Podcast Transcript: Toward a better system

[Narration] Hi, you're listening to The Purple Orange Podcast and I'm Carey Scheer. For the month of April, we've been bringing you stories and reflections to honour Ann Marie Smith. We want to keep her memory alive and fix the systems that let her down. In this episode, we continue on this journey. You'll hear from two mothers of adult children who live with significant disability.

Here is a warning because they do discuss distressing topics, including times their children have been hurt in supported accommodation.

If you need to talk to somebody after ring Lifeline 13 11 14.

But we share this episode not to bum you out, but because as mothers, they offer invaluable insight into what needs to change, so that their children and others are safe.

[Karen Rogers] Ann Marie Smith absolute brings fear and terror into my heart.

[Narration] That's Karen Rogers. She has a 40 year old son named Daniel who lives with intellectual disability and autism. He doesn't have much speech. But Karen said that does not stop his personality shining through. When they go out walking together, he loves to pick a flower and then carefully choose a stranger to give it to.

[Karen] Some people have cried. And I've had people say to me, I really needed that today. So he just has some sort of inner sense in himself. He knows who needs the flower. He's just such a lovely man.

[Narration] Daniel used to live in a group home. But last year, something awful happened, and Karen made the instant decision to bring him home. More on that later.

[Karen] I know now that Daniel living with us is safe. And I've got things set up for the future, he will stay in this house. And he'll need support 24 hours a day. And we will have that set up so that that will come into play when we're gone. But I know Ann Marie Smith's parents had things set up for the future too, so I'm terrified for his future.

[Linda Mackay] It's very scary. I mean, like Karen said, the parents have set it up so that she's safe and what happened?

[Narration] And that's Karen's friend, Linda Mackay. She's mother to Danielle, a 39 year old woman who also lives with intellectual disability and autism. Danielle is completely nonverbal. Linda says Danielle's been strong willed from the get go.

[Linda] She's got a very distinct personality. Very, I'd say that Danielle, if she could speak, would be very much like me, saying what she believes is right or wrong.

[Narration] Danielle lives in a group home that's four doors down from Linda. Linda said that even though her daughter is in supported accommodation, it does nothing to alleviate her fears about the future.

[Linda] Well, you worry all the time. Danielle hasn't got a voice. I'm her voice. And I step up to the plate every time something goes wrong. When I'm gone, she's on her own, you know.

[Karen] It's absolutely terrifying because we're at the mercy of those people who are caring for our children. And Linda and I hope that we outlive our son and daughter. Because if we're not here, what's going to happen?

[Linda] Yep, we've discussed it many times, I said I'd rather her die before me, you know, so that she's safe, is the words I'd use, safe.

[Narration] To wrap your head around such a statement, you've got to understand what they've been through that's led to so much fear.

Karen said that when Daniel was in a group home, she constantly went in to bat for him. For example, there was a time a staff member spent an excessive amount of Daniel's money and Karen complained. And then the next time she came to the house, she noticed Daniel had bruises on his arm.

[Karen] And I absolutely knew without a shadow of doubt that person who I complained about had grabbed him and been very unkind to him. They offered me to move the staff member who I believed pinched Daniel, and I said no. Because I wanted him in a place where I could watch him. I actually said no leave him there. Because if you put him near someone else, who has got no family, he could be getting away with whatever he wanted.

[Narration] And then there was the incident that led to her taking an unexpected early retirement and bringing Daniel home.

[Karen] Daniel had very severe bruising around his waist and down one of his legs. Bruising like you would not have seen before. The bruises were horrendous. He'd had those bruises for four days before the staff member who I guess we call the whistleblower, rang me and said, "Look, Daniel’s got some quite nasty bruising, and I would like to call in a doctor to have a look at it. Is that okay?" And I said, "Absolutely! Of course it's okay." And then about three or four hours later, the doctor actually rang me and said, "Daniel needs to go to hospital." He said, "I think he's got internal bleeding." We spent the whole night at the hospital. Fortunately, he didn't have internal bleeding. But that's how bad the bruising was. We think he'd probably been hit.

In the morning, we took Daniel back to our home. But we had to stop at the house where he lived to get his medication. And when we stopped at the house, he started crying, saying, "Don't want it, don't want it." So, we said, "No, no, you're not staying here. We're going to go in and get your medication, you can come home with mom and dad." And the service where he lived, they did an internal investigation, but nothing was ever, nothing ever came out of it.

[Narration] Karen's testifying to the Royal Commission about this incident.

Linda says over the years, she's also had many instances where she's had to go in and stand up for her daughter. Probably the worst incident was when she discovered her daughter was being totally isolated.

[Linda] When staff went into her, they held a chair up between her and them, so they didn't get hurt, because she's got behaviour problems, pulling hair, scratching. And so they felt their life was threatened. They actually sectioned off the house at the front with a fence. And they actually called it the 'dog run'. It was to keep Danielle away from staff. And she had access down the side of the house. And she could look through the window and she could see the other clients there. Say there was somebody there playing music or whatever, and she'd have to stand on the outside looking in. And when I said that that's not acceptable. That's abuse. She was out. Simple as that. Move. Get her out.

