefits – expense of getting to group• Time off work – 0 hrs contracts – Groups are in working hours• No evidence from group to get support/time off from work• Difficulties with GP's – getting support• Families have "old school" views of mental health and may not be supportive• Nothing there unless you're in crisis• Difficulties managing administrative tasks, such as letters, forms, etc• Waiting lists and being "in between services" - poor communication between services• Trust – one bad experience can mean your whole relationship with the service is compromised• Hard to navigate different parts of LYPFT services

What's working?

Journey
<ul style="list-style-type: none">• Contact from staff while on waiting list was helpful - knowing what was going on, how long to wait, etc. – helped "keep the faith".• Positive impact on normal day-to-day life• The closed group felt safe• Natural feel to activities• Phone calls received from staff between meetings were helpful• The opportunity for some confidential 1:1 time and some crisis support• The end of project report was initially upsetting but later was a good reminder of progress and positives – helps to prove what you achieved & validates what you did
DBT
<ul style="list-style-type: none">• The importance of an opportunity for 'normal' chat and interaction with others, particularly during breaks – helped me to feel 'human'• Feeling listened to by group facilitator (particularly during assessment)
Both groups
The benefits of being in a group: <ul style="list-style-type: none">○ Sense of not being alone○ Feeling supported○ Positive reinforcement from peers○ Being confident to discuss experiences as others might share similar things

Room for improvement:

Journey

- Workplace not taking self-referred services as seriously (i.e. don't see the service users problems as serious or as needing support)
- The session on building up to ending was mostly spent giving feedback and did not focus on dealing with 'Ending' – endings should be more structured
- Some things are not appropriate to discuss in the group - the option for more 1:1 input, encouragement, clarification etc. would be helpful
- Pressure to get through content of group meant that useful discussion often got cut short. Some extra reflection time would have been useful.
- Service users not told 'up front' they will have to pay for activities at the end of the group – this was then not affordable for some group members, but notice could have helped.

DBT

- Long waiting lists and unclear information
- New people joining part way through affected group dynamics and how this was managed
- Not being told about new people joining the group
- Disruption in groups was unsettling
- Lack of follow-up when people have to leave group early
- Limit to what 'skills' can help with especially when at crisis point - would like some individual input
- Hard to have a 'bad day' fear of how it will impact the group – tolerance of others' varying states.
- Flexibility (e.g. if finding things tough) depending on how you are.
- Managing expectations on ongoing basis

Both groups

- Lack of clear pathway through services
- Lack of crisis support options
- There should be options outside work hours for peer support
- No follow up or support after group program ends – endings feel abrupt
- A sense that services lack a sense of 'urgency' to help people quickly when they need it (although acknowledging that services are stretched and underfunded)

Rating Your Experience:

The group was asked to rate different aspects of the service provided by the Network.

Rate the Network!	
Use the emoji stickers to tell us how we're doing...	
Self-referral forms	🙄 🙄
Meeting your worker for the first time (assessment)	😊 😊 😊 😊
Where you meet your worker / group	😊 😊
Our website	
Making sense of your difficulties and what you need	😄
Involving you in decisions about your care and treatment	😊 😊
Journey group meetings	😊
DBT group meetings	
Your care coordinator / group facilitators	😊 😊
Letters we send you	😊
Helping you to achieve your goals	😞
Supporting your family / carers	😞
Being discharged from the Network	😞 😞
Helping you connect with other services or activities	😞 😞
Listening to your feedback	😞 😊

Whilst the numbers are small, the ratings given here give a 'sense check' of what might be working well and what might not be across the service.

The feedback indicates that:



