**Powys School of Carers and Volunteers – 25th May 2021**

**Present:** Anne John, Eve Lambrick, Liz Bickerton, Kevin Holcroft, Christine, Sally Duckers, Jenny O’Hara Jakeway, Jenny Hall, Ffion, Heather Maling, Owen, Becky Evans, Emily, Jennifer Browning (Pathways / Arwain Health and Social Care Project), Meiriona, Matt Rising, Josh Law, Blue Macaskill, Grace Barton, Ry, Deb Gerrard, Anwyn Jenkins, Josh Hughes, Hayley Beavan

**Minutes and Notes:**

* Intro from Eve and Liz – what good work is going on and what do we still need?
* Anwyn: is it physical or virtual?
* Ry: ‘School’ can sound patriotic / top down – prefer ‘toolbox’
* Liz: What to call it is a key question
* Owen: carers need physical training e.g. how to move someone
* Training on mental health important
* We will design the research together
* Ry: Where will information go? Needs to all be in one place
* Sharing of skills between carers from different areas
* Owen: first aid training? Info is out there but goes in the wrong direction – practical training e.g. CPR and defibrillators is needed to be safe
* Deb: concerned about adding another layer when there’s so much going on already
* Liz: training will be practical not just a certificate
* Unpaid carers already go on a learning process for practical skills
* Anne: the word ‘school’ does not bring back positive memories for many- Becky agreed: name needs to be changed early on or it will put people off
* Sally: place based approach is key – Jenny Hall: school bus, like a library bus? Owen likes the idea of moving the school around to different towns.
* Jen: Powys C.C. understand the area is rural and the workforce is largely unpaid carers and there are few routes into social care and carers need more skills – this is an opportunity for informal and accredited learning
* Deb: Organisations could teach and give info and training – they have specialised knowledge and already do this internally
* Matt: Important that Young Carers are also taught – they can’t be trained by the NHS so could professionals train them here?
* Owen: carers don’t have time – they would need respite in order to attend
* Anwyn: sign language lessons for carers of deaf / non-verbal people or sometimes those with ASD? Deb: Accessibility Powys currently offer these
* Anwyn: Academy could provide links / contacts to groups held on other platforms – ‘google for carers’? Deb: PAVO infoengine already available – Anwyn: search bar at top would make it easier to find what you need – *action for Jenny Hall to pass this feedback to PAVO*
* Grace: I had to wait until I was 18 for hoist, peg feeding and catheter training but I was doing it from age 9 – so important to train young people in skills e.g. how to push a wheelchair – Young Carers are currently taught informally by some district nurses and by family members. Jen: also training in administering medication to parents – Grace: it’s really hard to keep up with a care plan as a Young Carer – many don’t have close family networks and aren’t taken seriously – *action for Matt, Owen and Ry to feed this back to NHS in meetings*
* Owen: this is all about the safety of the carer and cared for
* Grace: the school is a really good idea as long as there’s no duplication of what we’ve already got but it is really important to link to everything from one place
* Ry: Specific resources for cancer carers would be good – