Person-centred, local and small: Small Supports and the future

Neil Crowther

Welcome everyone. My name is Neil Crowther. I am one of the conveners of a thing called Social Care Future. Social Care Future is a - a movement for - for change. A kind of vision of the future of adult social care or something that might replace it in future that supports everyone who needs it to live well, in the place they call home with the people and things they love - in communities where we look out for one another doing the things that matter to us. And we've long been interested in the Small Supports work.

I think it's a kind of high watermark in a way of kind of person centred support, imaginative support, support which draws on a much broader range of kind of assets, resources and ideas than - than typically happens and which is proven by evidence to be making a huge difference to the lives of the people that it is supporting who can otherwise find themselves commonly in models of institutional care um for long periods of time. Um, one of the things Social Care Future is doing at the minute is we - we agreed to write a book in 2022, and it's taken us this long to do it. I should advise never agree to write a book. It's one of the most painful things you can ever do. But it's quite exciting the point to which we've got. But depressingly, I dropped a line to the academic Chris Hatton because I had to get some updated figures on the situation of people with learning disabilities and autism currently. And he came back and said that different databases report either around 2,200 or 4,000 people with learning disabilities and autistic people in inpatient mental health services in England on any given day - with little positive change over the last 5 years.

People are in impatient services for an average of around 1,600 days or four years five months. uh around 300 people have been in impatient services for 10 years and over the course of one month August 2025 over 800 people were subject to over 9,000 instances of restraint in such settings. And it's quite clear that kind of - the sort of common models of support that are out there are having little impact really on kind of lessening these numbers and directing people to - to better futures apart from things like Small Supports.

Now, Small Supports. as Nic will kind of go on to say, has really been cultivated in this space. But what we're talking about today is whether the essence of it, the DNA of it, the principles that underly it offers opportunities to do other things with other people or people facing other sort of challenges. So, we're going to be talking about something that I'm particularly interested in and focused on at the minute is around the lives of people with dementia, but we're also going to be talking about other groups and communities as well throughout the session.

What I'd stress though is even though we've brought those in and we're really interested in doing that and those speakers are hopefully - will be sparking off one another and

kind of getting ideas that's open to all of you too. So, if this conversation is sparking thoughts and ideas for you, take those on board. What this isn't about and share them. What this isn't about is a kind of 'hero model'. We're not starting and saying Small Supports is this thing and you just take it and replicate it everywhere. We're going to tell you about it and what we want you to do is to sort of think whether it - it seems to hold something that would be relevant that you could maybe adapt or take on board or take into another space. I think that's a really kind of key thing to - to begin with. Great. Okay. What I thought it would be useful I imagine pretty much most of you on the call kind of know what Small Supports is or has been, but I thought it might be useful if we began just with a reminder from Nic, so we kind of have a have a common starting point and then we'll go into the conversations with our kind of planned contributors. So, Nic, is that okay as a beginning point? Do you want to just share a little bit about the background and what - what Small Supports has been?

Nic Crosby

Yeah, just to inform you, I've got a couple of slides I'm going to share, but the - these are available as a handout. It's easy, it very much hopefully helps people see some of the building blocks that can be taken and work used in all sorts of different ways. And certainly links to the conversations with Graham that we can have in a bit and other conversations with Khaleel and Alex as we go through the um discussion. So, this is - this is it's Mark and Debbie from Leads. You'll hear more from Mark in a minute because he's going to share his thoughts on a video. Um, first off is it's not a short-term kind of flash in the pan development. Small Supports have got their roots in the real closure of a long-stay institution on the outskirts of Glasgow. Um, this was Lennox Castle as is. It's a picture of it falling down, which is exactly what should happen to it. And there were a group of people when they came to close the institution. there were about 1,200 people at this institution who needed more support than was available in the local community. The first organisation they set up in response to that was called inclusion Glasgow. And there's a really cool podcast if people are interested with Simon Duffy who set up inclusion Glasgow. The second one was C-Change who are one of our founding partners. And if people want to read more, there's a link on here when we share the slides. You can follow through to a report by the European Association of Support Providers.

What is a Small Support organisation? There are probably four characteristics that would stand out. The voice of the person, it's their voice and the voice of their loved ones. And that is the core of everything. In practical terms, it's their story. And it's what matters to them. It's who they are. It's their essence of them. And there is no compromise. You hear Dave, you hear people who lead Small Support organisations themselves, there's no compromise because the moment they compromise on what works for that person is the moment they start to fail. And it's - it's really is that simple.

And that means that most people who work in Small Supports-land are very stubborn, very stroppy and very good at making a case on behalf of a person with commissioners who often want to see some sort of compromise. Um the core of Small Supports is all about relationships. It's about building sustaining, respectful and caring and often in a sense loving relationships with people that they work alongside. You know, we heard from Sam the other day about somebody who's just retired from C-Change, who's been working alongside one person for 16 years. You can imagine the journey that they've been on together and the relationship and the reliance, the - the interdependence probably that has built between those two people. And that's real relationships. It's not people who are kind of taking part in people's lives because they can work a three-hour shift on a Friday night. It's because people share passions, share hobbies, share interests, and they share a desire to - to they, I think I saw it recently written. They actually like people. So that those building of relationships is absolutely essential.

The connections that they forge are there because actually a lot of the people that we're thinking about at the moment in Small Supports have quite difficult days at times. And it's really important that there's something that binds people together that's more than just being there for work because you need those - those strong connections, those strong relationships to see you through those difficult times and they can be really, really difficult times. The whole thing is around a small um a supported living model. No residential care. Although there is some changes when we're thinking about under 18s and when it's providing people with single -single places to live. Um but the main majority of the of the model and its roots are in supported living where home is separate from the people support. It means the person can keep the home but sack the support organisation so they always have somewhere that's safe and their - their home their - their place of residence. It's commitment to stay small. It's not about supporting big numbers of people and local. You'll hear from Alex in a minute. It can be very local. It can be just in Somerset. Um, there's a foundation of human rights, inclusion, and being person- centred. Person- centred plan, personal funding, personal support. It's a simple individual approach to thinking about how what works for one person. There's no fitting square pegs into round holes.

And it's a very flat management structure where people - everybody knows each other. Um, interestingly, there's some challenge to the proliferation of small and micro providers recently. And we feel that certainly from the small Supports world, the fact that everybody knows each other is a real big factor for - for keeping everybody in the organisation safe. Once people have devoid or removed from knowing everybody in that organisation, certainly through hierarchical man management structures for example that's the moment that people stop being safe because people just don't know each other. Um two bits of evidence it's it doesn't cost as much to support people this way. The bigger evidence is in the change in people's well-being when you put financial values against a group that we worked alongside from Beyond Limits in Plymouth for

nine people seen that sort of improvement in people's well-being but there's a financial value on that improvement in well-being because it's - it's a reduction in demand on services in time in support and medication and similarly lower down there's is about a reduction in incidents. Good support means people don't get so distressed. They don't get so distressed they don't need so many emergency responses. Um, when you think about this for one person that's 156 incidents a year previous to being supported by Beyond Limits. It's three a year now. And reductions across six people within this group meant a value of nearly a million pounds. So it's not simply a reduction in support costs. It's the wider ripple effects of actually what Dorine from Beyond Limits would say, “if you do the right thing by people, it works for everybody.” And that's this is a really good demonstration of that. And the last is just because it's really important that we hear people's voices.