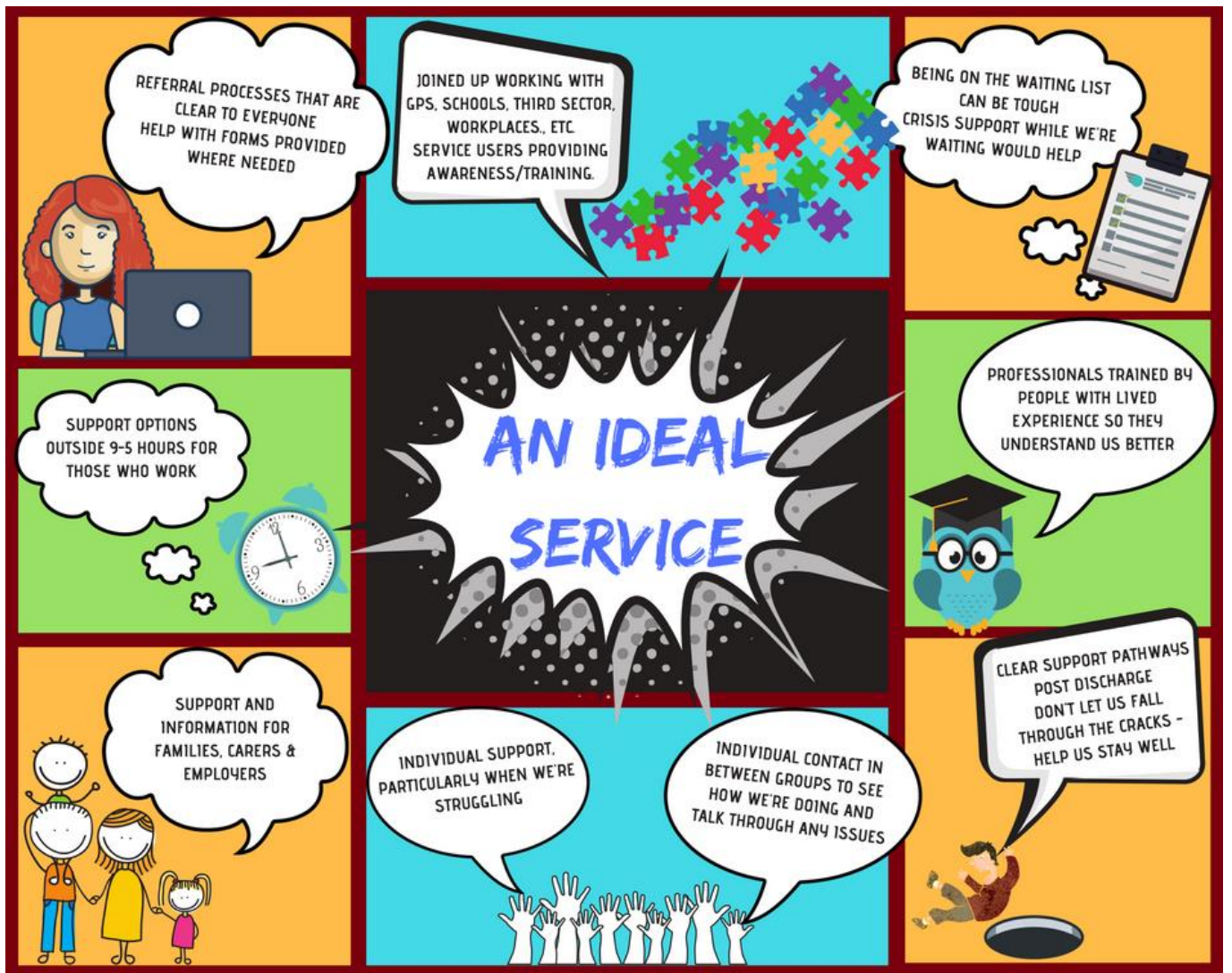
The young people's experience of initial assessment, group facilitators and group venues is generally positive, and that they feel involved in decisions about their care.

However, self-referral forms are difficult to complete, and being discharged is very difficult experience. Service users don't feel they have been well connected with other appropriate services or activities.



Your ideal service

The group was asked to draw or write about what an ideal service would look like.



(see appendix 1 for full details of feedback)

A Recipe for Awesome Service User Involvement

The group was asked about how they would – and would not – like to be involved.

Ingredients

Some great people
Some relevant and useful training and skills
Regular peer support
Meaningful activities and projects to work on
An occasional business meeting
A dash of qualitative feedback
A pinch of social media and communication



Method

Step 1: The foundation – people, skills and support

First, you will need some really great young people who are interested in being involved and changing services for the better. This will be your foundation. Nurture their enthusiasm, grow and develop them. Give them opportunities to do meaningful activities that will make a difference. Add in some quality training – for example training in how to facilitate groups, write blogs, or deliver training – and you'll have some well skilled and highly creative people for your foundation layer.

We all have a lot to give, but we also need support to reach our full potential and on days when we struggle. Peer support is an essential foundation ingredient because it gives people the skills to support one another in a safe and contained environment. This might also include specific groups or sessions for certain groups who face particular challenges, like LGBT young people or young parents.

Step 2: The filling – projects, activities, achievements

This is where we want our meaningful activities. What we mean here is projects for people to get involved in and accomplish something to build confidence and skills. Things like the opportunity to train staff and raise awareness in the community about the issues service users face – like stigma. Volunteering opportunities could include, for example, going out into the community to challenge stigma, helping to train frontline health professionals like GPs in how to respond compassionately to someone with a diagnosis of PD, especially when they're in crisis. Make sure to add a dash of creativity into these opportunities and encourage people to mix in some imagination. The filling needs a basic stabiliser as well as all the flavour and excitement though, so don't forget to take care of internal business and give people the chance to attend the more formal board meetings and steering groups if they want to.

Step 3: The icing and toppings

So when you get to icing your involvement cake, you want it to look good, but you don't want to overdo it and overpower the rest of the recipe. We still want to be able to see and experience the foundation and the filling – not overpower it with too many ingredients and flavours.

The icing – feedback

What we don't want here is a load of tick-box questionnaires. People don't feel like they fit into boxes, so instead add several good quality surveys, if you're going to use them, that give people opportunities to give feedback based on their individual experience. And then don't forget – you need to use that feedback. Don't leave it out of your recipe, because you'll miss a vital ingredient.

