

Family matters

Many services are ignoring the fact that family members need support too, and overlooking the positive role they can play in treatment. **David Gilliver** reports

I'll never forget the feeling I had when I walked in the first day and saw other parents there,' says Jane (not her real name). 'I realised we weren't alone.' Jane first accessed the Leicester-based Snowdrops family support service five years ago, after struggling to cope with her son's drug problems for more than a decade. 'I just talked and talked and cried and cried,' she says. 'It was the first time in 12 years I'd spoken about it.'

According to a new report from Adfam, *Identifying the role of families within treatment*, family members and carers of people with substance misuse issues are being woefully neglected by services. This is not only traumatic for the families, it says, but counter-productive as available evidence shows that participation of family members in treatment can have a genuinely positive effect. The paper calls for more research into family involvement in the treatment of adults, as up to now the focus has been on adolescent substance misusers, and states that when family members are willing and able to help, their needs should be included in treatment and support plans.

Jane's son has been a drug user for 18 years. 'I was in denial at first – as a mum I didn't want to believe it,' she says. 'We're a family with four sons and a mum and dad, very stable. He had a really good upbringing with both parents there for him. People associate drug taking with broken homes and families that don't care, but our son came from a loving, caring home. I never told people because I felt ashamed – I thought they'd judge me and think I wasn't a good parent. We felt so isolated as a family that I can't put it into words. There was just nowhere to turn.'

It is precisely this all-powerful sense of stigma that stops many parents and carers from accessing the services they so desperately need. 'Even if there is support available families often don't access it,' says Adfam chief executive Vivienne Evans. 'And they don't make a fuss about the fact that there isn't any because they don't want to talk about it.'

Christine McEvoy is parents and carers development worker at the Drug Advice Centre in Leicester and founder of Snowdrops, the service Jane turned to five years ago. 'Sadly by the time people come to me it's because they've tried struggling with the problem themselves for so many years in isolation and have come to the end of the road,' she says. 'They carry a lot of guilt and shame around.'

And of course when they do summon up the courage, there's often little or no support available. 'In Leicestershire and Rutland I'm the only worker who works specifically with that group of clients,' she says. 'It's very under-funded. Family members are an under-used resource, because they often very much want to be part of a person's treatment and recovery programme, with the consent of the client of course. To be fair community drug team caseloads are huge – there are the odd workers that will go the extra mile and try to involve families, but generally they don't have either the resources or the time.'

Often the first point of call is the family GP but the report points out that most are simply out of the loop and unaware of the services that do exist. 'I try to get information to GP surgeries as often as I can,' says Christine McEvoy. 'But it would be nice if they had someone they could refer parents and carers to rather than just writing them a prescription for sleeping pills, which is what we tend to hear goes on.'

This is certainly borne out by Jane's experience. 'First I took him to the doctor because I thought "he'll know", but he didn't,' says Jane. 'There was no referral to anything. I was desperately ringing any numbers I could find for advice and support, but for parents there was absolutely nothing.'

She eventually got her son onto methadone, but he continued injecting heroin and getting into more and more trouble with the police. 'I can't put into words the strain it put on the family,' she says. 'Our son was chaotic but so were we – we didn't know what to do. And of course a drug user is great at manipulating the parents, so I'd be giving him money and thinking I was doing the right thing while his dad was very angry with him, which put a huge strain on our marriage. His brothers didn't want to be in the same room with him. I knew nothing about addiction or how to cope with it. This went on for 12 years.'

Her health suffered and when the family moved for work reasons, Jane let her son stay in the house. 'I ended up working more or less just to pay his bills and keep him in his addiction,' she says. 'I was enabling him, but I didn't know that at the time because there was no support – we didn't know what else to do. He eventually went to prison.'