Video

I'm Mark. Uh, and I've been working with Unique Sport Solutions for just over a year. But when Unique Sport Solutions started welcoming me, I was still in hospital. So, they've helped me move from hospital back into the community, which has helped me a great deal.

Mark had been in hospital for over 20 years. So it was really clear that there was a need to think differently and to look at a really bespoke and individual model of support that would benefit Mark. That's where we identified unique support solutions. Part of our strategy was to build a relationship very early doors and we would talk about what his hopes and desires were. We talked about people that are important in his life, the location of where he lived. So, we gathered all of that detail to know him really, really well. Um, we said to Mark, you know, we, we can't make a guarantee that nothing will go wrong.

There will inevitably be bumps in the road, but what we can guarantee you is that we will be here. We will be by your side. We will listen. We will support you. We'll make sure we know what you want and your direction of travel, and we'll fix those things. will iron out those bumps in the roads. It's really important um to support people as individually and as person-centred as possible. This gave Mark a real opportunity for a successful discharge. This approach will benefit other individuals like Mark who are finding the future quite daunting due to such a length of stay in hospital. Unique solutions has helped me uh surpass a lot of things that I didn't think I would have done when I was in hospital. Uh I have staff who are willing to work with me and do numerous activities. I enjoy doing a bit of gardening, woodworking, magnet fishing and spending time with family and my friends.
Unique Support Solutions has helped me achieve the goals that I've been aiming for and also has had a big impact on my life. I wouldn't be where I am today if

it wasn't for them.
it wasn't for them.

Nic Crosby

That's Mark's words. I'm going to pick out the bit that I pick out every time I watch that video. There's a phrase in there about 'willing to work with me.' And I think that sounds stands out more than anything I hear from- from what Mark's saying is that he's so used to having people alongside him who he doesn't feel are willing to be there, they're just paid to be there. And actually, his big appreciation of what he gets now is that he feels that people are willing to be there and not just because they want to learn what magnet fishing is. So that's a bit about what Small Supports is. Now I guess the conversation is the interesting bit is okay. So how do we build on that? How do we take from that? Anyway, over to you Neil.

Neil Crowther

Thanks Nick. Um yeah, there's so much in that and such a kind of powerful film and - and for the reasons you outline and -and I think there are these kind of challenges that we- we might sort of visit in the conversation that are there which I know you blogged about the other week this sort of tension between this pull towards kind of scale and uniformity and just kind of meeting the large kind of numbers of people that need support versus um the evidence that kind of small scale bespoke support is what can really make a kind of difference particularly to people facing the most intractable kind of challenges and I think we face attention there. The kind of need to generate and prove that with social and economic evidence, including around kind of cost avoidance as well as annoying as that might be is - is clearly important to kind of unlock those resources. And I think the other thing that I've been thinking about a lot just recently is how there seems a tension between how social care is being thought about and pulling in that direction on the one hand and the fact that in a wider debate around public service reform there's sudden attraction to things like the liberated method and these kind of models that are rather aligned to what you've just sort of talked about.

So, it seems a sort of strange thing happening where there's a debate around public service reform on the one hand that's going in one direction and debate around social care on the other that's going in another. And I suppose the question is how we fuse them. Um we're going to move on now. I'm going to talk about um the possibility of - of this approach or the ideas it contains being valuable in terms of support for people living with dementia. And it's a particular sort of passion of mine. Uh my dad uh lived and - and died with Alzheimer's and sort of since he was diagnosed with Alzheimer's I'd sort of began to divert some of my sort of professional and activist past into sort of thinking around that because I think in common with many other families we were very quickly confronted with the fact that there is very little out there and what is out there is

very much in the vein of trying to fit square pegs through uh round holes. And I think that's why high numbers of people with dementia are perhaps accelerated into models of institutional care uh prematurely in the absence of - of other - other things. So, I think the Small Supports model could be really exciting and really valuable in this space. Um to my ends I'm actually working with Shared Lives Plus and working in Greater Manchester to explore shared lives as a model of day support early action and prevention support for people living with uh dementia. But we've been very keen to kind of explore that again not as a hero model in isolation but how it can be part of a wider ecosystem of kind of supporting places and I very much know that's how Graham thinks around the role of meeting centers in in Scotland. So I'm really excited that he's here and we're going to hear Nic and Graham have a chat now about the potential of Small Supports as - as a model support for people with dementia. So, over to you both.

Nic Crosby

Good to see you, Graham. This whole piece of work started because somebody at the Scottish Dementia Strategy Unit in the Scottish government posed a question at an online meeting about Small Supports: 'Does this work for people with dementia?' We didn't have an answer then. Um, but we started talking to lots of different people and ended up having a chat with Graham back in February, March. Saying Graham are you interested? Maybe the easiest thing is, and certainly because we're talking about the building blocks of Small Support, what was it that shone out to you, Graham about Small Supports and its possibilities?

Graham Galloway

Uh for me. So, I was um I was kind of aware of Small Supports before - but obviously hadn't really considered it in the world of dementia because it had always been kind of learning disabilities and physical disabilities beforehand. But when you got in contact, Nic, and I started thinking about the that that rights-based, inclusive model, person-centred model that you were talking about, it just links in perfectly with the work that - that we do with communities through the - through the meeting centre model. So, for - for those of those of you that aren't aware, meeting centres are a = a model that was developed over 30 years ago in Amsterdam through a needs assessment that was done by the medical university in Amsterdam into the needs of people who were still living at home with a dementia diagnosis and looking very much at uh families that were affected as well as individuals living with dementia. And what that model looks like in reality is effectively a social club. A social club where people with dementia can get help and support but holistically the - the carers are as involved.

So, it's not a daycare model where it's just simply respite for the carers. The carers are as involved in everything that goes in there as the individuals with dementia are. The - the psychological framework that kind of underpins meeting centres is called uh

adjusting to change and that's about preparing both the person with dementia and the family carers for the - the physical the emotional and the social changes that dementia diagnosis brings. So, we're all aware of - of the impact that memory loss can have but dementia does not just affect memory it affects every part of a person. Um the emotional impact very much particularly around the point of diagnosis where under the Scottish dementia strategy diagnosis is meant to be a trauma-informed process.

