



The law and social work in Scotland

Long-term caring

Nick Balneaves:

The voices of long-term carers, people who care for relatives and loved ones, can be difficult to hear in the clamour of competing interests. But theirs is an essential voice. Isobel Allan is a carer from Glasgow and this is her story.

Isobel Allan:

I care for my twenty-six year old daughter, her name is Susan. And I've been a carer to Susan for over twenty-six years, and my daughter is profoundly disabled both physically and she has very profound special needs.

Nick Balneaves:

What was your and Susan's introduction to social work services and to care services?

Isobel Allan: I guess our first introduction came when Susan was about thirteen or fourteen initially because that's when we started to use respite. That was a hard transition to make to let your child go to such strangers. That was the very first thing and then the big thing came in the transition when Susan had to leave the special needs school and come out into the big world, if you like. Only then did I realise that the education system cocooned her to some degree. She had a right to education but once she left education, she had no rights. They didn't need to provide a day centre. They didn't need to provide support mechanisms for her. And it was unbelievably scary.

Nick Balneaves:

So how did you go about getting more help in the end then?

Isobel Allan:

Partly through the social work resources, partly through my own investigation to try and find out what was out there for my daughter and partly through word of mouth from other parents. It took us two years to find the right centre for my daughter.

Nick Balneaves:

Tell me about your relationship with social work at that point.

Isobel Allan:

I think what I found at that stage was the social worker at that time wanted to direct her future rather than to work with the family and I found this actually quite infuriating and very disturbing because this was still my daughter. And for example, I found the social worker then at that time was really directing our future by making appointments without consulting me, without involving me.

Nick Balneaves:

What was your response to that?

Isobel Allan:

Well, quite frankly, I didn't permit it. I was absolutely determined that this was my daughter who I had lived and loved and cared for and unless my expertise, my knowledge, my skill was taken on-board, I wasn't going to permit somebody to walk into her life who didn't know this woman and tell me what was best for her, I mean that is arrogance at its worst at the very least it was uncourteous.

Nick Balneaves:

Did your social worker take your concerns on board?

Isobel Allan:

No, he took it quite personally, which actually reinforced to me that it wasn't a very professional way to deal with things. However, believe it or not, we worked together over the years and we worked our way through these things. But I think the power is a bit power based, you know. Many people who work in that very powerful situation, I believe, can use their power very inappropriately. Power at its best should be used that you never know that it's happening. It should be so... you should actually abdicate your own power in order to empower somebody else. So power shouldn't actually come into the equation. It's about being there and using your skill to support a family.

Nick Balneaves:

Let's talk about your situation now. Talk me through what sort of care services are provided these days.

Isobel Allan:

Mmm. Well, the care services that we've got, and I suppose that actually we're quite fortunate. And I say that tongue in cheek because unfortunately it's because I've fought for what I've got for my daughter. So it's not been handed to me on a plate. She goes to a day centre. Now the day centre she goes to was one that was actually created and built by parents of profoundly disabled adults because there was nothing there in the system. And she goes there four days a week. We also have a community-based service that comes in twice a week to help bathe my daughter. And then I also have a system called Independent Living Fund, which I think is brilliant and that is where I personally employ somebody to support Susan two days a week.

Nick Balneaves:

You described it as brilliant. Why is it brilliant?

Isobel Allan:

It's brilliant because it gives me the thing that I'm always looking for in life. It gives me control. It gives me choice and it gives me flexibility. And that's what's crucially important when you're looking after someone.

Nick Balneaves:

Do you not get that from the other services that come into the house?

Isobel Allan:

Well, no, simply because they're too vast, they're too large and they're too prescriptive.

Nick Balneaves:

Talk me through some of the weaknesses of the, the services that are provided to you.

Isobel Allan:

The weaknesses, well maybe in a general sense some of the weaknesses in the services are the fact that they are prescriptive. They have to, for example, if it is a statutory service, you know like social work resources. And this isn't a personal criticism about any individual; it's about the system as it stands. For example if my daughter was in hospital, and she's in hospital quite a lot, and we're discharged, the first call I would make is to a community care agency, not to the social work agency simply because I can get through to the Community Care Agency and I can negotiate what I want on the phone, like 'Could you send out an extra worker tomorrow?' Because Susan's been discharged I need that help. But you can't get that with the Social Work Resources because you can't even get through to the person you want to speak to or it's an answering phone they need to see such and such and such and such to authorise this extra care and it's just a nightmare. It doesn't happen spontaneously.

Nick Balneaves:

So what kind of skills do you as a carer have to develop in order to deal with that?

