ADP and Homeless Programme: Reducing Harm, Improving Care

Putting People First: Involving people with lived and living experience in the design and delivery of services - a family member's experience

As part of the ADP and Homeless Programme: Reducing Harm, Improving Care, we wanted to understand the experiences of family members and carers of people who access alcohol, drug and homeless services. To recognise the impact for family members and understand the need for support when navigating services.



Healthcare Improvement Scotland worked in collaboration with Scottish Families Affected by Alcohol and Drugs (SFAD) to gain insight into caring for a family member who is accessing alcohol, drug and homeless services.

This is Laura's story.

We would like to thank Laura for sharing her experiences with us and Scottish Families Affected by Alcohol and Drugs for their support throughout the ADP and Homeless programme: Reducing Harm, Improving Care.

If you are concerned about someone else's alcohol or drug use, you can contact Scottish Families via - Helpline: 08080 10 10 11

Email: helpline@sfad.org.uk

Webchat: www.sfad.org.uk



Background to Laura's story

Laura is a mother to 3 children who has been supporting her ex-husband to access mental health and homeless services for 12 years. He has been experiencing poor mental health, homelessness and rough sleeping after experiencing drug induced psychosis in 2010.

Laura wants services to understand her ex-husband's situation, the person he is and the change in his behaviour. The system is complex and has been a barrier to him successfully accessing the services he needs. Laura feels that family members and carers provide this support but it's exhausting, all responsibility is often left with them when it should be with the service providers. Services need to be supporting people wherever they are on their journey by offering a trauma informed, person centred service **"where every door is the right one".**

Laura has experienced difficulty being involved in his care coordination and decision making with services and there has been no continuity of care. No service or worker has stayed involved in his care over the years apart from Laura, she feels having continuity from services would have made a huge difference to his recovery. She doesn't think of herself as a carer, but as someone who is trying to support a loved one access the services he needs to be well **"never thought of myself as a carer as I can't care for him".**

Laura's experience engaging with services

As Laura's ex-husband is not well enough to access services on his own, she has been trying to support his engagement with homeless and mental health services. She has found it very difficult to be involved in his care and treatment as well as accessing information. She is not listened to as she is excluded by services from being involved in his care because he is an adult. Trying to take on a carer and supporting role has been both mentally and physically exhausting for Laura and her children **"every door is the wrong door"**.

Often, Laura's ex-husband is only able to access the services he needs when he reaches crisis point and is admitted to hospital **"In all points in time where I could have been involved, interventions could have been sooner"**.

Laura does not feel she is taken seriously by services, she also feels judged and stigmatised when trying to access support for her ex-husband and does not feel supported or acknowledged as a carer/family member by service providers. However, support from third sector homeless outreach organisations has helped her ex-husband build relationships and trust with workers to access services in the short term.

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Impact for family members

Because there has been a lack of coordinated support in Laura's ex-husband's care and treatment, he has been unable to navigate the system and access the services he needs without family support for 12 years. This has had an impact on not only Laura's mental health, but her wider family too, this includes her children, parents and her husband's parents **"nobody thinks of the impact on the family, where is our support in the system?"**.

Laura feels if just one service or key worker had stayed with her ex-husband throughout his journey, this would have made a world of difference **"the system needs to find the person, welcome them in, and not let them go until they are in a place where they are living life as it should be lived".**

At one point in her ex-husband's care, when he was rough sleeping, her son felt the need to step in as a carer to give Laura a break. Because of the upset and trauma of seeing his Dad rough sleeping and being unable to care for himself, this caused a significant impact on his mental health and wellbeing, leading him to step back from being a carer, he was 21 years old. **"We have fallen through the gaps as well, 5 lives were affected"**.

From Laura and her family's experience of trying to take on a carer role, they have found it very difficult to access family care and support from services and have spoken about being judged and stigmatised when trying to engage with service providers, feeling that the harm and trauma to the family is not taken into account. **"The impact on the family has been huge, given no support, we weren't coping and didn't get any help"**.

Her children also suffered from stigma and judgement when they were attending school **"the stigma of their dad going to prison is huge"**.



Summary and key themes

Laura's experience of supporting a loved one's access to services highlights why she feels services, and people who access services, would benefit from including family members in conversations about their care and treatment, particularly when they are able to provide information and insight about their loved one when the person is unable to. This can help service providers and health professionals understand the issues, get to know the background of the person, which can then lead to quicker interventions, enabling care and treatment before crisis point.

Laura's goal is for her ex-husband to reach a stage in his care and treatment where she can step back, where he is well enough to be able to create and maintain relationships with his children and access the services he needs with the support of service providers. With person centred, trauma informed care and support for both the family members and their loved one.

Family/carer Involvement in our future work

We understand how invaluable it is to learn from the experiences of family members and will continue to work with organisations such as SFAD to ensure the voice of family members/carers are heard in our future work within the alcohol, drug and homelessness agenda.

Need for continuity of care throughout care and treatment journey

As Laura's ex-husband did not experience a service or worker involved in his care over a long period of time, there was no continuity or opportunity to build relationships. To have this would have made a positive difference to his care and treatment journey.

Need for Care Co-ordinated support

Because her ex-husband is not well enough to access services on his own, the involvement of a carer or family member, where an individual needs support to access services, would enable a more coordinated approach.

Third Sector family support

Although Laura and her family were unable to access support through statutory services, they were able to find support through third sector organisations such as Scottish Families Affected by Alcohol and Drugs.

Benefit of involving family

Laura feels that, as a family member, she is not listened to by services, but that her involvement, understanding and support would help services understand her ex-husband and what his needs are. Not being involved in care and treatment has led to missed opportunities for interventions.

Support to navigate a complex system

Laura has found that there are many services who provide support in mental health, substance use and homelessness, but the system is complex. In the absence of service led care coordination, help is required for the service user to navigate around it, with family support being key to a positive outcome.

Impact for family member

Supporting a loved one to access alcohol, drug, mental health and homeless services can have a significant impact on mental health and well-being for family members, not just immediate family but wider family members too. Family support provision should be considered by services.

"There is no place that can address all his issues. Until this is created, until you get rid of the boxes and fit the services to meet the person's needs, do a proper trauma informed service."

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