However, we still hear about people getting five-minute appointments where they're told you have dementia go and get your affairs in order. And then that social readjustment that people need because very often people are losing friends, they lose family uh because of the fear and the stigma that still surrounds dementia. So that's the - the kind of the world that we're working in. It's very much about a peer support model. It's a relationship-based model. Um and uh it's about keeping people in their own homes uh for as long as possible. Now the issues around that are that there's only so much the centre can do because it's support in in a in a building. It tends to be three days a week if you're following the classic Dutch model. But that then leaves all those other days of the week where the meeting centre perhaps isn't giving support to people. So, there is a need for that kind of wraparound support. I've - I've worked in learning disability support myself before I was working in dementia years ago. Uh and I'm aware of how powerful that kind of relationship-based long-term working can be with people. As it stands just now and I'm living this firsthand just now within my own family uh where my dad recently tried to - to get some funding for a carer support plan and was told by the social work after a 20-minute phone interview that you don't meet the threshold because you're not critical. Now the - the local authority area where they stay their strategic plan for people with dementia says that it's as a preventative plan. It's about supporting carers. And yet when my father reached out for help, he was told, "You're not critical, so we're not going to give you any support." So this is a huge issue across all of the UK. We know this isn't just unique to one local authority area in Scotland. So when you got in contact, Nic, I was really keen to- to start that conversation about what - what this might look like to support families who are affected by dementia.

Nic Crosby

Yeah. I mean the - the building block you talked so much about relationship and connection and it was like if you go back to the slides I've just shared relationship and connection were two of the biggest things that we talked about and it feels like that's where when people's dementia progresses families are finding it more and more difficult to cope on their own, that there's the potential for support to cherish those relationships and connections and build their own but see that as the crucial part that they can bring um to people's lives.

I mean there obviously is in the background that is in a similar way to Small Supports more widely. It's an alternative to institutional care. That's certainly how we've started

talking about it. Um as part of our hoped for funding bids - is it's an alternative to residential care which is so often the - the jump. There is nothing available local locally and that's all you get. And there isn't an alternative. I know when we spoke with the uh dementia strategy unit, the Scottish government, they were very - very clear that their huge consultation programme, one of the most consistent things that came back was families wanting an alternative to residential care. We've just done a little bit of - gosh um tiny, tiny bit of asking people via meeting centres and it's - it's the same thing. People want an alternative.

People want and if you think about it from the point of view of the family and the person to be separated at such a distressing and, and difficult time it from the from the very things that have kept you together for the last 50 years or 60 years or lifetime. It just seems to be the wrong way of doing things.

Neil Crowther

This does relate across to the work we're doing around shared lives in in Greater Manchester and kind of elsewhere. where we kind of built this program off the back of the fact that some earlier work kept finding rather like Graham said that people were not unlocking publicly funded support until they were deemed to be in in a very kind of I don't know I don't know what the right phrase is that their needs become particularly extensive but a character of that very often was they were met or they were meeting the local council or were met by the local council in a state of crisis so it wasn't just about the needs it was the fact that things were right the point just fallen apart completely. And that meant there was a perception that Shared Lives was a problematic idea because Shared Lives by its nature involves the matching process, the building of a relationship.

So, most people's trajectory at that point is straight into a care home typically for a couple of weeks at respite and very often never coming back again. That's - that's kind of what's happening. 70 - 80% of people in residential care homes and nursing homes in the UK have dementia. So, any council that's wanting to actually reduce its expenditure in that place should have an interest in alternative models that can actually delay or offset that process. So I think that is the most powerful space to operate when we're talking to local councils. But the other problem when we talk about dementia is most people have no relationship with their council whatsoever until they reach that point if at all because a high number won't be financially eligible for support. So actually, it's the NHS and this is what's kind of fascinating in terms of the kind of mix of things.

So, in Greater Manchester the NHS is funding things like music for dementia, creative health, there are kind of models where it's supporting models of kind of independent living and rehabilitation. So, the NHS is engaged, and I was just wondering your experience in terms of Small Supports and people with learning disabilities and autism.

Is it local councils that are funding this support? Are the NHS engaged in any way? And is there some kind of similarity here in terms of where responsibilities kind of fall; because we in Greater Manchester are obviously trying to encourage the resource to move upstream to try and meet people earlier where that relationship can be built um rather than allowing that crisis to kind of emerge and that's the evidence base that we're trying to establish and actually talking to Mike and colleagues at NDTi, as well as about how we do that.

Nic Crosby

I gosh, I think Graham and I can both answer on that one. I think where we are is this is what these are the discussions that you get into when you're looking at developing a new piece of work and a new approach, because in Scotland there's £894 allocated if you put get put in residential care per week because they have and then on top of that it's personal funding, if you can pay it and if you can't you get your £194. So, we know how much it is per week.

And we have started the discussion about what happens if you spent a little bit of that prior to residential care on individualised support. Yeah. And there's a willingness to have that conversation. Um there is an SDS route, a very clear route in Scotland. Um I feel it's probably clearer than the SDS route in England. Where there are ways of that money coming out being paid and um and you know there are eligibility but we're trying to we're very much starting the conversation. We've had the early conversation. There's a willingness to talk about it. It does mean quite major changes though because at the moment there is a large amount of money pushed straight into residential care to allocate on places. It's not allocated individually necessarily. So, there are big challenges ahead, but there's definitely a willingness to talk about it. And everything that we've been publicly or we've - we've introduced,

Graham and I have introduced into conversations has been saying this is where it's aiming. It's aiming at reducing the - the reliance on residential care and it's doing that through reducing through looking to see how we can access support funding earlier in people's experience of of - of um of dementia. That's where we've got to. I don't know if you want to add anything to that, Graham.

Graham Galloway

Yeah. Well, just I think Alex in the chat there was asking about what SDS is. It's self-self-directed support. So, it's P personal budgets for people. Um I would question your - your comment there about how straightforward it is in Scotland. I don't I think if you as people on the ground that's probably not the answer you would get and certainly you know with 32 different local authority areas that are implementing SDS in 32 different ways. And we even have experiences within the same teams of people generating different budgets and being denied budgets when we know other people have - have

had them. So, it - it is a it's a tricky one and it's one that I think the Scottish government is very aware of. Uh they - they just reissued a couple of years ago more guidance around what SDS is and how it should be uh implemented. But um yeah, I mean I think we're - we're talking about prevention here and - and I was listening to something the other day where you know sometimes you forget where terms come from and I think it was uh Desmond Tutu I think initially made the statement about, so 'at one point you need to stop pulling people out of the river because they're drowning and go upstream and see why they're falling in.'

