Appendix 2: A case study of a carer in B&NES

Overview

* This carer has been caring for their child in Bath and North East Somerset for the past 30 years who has autism and other mental health issues.
* The person does not live with the carer but is with them most of the time. The carer has had to turn down work opportunities to be there for the person they care for.

The invisibility and isolation of the carer role

The carer is often excluded from the decision-making process and is ignored by professionals, despite their central role in the person’s daily life.

*"I’m rarely asked for my opinion by clinicians.”*

*"Confidentiality is always used as the reason for not being involved – and this is the case for all other carers I know."*

*"They ask me for personal info about the person but won’t tell me anything in return."*

Constant state of crisis and hypervigilance

The carer lives in a near-permanent state of readiness, anticipating regular emergencies without external support.

*"I always have to keep my phone charged and a full tank of petrol in case something happens."*

*"There’s an emergency at least once a week."*

*"There have been occasions where I’ve been out all night looking for them."*

*"Crisis lines just tell me to ring the police – but the police don’t know how to deal with autism."*

Systematic barriers to accessing support

Legal and healthcare systems often fail to support the carer, especially since the person being cared for is an adult

The carer feels that healthcare professionals use things like confidentiality to their advantage by asking the carer for personal information about the person but will not tell them any information they deem to be sensitive.

*"The police are no help – they don’t understand autism."*

*"Because they’re over 18, I’m told they can spend their money however they want – even if it means I have to pay for food.”*

*"I don’t feel like any of these organisations actually listen to what carers want."*

*"Professionals just blame me if they miss appointments."*

The mental and physical impact of caring

The carer experiences lots of physical and emotional effects as the result of long-term caregiving with very limited support.

*"I feel mentally exhausted – like there’s never a true picture of what’s going on."*

*"Sometimes I have to just shut myself off for a few days."*

*"It’s all-consuming – it’s what I’m thinking about all the time."*

*"I have psoriasis and heart arrhythmia – it’s all stress-related."*

*"I also care for other family members and support other carers – it’s too much to contain."*

Suggested recommendations from the carer

The carer argues for a more tailored and effective system of support that respect the realities of caring for someone with complex needs

*"There needs to be a crisis line for carers – one that actually responds and doesn’t just signpost."*

*"I understand they’re an adult, but there should be better options for emergencies."*

*"Professionals need proper training around conditions like autism."*

*"It feels like no one’s actually listening to carers.”*