Toppings – social media/communication

Be careful with the toppings. Don't just throw your communications out there without thinking about how you do it, because nobody likes social media for the sake of it. Social media needs some careful filtering and thought putting into it before using it in this recipe. We need to think about safety and privacy, for example. Social media has some positive uses, for example making sure everybody knows about the awesome opportunities available and to celebrate our achievements. But too much of this can quickly spoil the recipe if it's used too much or in the wrong way at the wrong time.

Summary

There is a clear need to involve young adults in ways that are creative, engaging and collaborative. Young adults want to meet together to provide peer support and to engage in meaningful activities that bring about real change.

Action Plan

	AIM	ACTIONS	WHO
1	Develop an involvement group for younger service users (18-25).	<ul style="list-style-type: none"> Consider times and venues. Discuss existing involvement guidance documentation and consider what needs changing/adding for young people's group. 	RS & YP
2	Learning about and engaging in the debate about the diagnostic label of 'Personality Disorder', to inform development of training programmes	If possible, for YP to attend event on diagnosis in Leeds, 9th November: https://www.eventbrite.co.uk/e/a-disorder-for-everyone-challenging-the-culture-of-psychiatric-diagnosis-exploring-trauma-informed-tickets-44284832125	RS & YP
3	Develop post-discharge Peer Support Groups	<ul style="list-style-type: none"> To engage in consultation with DIAL House about Peer Support To attend Involvement Event on 'Transitions' on 13th November 	YP/LS YP/RS
4	Develop training programmes for Junior doctors and GPs	<ul style="list-style-type: none"> Sharon to send information to Ruth about link people. Ruth to arrange planning meetings with YP 	SP RS/YP
5	Promote support for carers	Ruth to support liaison with Carer Consultants Involvement group	RS
6	Improve information provided to service users at the point of discharge about support available and opportunities for involvement	RS to discuss with team at Involvement Steering Group	RS
7	Develop information for workplaces about supporting people with personality disorder / experiences of childhood trauma	<ul style="list-style-type: none"> Sharon to support in connection with developments at 'Visible Leeds' JS to write a brief 'case study' about his experiences in the workplace 	SP JS
8	Ensuring specific feedback about the Network services are circulated to relevant staff and responded to.	Ruth to circulate document and discuss at Involvement Steering Group	RS
9	Consider development of a volunteer 'link role' for young people	To be discussed at Involvement Steering Group	RS

Appendix 1: Your ideal service - All comments

Referral

- Support with self-referrals and other administrative tasks for those who struggle – ensure it is clear how to access this help
- Be clear that referrals to DBT/Journey can be self-referrals OR professional referral (some professionals have said that service users **have** to self-refer)
- Crisis support should be available whilst service users are on a waiting list
- Provide good quality information e.g. through social media

Care and Treatment

- More consistent individual support
- More awareness of job commitments for those in work - groups (including those in 3rd sector) typically fall during 9 to 5
- Longer sessions in groups
- Follow up contact between groups – for crisis support, skills practice, etc

Support for families and carers

- More support for partners / families, particularly for those in crisis

Service User Involvement

- Helps you see a future and helps to gain trust
- Involvement should be 'real life' not 'text book'
- Service user led training for professionals.
- Co-develop meaningful questionnaires for assessment and outcomes
- Contribute to a service 'Blog' (anonymously)

Provide training and resources to other services

More awareness is needed regarding the needs and difficulties of people with a diagnosis of personality disorder. The service needs to communicate and liaise better with professionals in health care, social care, education and in the workplace. This might include:

- Service user led training for professionals
- Training and support in schools
 - More resources for teachers / tutors to identify mental health issues
 - Mentors for young people
 - Help young people identify issues / self-help before crisis
 - Clear information and support for young people to access help
- PD Awareness events or open days for Service users, family/friends, GPs, teachers/tutors, bosses, which provide information on :
 - Understanding personality disorder
 - Know when to help and how to help
 - Identifying and avoiding crisis
 - Information on where to go for help or support

Discharge/endings

- The service should create a booklet that can be handed out at the end of services, which includes information about other services / help / groups / peer support.
- Don't tell service users to self-refer into services that no longer exist!
- Service users are likely to need help to transition into other services/support groups - a recommendation may not be enough, making the first step into a service takes a lot of confidence.

Post-discharge

The transition from being part of a regular, intensive group programme to 'nothing' is difficult. Service users feel they are 'falling through the cracks' – they are considered 'too well' for specialist services, whilst 'too complex' for primary care (e.g. IAPT). Instead, an ideal service should provide follow up in order to improve this transition and prevent crisis/relapse. This could include:

- One off last group session focusing on the ending
- Phone calls or 1:1 appointments
- Follow up session 1-2 months after discharge to re-enforce everything learnt in group
- Crisis support after discharge
- Structured and safe peer support - maybe one a month, maybe more frequent.