And that to me is it just sums up perfectly the crisis that we see with people with dementia all the time. When they hit that crisis point, they end up in hospital and if they end up in hospital, the chances of getting home are very, very slim. Yeah. Um because they'll be in hospital for a prolonged period of time because they can't get a package to get out, which then means inevitably they're discharged into full-time care. Now the thing meeting centres can do um as - as that local support and we're really working with people from the perry -diagnostic stage. So, we're working with people and supporting them through diagnosis. So that kind of relationships that we're talking about in Small Supports that's embedded in the way meeting centres work. We're working with people supporting them through the diagnosis process; standing alongside them not signposting. I hate the term signposting because if you signpost, you're just leaving somebody to get on with it. And the post-diagnostic support service. Again, I've just experienced this with my own family in Scotland, meant to be supporting people, but just giving people forms and then leaving and expecting them to fill forms for attendance allowance in, um giving them blue badge forms and just expecting them to fill these forms in without any support.

We need to be there alongside people when we're doing these things. Otherwise, they're just going to drown. And that's what happens. They - they get overwhelmed and they - they don't ask for help until they hit the crisis point. So, if we can be there at the start with people, build that trust with them, um then we're much more likely to see that crisis coming well - well down the road and we can - we can think about what do we need to do to prevent that happening because we're there alongside the person. We're not just dipping in and out of their lives.

Neil Crowther

You're also, I think, going to have a much more of a sense of who that person is around which to more successfully build a personalised model of care and support than simply meeting them in a crisis when it becomes much harder to establish those things and to know the person as well, doesn't it? I think that's - that's one of the - the sort of challenges here and I suppose presentationally Nic, to um you know if Small Supports became associated only with people deemed to have the most significant support needs there might be a kind of assumption there that you're kind of only meeting them

at that kind of stage where their needs have become very significant. So, it's kind of how it links I guess to other - other things. And again, just sharing a bit from the – the greater management work with - with shared lives um two things I think are emerging. One is I think there are people that would be eligible for adult social care are not making the approach because they're fearful the only option that's going to be there is a care home and they're putting that of for as long as they can. So actually, having more options is more likely to mean that people are kind of reached earlier. I think the other thing, and it might kind of move on into the conversation with - with Khaleel and others and - and to Graham's point about his dad not being deemed to be um of sufficient level of need. I wonder whether or not the system is kind of prioritising needs for personal care, needs for support that perhaps aren't priorities for people with dementia or for people with mental health problems and so on. And - and we're kind of not recognising that enough. So actually, people's situation is potentially very, very serious, but they don't actually have a need to kind of help with washing or dressing or anything like that. It's - it's some other kind of sort of support. So, there's something like that kind of going on. And the effect of that if it's not recognised as a need is it's not valued as a service or a support kind of either because it's not recognised there. So that kind of storytelling piece and really showing why that matters seems key. Alex, do you want to come in?

Alex MacNeil

Thank you, Neil. Yeah, I just wanted to hop in, on what you said about that there's a - there is a broad illiteracy around eligibility under the Care Act and adult social care, and we find it all the time and there is that and that language Graham I know you were talking about Scotland possibly but the language about critical is 10 years out of date anyway and then when you look at the - even when the, so I spent 10 years training social workers in the Care Act and really drilling down into actually it's well-being is the final eligibility criteria. It's not about personal care. Um, but I know that all of those social workers and care managers are going back to work to systems and processes, let alone cultures, that still champion personal care as being the be all and end. And I think there's a story that we could be telling much better around that to help people advocate for themselves because if you don't know what you're asking for when you go in, then you hit somebody saying, "Oh, you're not critical." Or, "Oh, you haven't got any personal care needs." You just go away, don't you?

Neil Crowther

Yeah. I suppose that's further complicated in Scotland by the - the availability of free personal care and the fact that - that's a kind of limited kind of menu of options. A kind of beneficial thing on the one hand but potentially a sort of challenge on the other. But I wanted to uh to introduce Khaleel from Coffee Afrik CIC um again Nic and Khaleel are going to have a bit of a conversation. But Khaleel, do you just want to introduce yourself and your

organisation first and tell us a little bit about it.

Khaleel Mohammed

Thank you very much. Thank you, Neil. My name is Khaleel Mohammed. I'm the Youth Lead, and Social Action lead on - on a research project and also a Health Equity Mental Health Lead for our - our department in Lead Tower Hamlets. Um we are from an organisation called Coffee Afrik uh which is a community- based organization uh which is lived experience-led based in Hackney and Tower Hamlets, rooted in the realities of the communities that we serve. Our work reimagines care, justice, and well-being through seven hubs and 31 projects currently, such as youth hubs, women's hubs, community healing spaces, community connected services that centre dignity, belonging, and self-determination.

Our approach begins with trust, safety, and care as a foundation for transformation. Every programme, conversation, and partnership grows from the soil. And we that - that basically covers some of the work we do and I don't want to take too much time on that. Thank you very much Neil.

Neil Crowther

That was great. I love the phrase grow from the soil there. Um it's fantastic. I'm going to hand over to Nic just to sort of - to shape the discussion a bit and then again I'll maybe come in and others want to come in as well and explore that with you Nic. it.

Nic Crosby

So, my contact with Khaleel came through my contact with Abdi Hassan who was one of the founders of Coffee Afrik. He came along to the NDTi Away Days in the summer, and I just was just like 'I need to talk to Abdi about some Small Supports' because it was a bit like what happens if a community just takes hold of the approach themselves owns it with a - a kind of the driving force of what Abdi and Khaleel was just saying which is a community taking care of their own people and what happens if they kind of say well what would 'Small Supports' work mean and so that was the kind of introduction to the the - the discussion and - and Khaleel I know that you and Abd have had a chat and we've been exchanging a few emails and sent you lots of information as well and I'm just wondering kind of where the thinking might be around what happens if we do Small Supports or what could Small Supports mean to Coffee Afrik? And that could be young people, it could be older people, it could be any group of people within the community.

Khaleel Mohammed

Uh for us at Coffee Afrik, Small Supports is not a new concept. It's how we've always worked. We started off in a as a cafe in - in Hackney offering crisis support centres as well to the community. And these centres, you know, they had a large minimal capacity but a large - a large requirement from the community, of, you know, different services

that they wanted to expand into. So we moved into our first hub in Hackney at Faster House Club. Um at this hub we offered a range of services where we allowed the community to reimagine their own care. And from that we moved into culturally sensitive services where we offered more relational approaches ranging from now where we have a community-connectors placed in GPS and NHS services allowing people to access care that is more reflective of their - their backgrounds, their upbringings and where they come from. Um the areas we are based in is the most diverse and economically challenged boroughs in London.

We came from like you know a lot of lived experience with a lot of our family members experiencing racism, poverty, mental health struggles, exclusion. So, the community organisation came together to build something for ourselves by ourselves. Um it started off with volunteers. Even I started off as a volunteer in the youth department offering support to the community, because growing up I never saw that young people had access to services. Youth hubs were closing down rather than like running detached services for in open spaces. We - we try not to be limited in any capacity but there's always opportunities to grow as a community. We stayed grounded in the same principles of healing; change coming from within the community not from outside it. Some of the work that we do is like hosting mental health and healing spaces um through culturally grounded support groups where people can speak in their own language, reflect on trauma, rebuild trust in the community and from there heal. Uh this could be through arts and well-being hubs and physical sports, mental sports; however, the person wants their support tailored to them.

