

Nothing for us without us

We want young people with lived and living experience of substance use to be at the heart of the design and delivery of young person's services.



Who are people with lived and living experience of substance use?

Definitions differ depending on the source, but essentially, people with lived experience are people who have previously been affected by their own or a family member's problem substance use, and the individual may define themselves as in recovery. In relation to people with living experience of substance use, this refers to people who are currently affected by their own or a family member's substance use, and the individual may be accessing treatment services for support. We seek to effectively engage with people with such experiences and involve them in as many parts of service delivery as possible. However, we feel there is a significant gap in engaging with young people with lived and living experiences in the design and development of services, and subsequent delivery, that are aimed to support them.

We believe that young people with such experiences have much to teach us and we have a lot to learn from them. Subsequently, young people have a significant amount to offer when it comes to designing services that are for them, and to support them in overcoming challenging and difficult situations, as well as providing the foundations for them to develop and flourish, as they move into adulthood. Not only can we learn from young people but one of the main benefits of involving them in such processes is that they have privileged access to other young people, which allows for the creation of additional ideas regarding the development of services, as well as develop critical communication pathways among their peers that could help minimise stigma and associated barriers to accessing treatment services.

What does the evidence suggest?

When it comes to the research regarding people with lived and living experience being involved in the delivery of substance use treatment services, much is in the context of adults. However there have been some studies undertaken regarding youth participation in various aspects of substance use, such as their involvement within research. What has been found is that it has enabled young people to develop a wide range of new skills in communication, leadership, and professionalism [1] as well as highlighting how youth involvement in the co-designing and co-delivery of services aimed at this age group can improve and ensure relevance, credibility, and quality. [2] By involving young people in such processes allows for the design and delivery of a service to ensure as many barriers to accessing support are identified and mitigated against, as well as ensuring that the service mitigates the feelings of being unworthy of support, especially at the prevention and early intervention stage. [2]

Youth Ambassador Service (YAS), Gwent N-Gage

"The YAS allows us to have our own voice in how we think services and the delivery of services should improve. It is about how we think we can get more people involved, because it's all good you adults trying to get us involved, but the people who know us and our age group, is us.

"Gwent N-Gage have reached out, by developing the YAS, to get our advice and opinion on how we would like to see things run and then you guys (services) can help facilitate these for us.

"Being involved in YAS gives me something positive to work towards and be proud of and gives me another reason to keep off the smoking (cannabis)."

Rin, founding YAS member via Drugs Unwrapped podcast. [3]

Meaningful inclusion of young people who are, or have been affected by substance use, is fundamental to harm reduction including in the design of services, service provision, policymaking, and forms of advocacy. [4] However, across academic literature, there are very few examples of best practice and equitable engagement of young people on such matters, not just in Wales and the UK, but across the world. Evidence points to that when young people have been involved in harm reduction development and policymaking, it has often been tokenistic that doesn't provide clear expectations or autonomy over decision-making. [4]

Why now?

Within treatment services, there is a big emphasis on the importance and value of involving people with lived and living experience of substance use, in the delivery of harm reduction interventions. Advocacy for this has grown significantly over the last few years, which has seen many services across Wales facilitate peer to peer naloxone distribution, to complement existing models of disseminating the lifesaving medication. [5] Such projects include people who have both a vested interest in naloxone, as well as privileged access to individuals at risk of being affected by an opioid overdose, that may not be in contact with treatment services. While that is just one example of people with lived or living experience being involved in the delivery of substance use services, their involvement within the design of services, in particular young people, is much less limited.

People with lived and living experience of substance use bring a different perspective to service design, its delivery and related policy as their own experiences can help highlight gaps and flaws within the substance use treatment system, as well as across other societal systems that may better harm reduction interventions overall. By recognising and utilising a young person's experience and knowledge of navigating systems and their first-hand experience of stigma, enables policymakers, in conjunction with young people, to identify barriers and associated solutions thus develop and design high-level, cost-effective, and equitable services.

It has been recognised that including the perspectives of people with lived and living experience results in guidelines, strategies and policies becoming more consistent, while recognising their experiences are integral at all levels from service design to evaluation. [6] However, what is significant is the benefit people with lived and living experience gain from being part of such processes, including increased confidence and self-esteem, increased stability and structure, opportunity to gain new skills, empowerment, and increased recovery capital for both individuals and communities. [7]

What have Barod done and our next steps?

Over the last few years, we have recognised the need and desire of young people to be involved in how harm reduction services, aimed at them, should be developed, and delivered. Subsequently, many of our young person's services have established forums that enable young people to have a voice and express their ideas on ensuring services become as equitable, appropriate, and relevant, as possible. Most recently, the Youth Ambassador Service, a young person's forum within Gwent N-Gage, [8] helped write our responses to the recent bid for the tender of young person's services in Gwent. We see this, as well as the development of such forums and inclusion of young people within interview panels, as just the start.

What do we want?

- We call on all Area Planning Boards across Wales, to include young people with lived or living experience of substance use, within service design, development, delivery, monitoring, and evaluation of young person's services.
- We also call on Welsh Government to include young people with lived and living experience of substance use to be included in consultation exercises related to the development of frameworks, strategies, and policies, that directly affect them.

References

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6. Sunkel, C & Sartor, C. (2022) Perspectives: involving persons with lived experience of mental health conditions in service delivery, development and leadership
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