[Narration] The group home Danielle is in now is significantly better. But Linda says that she still feels she has to be on guard all the time. In fact, she put a complaint in the week before I recorded this interview.

[Linda] My complaint was the supervisor in the house did not know my daughter at all. I could have gone there any time of the day when she was on duty, and she was sitting in that office. And one of the staff members had reported to me that she said, "It's not all about Danielle." And she'd said that she didn't like her. So I said, "Right don't want to work with her, get out." And so I reported it to the manager of the service. And he moved on it very quickly. But he just moved her on to another house to do exactly the same thing with somebody else.

[Karen] Unless things change, I mean the system as it is, is broken. The Daniels of this world get hurt. The Danielles get hurt. And then the Ann Marie Smiths of this world die. We need to work towards it being better than it is.

[Narration] So how do we do that?

First up, they said the support system needs to be revised, across the board, but especially in group homes. They said it's just not conducive to meaningful relationships. They see staff overwhelmed with paperwork and admin.

[Karen] That is the system that we're working with. They have got so much paperwork, and what I would call administrivia that they have to complete that a lot of their job is about doing the paperwork.

[Linda] But that's not what Danielle wants. She wants attention. She wants to be looked after. She wants to do things. She wants to feel important.

[Narration] And remember how she said her daughter was being isolated because of bad behaviour? Well, those behaviour issues diminish when her needs are being met. So making sure staff have time to meaningfully support people, it's key.

Their next suggestion-

[Karen] There needs to be much more independent advocacy and advocacy services that are not attached to any, any service provider, at all.

[Linda] And go in whenever, not just an appointment, just can just drop in and see what's happening in the house to make sure that people are doing their jobs, to make sure they're safe, and an independent person seeing through their eyes what's happening.

[Narration] So there's a Community Visitor Scheme, which does send advocates into state run disability facilities to check on people. But they said this needs to be strengthened, so they're doing more of this. But it also needs to be expanded because they could check in on Linda's daughter, Danielle, but not Karen’s son, Daniel, because he lives in a private residence. And they couldn't have checked in on Ann Marie Smith either. Karen says they need to figure out how to change this.

[Karen] Other states have done it. Our state keep saying that it's jurisdictional and um you know, it's legislative, and the legislation doesn't allow it and, but other jurisdictions have done it.

[Narration] They both agree that while incredibly important, advocacy will never be enough. They also need the eyes of the community.

[Karen] People see things. They don't know who to tell. So it needs to be more than just the advocacy agency, there does need to be an investigation line, that's a 24 hour line.

[Linda] Where people ring up and say, "Look, I saw this today, might be nothing but it's worth an investigation." It would make them feel, you know, they are being checked.

[Karen] There should be billboards with this is the number that you ring, if you see something inappropriate. This should be on TV ads. It should be on radio ads. And it should be a constant ongoing investment into this. If you see something that's not right, act on it straightaway.

Because you could save someone's life.

[Narration] So here are my takeaways from this interview.

One. When support staff have too many people to support and too much paperwork, the integrity of their role is lost, and their clients suffer the consequences. And that can't be very fulfilling to people who have chosen to work in a meaningful field. So service providers need to make sure the role of the support worker stays true to its purpose: Supporting people to live their lives the way they choose.

Two. There needs to be more independent individual advocacy. Government should invest in advocacy services that aren't attached to any support provider. So when people need the help of an advocate, they can get this without having to wait and without the advocate having a conflict of interest.

And Three. As a matter of urgency, the state and Commonwealth governments should work together to make sure Community Visitors are able to check in on all people living with disability who are receiving services. Because as it stands, some South Australians living with disability may be more at risk because the Community Visitor service doesn't reach them.

And four. As citizens, we all have a role to play in safeguarding people. We should sound the alarm if we see or hear anything that doesn't seem okay. In South Australia, this can include a call to the adult safeguarding unit hotline on 1 800 372 310

If you're not sure, call anyway. And don't assume that just because someone has a support worker with them, that everything must be okay.

If you've listened to the three podcasts in this series, you'll realise we keep arriving at similar conclusions; better support, more advocacy, and a community that's aware and cares. So keep talking about these issues, and keep saying her name.

Ann Marie, until it's fixed.

We did discuss some heavy stuff in this podcast, so if it has raised any issues for you, and you need to speak to someone, don't hesitate to ring Lifeline 13 11 14.

I also want to let you know that we're continuing to follow Nat's story. She was in the first podcast in this series, and it was about how she fears she could be the next Ann Marie due to inadequate support. If you go to our website, you'll see a tab called Where's Nat At? We’ll continue to update you there. Our website is www.purpleorange.org.au. You can also reach us on email admin@purpleorange.org.au or give us a ring 08 8373 8388.