We-we work in liberty harm reduction practices where we support people facing for example in one of the hubs addiction without stigma; combining practical help with dignity, cultural understanding and connection. Some of the work that I primarily do is running a space for young people between the ages of 11 and 24 – for - for a like a range of young people even uh with those with SEND, staying with us a bit longer - providing safe spaces, mentoring, creative programmes that tackle boredom, mental health and employability. The issues are named primarily by young people themselves. Every quarter and uh regularly, every couple of terms we get together with the young people to make sure that we're still aligned with their needs and are supporting them with issues that they're directly facing themselves. We have multiple women's hubs where local women themselves lead the groups addressing domestic abuse, mental health and rights, rooted in sisterhood and healing. The community advocacy and design models are co-produced uh with mental health - with mental health and well-being plans, strategies and data collection systems always ensuring that the voices of the residents shape local policy.

We champion people regardless of what is said, again Nic I really agree with what you said of no compromise. So, we never back down from the demands of the people and

we always champion their voices. What ties all of this together is that is designed and led by local people, not professionals coming in but residents taking ownership of their collective well-being. I grew up in Tower Hamlets and born and raised here and I deliver now the youth services as a former participant in their service. Our growth has been relational and not institutional, but every strand comes from listening to what people say they need then acting together. It's taught important lessons; that people don't thrive in programmes; they thrive in relationships. So, we come together as like a community um meeting regularly, listening to each other, connecting from one hub to another and building our community system stronger.

We kept things intentionally personal and human even as we've grown because healing happens in the community. The work that you do like with the Small Supports resonates with us because in many ways that's what we already see happening every day. Um just without the formal structure or recognition. And when we talk about community ownership we mean like real ownership. So, we advocate for them to run their own programmes; take healing into their own hands and not through consultation not through participation but through their own leadership. These issues, um, for example, a model could be in my in my centre that I run with the young people where they previously had a youth council model, but it wasn't as empowering for them as they - they wanted. So, they transitioned that model into a youth intern model where it leads to a more direct route to leadership in their centre. So, they become their youth workers. They run their own programmes. They run their own space. And the only thing they need from any adults is that safeguarding support to make sure that they can have the freedom to express themselves in any ways they want.

So, when we think about Small Supports, we see the huge potential for this approach to grow from the same foundation led and shaped by the people who live the realities we're trying to respond to.

Nic Crosby

It shines out to me, Khaleel. And it was the same way that when Graham was talking is that - that there's this common thing about - it's about relationships, it's about connection, it's about no compromise, it's about people's voice. I think you, what you're talking about brings a real 'it's not just about participation or involvement'. It's about leadership. Um and that's taking it further. So it's those and it's - it's interesting, isn't it, that success seems to come with those sorts of values in the heart of them. And they lend themselves to Small Supports, but it's not because they come from Small Supports. They've actually grown from communities. They've grown from meeting centres around people with dementia. They're the same things that keep shining through. And it's very much that. Yeah. So, I think there's that - there's that thing of that I don't want to talk about 'golden threads' but it's almost like there are those things that are common where something's working really well because it's led by people

themselves. And yeah - the potential for Small Supports has always been around - it's a bit more structured because it's around a group of people with very, very complicated individual support needs who are often the most invisible because they moved away very quickly. And I know, you know, I know, there's constant challenge in - in London, other boroughs that I've worked alongside where people are moved away and then because of the price of housing or the difficulties with housing and all of that ,and the right support in place, they - it's very difficult for them to come home to their home communities. We've had previous discussions with others about, you know, community land trusts or community housing trusts. Could we, you know, can we link up this Small Supports with a community housing trust where they lease the premises to a person or there's some tenancies and the money goes back into the community. So really trying to think about what happens if a community takes ownership of the whole part of it. Um, so it's, yeah, I feel like the conversation with yourself, with Abdi, with – Coffee Afrik is- is one about gosh, there's potential and you guys know the roots. And where could this go? Um, I think that's and - and in particular around young people, which is kind of part of my long-term background, the - the idea of being able to do something for that small group of young people who are placed away, a long way from home and their loved ones and their home – home and community and do something radically different seems to be Yeah. is it's just really exciting, you know.

Neil Crowther

Just - just another sort of thread that I - I heard when we did the Social Care Future, the movement I'm involved in, we have an annual gathering and at the gathering we had back in September we'd worked with an organisation called Reframing Race who are about building sort of anti-racist futures and we had a lot of conversations in the run-up to that and realised how much kind of commonality there was in what we were up against and what we were trying to bring about and Sanjiv who runs it characterised it as building kind of sources and places of power outside of the state because the state has often been a kind of you know - focus of racism or where people have experienced racism, whether that was to please the NHS of building these sources of power and I sort of - I'm struck that - that's probably quite similar, even if it wasn't necessarily overtly recognised to the foundations of Small Supports as an idea to actually build these small sources of power for people away from what can often be quite kind of abusive uh state run systems. So, I wonder if that's kind of - a kind of thread in here as well and that's why maybe it kind of connects. It's kind of how you build that kind of power in people's own communities and their own sort of lives.

Nic Crosby

Uh -I don't if you want to jump in Khaleel?

Khaleel Mohammed

I'm more than happy to. Um, so at my work at the mental health um board uh for the health equity in Tower Hamlets uh it involves a lot of challenges and the challenges involving data KPIs, tracking not being informed and not being anti-racist in - in practice really. So, there's a lot of struggles when it comes to facing borough level organisations or councils. But when we're working with people, we tend to advocate for them. We want their data, their rights, their - their voices protected and heard. So the model itself, it's more centred in their lives. And it recognises the support systems already exist in their own communities, in neighbourhoods, people already check on each other after, for example, it could be prayers on Sundays, it could be prayers on Fridays. They drop off food when someone's feeling unwell. Uh, neighbourhood and neighbours are working together to make sure everyone's supported. I - I visit my grandmother every week who lives in a community for uh elderly people, who is like you know very well like connected in in that circle because everyone's checking on each other very in - in an almost daily manner or so, or could be sitting with a young person who's struggling. These are support – 'Small Support' systems. They're invisible in the eyes of the larger institutional systems but they already exist. Uh so the first step is naming and valuing what's already there and using - and using the voices of the people to champion where they want the vision of the Small Supports programme to go. Um then maybe we can think about how to strengthen it and may - through peer training, shared learning spaces like you know the - the vision that Nic mentioned, of like community land trusts as well is something that we are aiming to, like work towards, as well is an aligned vision. The community themselves are speaking up for it. They don't want that oversight coming in from institutions or coming in from councils or local government due to the many policies that are not informed in a sense like you know to - to their daily lives. There's a lot of barriers and structural racism involved in like you know a lot of the policies that are affecting them and their care. Um, so what we want to do is make sure that everything remains locally owned, championed. Once it becomes too professional and professionalised, it becomes too bureaucratic. It loses the relational sense of care. And that makes it powerful. In other words, the future is like a project of the communities. It's a quote from Adrienne Maree Brown as well. Um so we just hope to work with others including those here to build like a model of 'Small Supports' rooted in the realities of urban, rural multicultural communities. We see it as a bridge between like the informal care and professional systems between isolation and belonging. Um that's - that's all from me Nic.