Isobel Allan:

I think, well the greatest skill – is it a skill or is it a survival technique? – is endurance. You need a degree of patience. You need a great deal of knowledge about the system, so that you can argue your corner and fight for what you know to be right.

You need to actually take care of yourself enough to, to withstand these knock-backs and you need to be able to say no and say what's unacceptable. Because I'm, please take this tongue-in-cheek - nobody can sack me. I can say no to things. Nobody is queuing up to do what I do, to look after my daughter twenty-four/seven. But I need to work with people who will respect my position and offer me the support I believe I need, not what they think I need.

Nick Balneaves:

But surely they should be making that system easy for you. You are obviously quite a strong woman and you have developed these skills over the years. What about people who are not as strong or as knowledgeable as you?

Isobel Allan:

That's a great sadness because folks should get the right kind of support with the right attitude because it should be the way it is, not because they're stropky like me or because they know the law or because they know their rights.

Sadly, that's not the case in life. It's usually the folk who scream and shout the loudest will get the right things simply because they know what they're asking for. In addition to that, staff need to be resourced with the right kind of information, but they need to have some degree of their own power and authority, to free them up from the bureaucracy. So, for example, if I said 'Next week I'm going to a wedding and I really need a bit more extra care', it should happen or they should have the power to be either say yes or no rather than to say 'Well, I don't think that's not allowed in this budget or whatever. This when you get tied up in all these bureaucratic systems that will deal with all these issues but not with the reality of people's lives and the changing element of people's lives.

Nick Balneaves:

Thinking about the day-to-day practicalities of people coming into your home to provide care. What do they do well and what could they do better?

Isobel Allan:

Well, the people that come into my home, what they do well is that continuity. That is absolutely crucially important. There's continuity of the same people coming in knowing my daughter, knowing my home, knowing the layout. What they do well is relating well to my daughter and also keeping within the boundaries of what I'm asking them to do. And appreciating they're working in my home, not in a care establishment. This is my home, where myself and other family members live and respecting that as such.

Nick Balneaves:

Do you think the people coming into your home take your views and needs into account as well as Susan's needs?

Isobel Allan:

I believe they take my views into account simply because I make it very clear of what I'm looking for myself and my daughter. But I also have to resource the folk that are coming in by the right information. So, apart from me saying verbally what I want, I actually have profiles of my daughter, which are updated all the time. Because she's very complex, I have a duty, I think to support workers coming into my house in that respect.

However, when I provide them with the right equipment and the right information I really do expect then they adhere to what I'm looking for for my daughter.

Nick Balneaves:

On a personal level though, what is it like for people who are not family members, who are not friends coming in to your home, to work in your home?

Isobel Allan:

On a personal level, if the truth be known, who in their right minds would want to do that? Nobody in their right minds wants strangers coming into their own home? The reality is I have to live this life. Not because I choose it but because it's necessary, because I cannot care for my daughter on my own. I need other people, but if people could just realise and look at it from where they're at, in their own home, would you value strangers walking in when you're not there.

I mean for example, if I've come in and I'm looking for the butter knife. It's my house, it's my drawer where I keep all the utensils but I can't find the butter knife cos somebody that I don't know has put it in a different place. It's a very surreal life. And in addition you've got to think of, when you've got other family members. Now my sons have grown and left, flown the nest, but when my boys were living here how invasive for them this was, when these troops of people would come in to look after their sister, but this was their home as well. So, not only were they invading the privacy of our home, but my sons' lives were being invaded as well. And that was very difficult for them.

Nick Balneaves:

In a sense, it is an impossible situation. They have to come into the home to provide care, how could make it easier for you?

Isobel Allan:

What can make it easier is if the people coming in have really good boundaries, respect your home and also show good warmth. Use their skill, if you like, but you're meeting a real person. It makes life a lot easier. I think what's crucially important as well is issues of confidentiality because this is my home. You don't want folk carrying things out of your house about yourself and other family members.

Nick Balneaves:

And I guess that again comes down to the continuity of the relationship between you and the people that come in. You can learn to trust them, for example.

Isobel Allan:

That continuity is absolutely critical for the relationship. Not just for my daughter, she needs to see familiar faces, but also for me. I truly would not accept different faces coming in to work with my daughter. Not only would it not be good for Susan, but I couldn't develop that degree of trust. I need to know someone and get to know them and have that relationship with them.

Nick Balneaves:

In practice, how easy is that though? Because there must be situations when people are on holiday, when people are ill, that new people have to come into the house.