Jane finally heard about Snowdrops through the local church. The effort of making the first call, however, was overwhelming. 'I thought "I'm going to let people know I can't cope, and they're going to think I'm a bad mother",' she says. 'But I made the call, and once I walked through the door and saw there were other parents there – I'll never forget it. I could speak openly and honestly and didn't feel ashamed – to be there with people who understood and without being judged was amazing. I remember coming home and just crying with my husband and saying "we're not on our own, it's ok, there are other people out there like us".'

One of the main benefits of the support was to enable her to establish boundaries with her son for the first time. 'As I went to the meetings I started to get stronger,' she says. 'I was going on training days and was able to empower my husband and my other sons as well – the dynamics in the family really changed for the better. I'll never forget the first time I told him I wasn't going to give him money. He was astounded, saying he'd have to go out and steal. I just said if he did that he could face the consequences. I wouldn't have been able to do that before – I would have given him the money.'

Adfam's report, however, makes the point that some services may be reluctant to involve family members and partners in treatment because they feel they could be a negative influence – especially if they have their own substance misuse issues. 'Clearly practitioners will come across dysfunctional relationships in families, co-dependence and situations where the family is either unable to help or a very real part of the individual's problem,' says assistant director (policy and service development) at Princess Royal Trust for Carers, Alex Fox. 'But that shouldn't stop them recognising the potential for some families to contribute to their relatives' support and work with them to raise their understanding of substance misuse, the factors that influence it and what's helpful and what's not, because that's not necessarily something families will intuitively understand.'

So from a policy point of view, what needs to happen? 'Obviously it would be

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great if there was a specialist support service for carers and family members in every locality,' says Vivienne Evans. 'If I'm being realistic, that's not going to happen, so I would say we need to encourage existing services for carers to get skilled up to deal with drug and alcohol issues – perhaps second a specialist worker, as well as encouraging drug and alcohol services to run a family service. But you need to have a great deal of sensitivity, not just people walking into a drug service and someone saying "the family bit's over here". It needs to be thought through.'

Another problem is that many of the services that do exist focus exclusively on drugs. 'Specialist services to support families tend to be in DAAT areas where there's a commissioner who's passionate about family work and prepared to put some money into it,' says Vivienne Evans. 'But there's a disproportionate focus towards drugs rather than alcohol which needs to be addressed, and there's also all the people out there, and we have no idea how many, living with someone with a drink problem who don't go for help at all – people nowhere near treatment because they don't want or think they need it.'

Is there some hope that things could change? 'I haven't seen any signs of it,' says Christine McEvoy. 'I've been in post six years as a lone worker and each year we hope things will improve, but nothing seems to change. We thought families would be more of a focus in the new drug strategy, which they are in terms of children and siblings but not parents and carers. I know it always comes down to funding with everything, but I would like to see some core funding made available because projects are struggling from one year to the next.'

'I think the NTA's new guidance for DAAT commissioners on family support is going to be a positive step,' says Alex Fox. 'What we'd like to see is some resources behind that in terms of training and awareness raising, because there are still DAATs that would probably take the view that supporting families isn't their business. Many people with substance misuse problems never reach formal treatment, so the only way of positively influencing their substance misuse is by reaching their families, and that doesn't necessarily have to be a particularly expensive exercise.'

The irony, says Jane, is that investment now would save money in the long term. 'We could save the NHS so much. I'm closely involved with so many families who are suffering through drugs and alcohol and I'm not even a worker. I've had meetings with the NTA and DAATs and it still feels as though people aren't listening, or not acting on it if they are. I'd love to go and meet the government face to face in their cosy offices. They're always banging the drum about how important families are and the holistic approach, yet there's so little family support – let them put their money where their mouth is.'

Jane's son is now using again after being drug free for 18 months, but the support they've received means the family can now cope with the situation far better. 'The help we've had has united the family,' she says. 'His brothers get on with him now, and we've set boundaries – like him not using in the house – that more often than not he'll respect. Years ago we wouldn't have been able to do that. I don't judge him any more.'

Identifying the role of families within treatment is available at www.adfam.org.uk