Nic Crosby

Oh, spot on Khaleel. Over to you Neil. I couldn't say it better.

Neil Crowther

Yeah, I know. It was brilliant. We'll hopefully maybe hear a bit more from you in the - the next sort of 40 minutes as w sort of open the conversation out, but we're going to move to Alex now. Um Alex, if you want to introduce yourself and your - your work.

Alex MacNeil

Thank you. So, I'm Alex MacNeil and I am the director at Open Storytellers and Open Storytellers is a charity in Frome, which is in the east of Somerset, right near the Wiltshire border. And we are a community arts organisation. And we spend, we have about 50% of our income comes through day service funding for people with a learning disability, about 50% through grants because we spend most of our time trying not to be a day service. Um, I want to just start off by acknowledging that the word we're using for our Small Supports project is the allyship and that's because we've done a lot of work over the last couple of years. And, we became aware that there was quite a large amount of grant funding that was being prioritised for user-led groups. And when you listen to people speak today, you can see exactly that - that's where you want the money to be.

But there are lots of people within the community who people who come to Open Storytellers who can't be at the forefront of running that for them. So, we need to be really clear that when I'm talking about our community, I'm intentionally acknowledging that I do not have a learning disability. I don't have lived experience of it, but I am walking along in kind of allyship along with people who do. And it was really interesting listening to some of the parallels around things like developing internship roles for people. So that **-** that's a really great way of coming in and taking over more control. So that was um that was really lovely to hear. And I'm just a big fan of anybody that uses the word healing as much as you did because I think we ought to probably use that a little bit more.

So Small Supports **-** we have a community of about, I don't know 25 - 30 artists who all have a learning disability and maybe other stuff going on, and they come once or twice a week to Open Storytellers within that community what became clear over - when over the last few years, especially is people saying that outside of Open Storytellers the rest of the stuff wasn't working. So, there's a core of people there who are uh between 18 and probably early 30s and still live at home with mum and dad because they're not to say- not attracted by what else is on offer is - is an understatement. It's - it's looking at what else is on offer and saying that's - that's not good enough. Um so, what I felt able to do for the first few years of working at Open Storytellers was commiserate. Um offer a little bit of support. I would get in and help people with funding because I got some experience of how the Care Act works and how funding works under the Care Act. So, we would have people arrive with no funding at all who would take a place at Open Storytellers and then we'd spend the next six to ten/nine months trying to sort out funding from adult social care.

During that time, we were approached by a family who had nothing to do with Open Storytellers who had a son who was approaching leaving a special school - they were really, really struggling to find any alternative and anything that was available and so we - we drafted. So, it was really interesting talking - I put in chat what - what does STS stand for? Um because I thought you said STS not don't tell Simon Duffy that I didn't know what SDS for. Um but I didn't have that in mind when I sat with her and came/put this together. You'll see that the name Joe is used. Apologies for the confusion. Whenever we do anything written, we use another name and it's just to protect the privacy of him and his family. But if we think about what we were what didn't exist um in Frome at the time was something that is deeply collective. So designed and run alongside mum, dad, and the cat because she's really key. And that sense of family being an equal partner that it is a collective. And the part that I've bought to it is the - the support needing to be separate to housing. I feel passionately about this. And Neil, when you were talking about Chris Hatton's stats earlier, I'm currently reading, and it's taking me a really long time because I need to keep putting it down, but I'm currently reading Sarah Ryan's new book um about social murder. And what was - what was becoming clear to me, from not only his family but the other people at Open Storytellers are the kind of everyday injustices that happen in - not ATUs, you know, not the things that are as dramatically wrong as ATUs, but actually bog standard run-of-the-mill supported living where they feel more like an institution than any kind of meaningful tenancy.

So, one of our commitments is to make sure it's floating. And you can see, you know, we are an arts organisation. So, it was really interesting hearing you talk about things coming from the soil. Um, I employ a bunch of artists instead of support workers. And I think most of the stuff at Open Storytellers comes from the air, which some days is lovely, other days can be a little bit difficult. Um so we were looking to build something for his family and because he was 18 and because he was leaving the school there was the education funding that was a thought. So, I thought in terms of self-directed support and individual service funds - let's see if we can get social care funding because he will have turned 18. Let's see if we can get some education funding and build something beautiful. And that was the first plan that we pulled together. kind of costed offer built alongside his family. Um Doreen from Beyond Limits came up and did a beautiful visioning and planning session with him and his family and his sister. Um my dream was that - that lovely, costed plan for SEND and adult social care would have a chat, work out how to fund it and get back and go, "Oh, that's fab." Um but obviously that didn't happen. So, we had to come up with a distinct education plan and a distinct adult social care plan. And I didn't know I hadn't heard the term EOTAS. Um E O T A S. It means educated other than in a setting. I didn't ask for that. That wasn't written into the plan. I had no idea that that's what we were actually suggesting because I do not have a good background in SEND at all. But when but what we pulled together was an

education plan that didn't happen in our place. So, it's not a place-based education offer. Um so we hire places to go to because can't come to Open Storytellers and be part of a group at the moment. He might one day but not at the moment. Um and we engaged tutors that work to what is most interested in which is anything acoustic, anything musical. And - and we're also trying to push his boundaries a little bit around sensory stuff around touch and things like that. So, his curriculum reflect his EHCP but we're focusing on really key bits and - we managed to get funding for that uh which was it was a real punt. We - we as experts. We're not doing it as experts. So, we blend service with adult social care money and education money. And we have now just had his EHCP agreed. No, we've had the funding agreed for another 12 months. The review of the EHCP is pending. And when Nic asked if I would come and chat today, it would have been a 'no' if that hadn't happened because I very firmly was sat thinking this just could be a really random thing that somebody signed off to get me and mum off their back. I - I wasn't sure. But now we've got the confidence that actually this is something we can do and we're working with another young person, a young woman um who comes to Open Storytellers because she's moved to Wiltshire. Actually, she lives just over the border. There isn't any appropriate further education for her. She has huge potential to progress further within education. So, this week I'm working with her and her family kind of developing a new plan.

Nic Crosby

You've done it brilliantly, Alex. It's another It's a story of potential. You've taken the Small Supports stuff, but then you've thought about what does it mean for - what does it mean locally? Can we do it? Yes, we can. Blending social care and education funding. Wow. Um because and - and that's why I asked you to come along. Um because it's very unusual to see the education component included in someone's support.