Isobel Allan:

Again, I think I've been fortunate or else it's because I've demanded it. That I have requested that there be a core group of people that work with my daughter. If one leaves, for example, I would fully expect somebody else to be trained up. And I think carers need to be more assertive and say 'I'm sorry I'm not accepting that'. I want at least three or four faces that I know to work within that ratio so that there's always one of the four is always coming in.

Nick Balneaves:

Was that forthrightness something that you had to learn?

Isobel Allan:

It was, simply because I had to feel assertive enough without it coming across as was aggressive, but I had to get out of this passive position. There was no point in having folk coming into my home and dealing with something and then leaving and me having felt aggrieved about something.

I had to be open, upfront and deal with issues as they happened. I think this has been a natural evolution in just caring for Susan. Most definitely in the last fifteen years I've been far, far more assertive than I've ever been perhaps because of the revelation that it is me that

lives, loves and copes with her and I don't do a job of work, I live a way of life. Everybody else involved with my daughter in the professional capacity can walk away. I can't walk away.

Nick Balneaves:

What effect does all this caring have on the rest of your life? Is it tiring? Is it stressful?

Isobel Allan:

It's always stressful because you're living a life twenty-four/seven. The stress levels are acute. You have no opportunity to be spontaneous. You have to plan everything. And when you plan everything even to the finest detail, all those plans have to be changed at a minute's notice – if the person takes ill, for example. You're living with chaos practically all the time. You're living with unpredictable situations all the time. You might not be able to get all the sleep you want. My sleep pattern is very erratic cos it depends when Susan is up in the middle of the night. You might not be able to finish that cup of coffee you had cos the person's need always comes first. That takes a very challenging demand on the carer.

Nick Balneaves:

Have you had a carer's assessment?

Isobel Allan:

Well, there's two things about carer's assessment. One is being informed about it. One is having it. I know of carer's assessments. Have I had one formally? Absolutely not. I've never been shown the pro-forma. I've never been involved in the process. I think there's been something done in a very intangible way. But I haven't actually been offered one. However, I should have been offered one. So should many thousands of other carers out there.

Nick Balneaves:

So how easy is it for you to look after yourself and the needs of your family?

Isobel Allan:

I think for me, what I had to learn years ago was how to be selfish in order to be selfless and that means I have to take care of myself first. If I'm not okay enough, I'm not a good resource to my daughter or to the rest of my family.

Now, the paradox is that means I say 'no' to the very people I love, either to my daughter or to my family. And when I say 'no', I've not thought are they're gonna like it. But if I've had enough, I've had enough and if I need a break, I need a break, so that's the way I take care of myself.

Nick Balneaves:

People listening to this interview might think that we've been talking about caring in a, quite a negative way. Is there a good side to caring? Is there a rewarding side to caring?

Isobel Allan:

I hope this doesn't come across as negative either, but I have to be honest with you: I would rather be a mother to my daughter than a carer to my daughter. And the reality is that nobody but nobody chooses to be a carer. If you choose to be a carer it means somebody that you love is sick or ill or is elderly. The minute you become a carer, you can choose whether you want to continue to care, but nobody chooses to be a carer. That's the first thing is I would rather be a mother than a carer.

What's rewarding about being a carer from my point of view is that I have fought really hard and it is so difficult, but I have tried to form an equal relationship with my daughter. And this is a woman of twenty-six who has the cognitive level of a year-old baby, but I still treat her as an equal. That is the rewarding part for me. I do things with my daughter. I don't do them to her and I don't do them for her, I do it with her and that's what's rewarding for me being a carer. Is that easy? No, it's the hardest thing I've ever had to do on God's earth, because it's so much easier to control somebody who can't be involved in that level but to actually treat them as an equal is really, really hard work.

Nick Balneaves:

When you look to the future, when you look to your life and Susan's life ten years or twenty years down the line, what are your thoughts?

Isobel Allan:

I guess when I look to the future, it, it looks quite scary. Susan is twenty-six now. The problems my husband and I are facing now in dealing with Susan are not the problems we faced ten years ago. When I look to the ten years ahead, I wonder where we'll all be. And this might sound a really strange thing to say but for most carers in our position, we would all say we wished the person that we'd loved would probably go before we did.

Now that's not as weird as it might sound, simply because most of us realise that there's not the kind of system out there that all of us would necessarily want for the person that we love. An awful lot of people would dispute that, however, if I had a wish list, I guess what I would love for her is for her to have her own security and her own life with people around her that would care for her the way that I would want them to care for her. I don't know that I feel confident that that's out there yet. So, I guess what I'm looking for for the next ten years is for us to continue to care for her but for us to have increased support to enable us to do that.

Nick Balneaves:

Isobel Allan, thank you very much.

Isobel Allan:

Thank you.