Well, no, included it as part of the funding that's there for them to have a good better life.

Alex MacNeil

And that that was a real challenge because in order to - so it was it was initially conceived of and designed as one thing. We then had to kind of divorce it into well that's the social care bit and that's the education bit, but in its delivery we're trying to bring it back together. Um, I used the word individual service fund earlier and having worked with Beyond Limits this year. It's probably a little bit more back of the packet than that at the moment, but our intention is for that to be kind of clearer and better managed. Um, I think I - I would like I'm going to share one more slide. So, this is -this is not what is happening but this is and it's really interesting listening to about Coffee Afrik and Open Storytellers is the main organisation at the moment the allyship sits as a project within it um but actually what I'm really beginning to wonder in years to come - because we with

Open Storytellers we're constantly trying to respond to needs that people bring in so pigeon - pigeon is there because that's our social enterprise Pigeon Productions because, we provide employment for people who want to be employed um either as experts by experience or as creative um consultants. So, we make films and make information by and for people with a learning disability. We have a day a week that is for people who have no um other funding and that has got a focus around well-being in the arts and then the kind of support brokerage. So, we've - we've moved away from the thought of becoming a CQC registered service because that's not right for us at the moment. We've tried that this year and we know that's not right. Um, Neil, I was relating to what you said at the beginning about Small Supports not being seen as a hero model, but about working out for us and it actually it wasn't, you know, this wasn't led by us. These mum and dad were adamant that they didn't want to go anywhere near a direct payment. So, because of that, we knew it would need to be a regulated service.

The reality of trying to recruit into a regulated service is actually the people that have the best relationships are people who are often freelancers because they're often artists. They were often about doing other stuff. So, we've so - we're very deliberate at the moment are moving into a kind of support brokerage or PA agency type space and we're going to explore that for the next couple of years. Um, and already I'm finding it so much easier to recruit team. I mean, it's - it's like night and day, but I'm actually really beginning to feel that things might shift a little bit. And the allyship being the wider response to all of these areas that people keep saying this is what's not working for us. This is where we need help. And then Open Storytellers as an opportunity to part be part of a company of artists who also have additional needs or learning disabilities is just one of the things one of the ways that we can support people rooted in the community rooted in the arts.

Neil Crowther

Yeah, I think that's amazing. That's great. Thanks, Alex. Um, so much in all of that, isn't there to try and kind of thread together. I think something that interests me I before everyone joined you and Nic were talking about how you'd met in first worked together in 2004 and in 20045 I was - I think I was by then Head Of Policy at the Disability Rights Commission and the number 10 strategy unit with Jenny Morris were developing the report on the life chances of disabled people and at the heart of that was a division of independent living that would integrate various funding streams into kind of one individual budget with - with support in kind of every area. And so what's exciting to me there because there's so few examples of that ever practically happening is I think Nic's point the fact that you are beginning to kind of distil different kind of funding pots into around the person rather than that kind of siloed effect that is still - is still very present. So even though legally we've got the means to do this and in things like personal health budgets there is a supposed openness to being able to integrate those with other

sources of funding it doesn't - doesn't happen. But I was interested in there and what you were talking about the kind of the best model with which - uh with which to do that about stepping in and out of that kind of regulated - sort of space and also the fact that you're - you're successfully managing there to do something else which you know Simon Duffy and others have sort of pointed out was always key to the idea of self-directed support, personal budgets - which was this integration of formal and informal resources and support which is very much lies at the heart of the Social Care Future vision but which again is incredibly difficult sort of to do because of a kind of distrust on the part of the - the kind of the state when it's doing that and it's reluctance to do it. So, it's a tricky space that you're operating within. Nobody should underestimate how hard what you're doing is to actually pull off, I don't think.

Alex MacNeil

Yeah, it is. It is really hard and it we've benefited massively from the Small Supports Network and Nic and Tom in Plymouth - um wiping our tears on certain days and uh trying to kind of help us to the next stage. It - it has been an a really, really tricky year to be at a point now which feels like a point of a bit more clarity.

Nic Crosby

I think - I think there was something that you were saying and it was very similar to what Khalia was saying was it's responding to what the community are coming and saying look something that's happening for us.

Alex MacNeil

Sorry can I just jump back in then? So what - what I was thinking was when - when mum came to us, I've - I've said this a lot all the way through. If we can if we can make this work, I think we can make it work for anybody. And that's partly down to absolute uniqueness of human spirit and who he is. I haven't I've never met anybody like um and also it go went back to something that Simon Duffy always used to say which was you start with a person. Just start with a person. Start with a person and then you kind of build. I think what's really challenging when you start running that alongside that regulated environment is you can't start with one person because you can't employ a registered manager if you've got one person because their budget can't sustain that and when and trying to do that you know we were looking at setting a trading arm up within the charity I'd prepared papers we'd had solicitors around that we were going to get social investment funding for the first, I mean it had got absolutely massive um and we had to go we - we - we can't do that. But then but then what happened going back to community is that day with Nic and Tom when we went down in a little bit of a flat spin if I'm honest was where are - the, but you talking about all the other families that have been coming to you over the last few years but I'd kind of gone ‘let's make it work then when that's ready I can go and talk to all the other families’ and I thought no no no no. So

sat down with all of them. They - they came for an evening. We had an evening at Open Storytellers and every single one of them was like, "Yes, yes, brilliant. What do you need from us?" So, we - I immediately - wasn't looking at a marketing plan to engage with five new families in the next three years that I haven't met. I was working with our community of people who've been kind of going, "Yeah, it's taking you this long." Yeah. Yeah. Yeah.

Neil Crowther

Um can, I ask, why are you called Open Storytellers?

Alex MacNeil

Before my time. Um, very much - so it's it was founded by a speech and language therapist called Dr. Nicola Grove who's an extraordinary woman and she founded it so oral storytelling for people with learning disabilities and profound and multiple learning disabilities and storytelling for non-verbal people as well as a really critical part of developing as um healed humans but also just as citizens. You know, we tell stories about our lives all of the time. So, it started off as Open Storytellers. It's in its - I think it's in its 15th year now. Um but uh yeah it's an interesting one because it - it often confuses people.

Neil Crowther

But it's - I was fascinated just thought of the idea of people as Open Stories is rather a nice idea in terms of what we're - we're talking about isn't it?

Alex MacNeil

Yeah and the logo is the um is the Knights of the Round Table. You've always got the open space. So that's always open for new people to join the storytelling circle. We're very clear for us that what we're able to do at the moment is support anybody 18 plus. All of the transitions meetings that his mum was being asked to go to the options she was given basically an opt list of options for when he left the special school where he was at. So, he'd had his EHCP all the time he was at Critchill. The options when he left none of them were suitable. She kept being told go and see this place. She said no I've already been told they can't meet his needs. Um so we - so that's - why we kind of went right let's take this and put it into a further education contact.

Nic Crosby

I - I could spend hours talking about the fact that the - the potential of EHC's to combine funding and the commitment to personal budgets across education health and social care and the allocation of indicative budgets. It's all there. Page 1975 in the code of practice because I've pretty much wrote the - the quotes are all there but they've never been realised. So, it's why it I get excited whenever I stumble across an example is that's

why the legislation was there. The potential of Small Supports and it's the same maybe thinking about some of the young people Khaleel might have in mind or the some of the older people that we've been talking about with Graham is – it - we don't talk about health social care - education we don't talk about compartmentalised people we're talking about whole people and support that fits that whole person and that and - and that's the bit and the thing about all the evidence today is everything works when you do that and it works to a degree agree that when you start carving people up into sectors of funding and eligibility and all that kind of thing, that's when it all goes wrong.

Carol Hayden (NDTi)

Put my audio on. Thank you. Yeah. Um I wanted to um go back to what Graham and you Nic were saying um about Small Supports and that approach um for people living with dementia. In terms of sort of personal experience, family, most recently our neighbour - one of the difficulties in accessing support early as a preventative before a crisis is reached is the stigma that's felt by often the carer and – and denial really that there's a there's - there's a problem that might be about dementia and then it gets to a crisis stage. I mean, I've got three sort of personal experiences in which that's happened. And I wondered um what your organisation does um to try and sort of reach out to uh family carers of people with - who are developing dementia fairly early stage in a way that maybe can reduce that stigma so they can take advantage.

Graham Galloway

Yeah, I mean stigma is a huge problem. Um the - the Scottish government introduced its latest dementia strategy a couple of years ago and the first thing it did was run an anti-stigma campaign which fortunately was running at the same time as that absolutely horrific Alzheimer's society advert. So there was a little bit of a mitigation in Scotland at least for that. Um so it is it's - it's - a it's a huge issue. The way a lot of the meeting centres deal with it a lot. So, the meeting centres in Scotland have very much grown out of the network of dementia friendly communities that we have here and many of the meeting centres are an evolution of dementia friendly communities and a key part of the work that they do is about community education. It's about going out speaking to churches, speaking to women's guilds, speaking to the Rotary, speaking to the schools, uh, and just trying to raise awareness around what dementia is and that it's not something you need to be frightened of. You know, we're - we're still very much coming out of that where we were in the 70s and 80s with cancer where it was the 'C-word' and you just didn't talk about it. And dementia, I think we're starting to get out of that now. People are starting to be a little bit more open but the - the stigma is a is a huge, huge issue. So, a key part of the way the meeting centres work is that as I mentioned earlier it's not just about respite - it's about working with the families. So, when - when this meeting finishes I'm just going to head up the road to our local centre where every week there is a carers peer support group and the carers come together as a group. Um, just

reflecting back, it was really interesting hearing Alex and - and Khaleel talk about - about their work because there's a lot of that very much resonated with the way the meeting centres work because it's about community development model. That was what really appealed to me initially before I worked in dementia. I helped support a youth project that had a very similar progression that Khaleel spoke about where our young people were encouraged to volunteer to mentor and eventually become employees. Um the creative work that Alex was talking about, the Stornoway meeting centre doesn't employ support workers, it employs artists. It's run by artists. Um and that meeting centre was responsible for uh birthing the Scottish Dementia Arts Festival which had its third iteration this year - where all the art was created by people with dementia. So, I think that's how you get around the stigma. You give people the space where they can take power for themselves and give people their voice because that's very much what that dementia arts festival is all about. It's about showing that people with dementia can still be creative um and very much can still speak up for, um what they see are the wrongs um in in their lives.

Neil Crowther

Thanks, Graham. And for what it's worth, my sort of view of this as well is that I think it's about how social care is understood and framed and anticipated. And for many people, it's something to be avoided. Um, not something that's seen as likely to undergo and improve your life situation. And most people, as I said, make a complete straight intellectual leap to it's a care home and don't have much of a sense of what's in between. And in a way, that's because there isn't much in between for a lot of people. So I think there's a kind of challenge ‘chicken and egg’ here about kind of telling stories about the potential of other sort of models that are much more life affirming rather than I'm not saying residential care can't be a positive thing for some sort of people but my sense is a lot of people are ending up there when they needn't have been - um and the trauma that can cause them and their families and everybody else is significant. So, uh, a big lesson. Thanks for that.

That was really, really powerful and a kind of good way to begin to sort of, um, bring things together towards the end of end of this session. I hope - hope Nic's kind of, uh, got what he wanted from that. I thought that was an amazing discussion. It was absolutely um, absolutely fascinating. I think those challenges, for what it's worth, I think we are beginning to get better at this, but I think it's going to take two things in particular. One is we have to be much more confident at storytelling. I was on a call yesterday with every uh director of adult social services in Greater Manchester to talk about the work we're doing with - with Shared Lives there. And actually the stories we were telling about some of the matches that were kind of being made through this live more dementia programme were the ones that was really kind of capturing people's kind of attention. The Elvis impersonator in Bolton and the sports fanatic in Wigan and

things like that. Let's - let's get out there and tell the stories of the lives people are living as a consequence of this sort of support because they're just much more engaging and interesting and human than **-** than often what - what people in the system are confronted with but backed up with that kind of harder evidence that I know NDTi and others are looking at to really sort of show the monetise the kind of well-being the cost avoidance and everything else. I think that's the best thing we can be doing now is to sort of build that evidence base. But it's not just hard numbers and throughput because that's - that's going to kill the idea. It's got to come with that big dollop of humanity around the difference it made. You know, very much similar to the experience of my sort of family and the impact circle, community circle had on kind of extending my dad's ability to live at home. The amount of time I've told people that story, they just were not aware of that possibility. No idea you could do something like that. So, you know, we've got to get out there and create that sense of possibility for people, haven't we?

Nic Crosby

A better conversation than I could ever dreamt that we could have had. Um, and I feel like there's some sort of start. Um, I would really, really like to stay in touch with everybody. I'd like to come back to this conversation in six months and say see where some things might have got to and where other things that we don't know about yet have suddenly cropped up. The - the number of times the key words have come up. The number of times the same things have been talked about across all ages and across very different communities speaks so clearly and loud about not just my stake the bit Small Support bit but actually about what works.

Neil Crowther

Yeah, it's been a brilliant conversation and I think spaces like this allow for this kind of cross-pollination, don't they, of kind of ideas and thoughts and so on. And I hope we can all sort of stay in touch. I've really enjoyed spending an hour and a half with you all. Um, but I better let you go. Um, thanks particularly to Khaleel, Alex and Graham for their contributions, but obviously everybody else for all the things you brought to the table and, um, hope I get to see you again in future. Okay, take care. Have a good day.

Thanks everybody. Thank you.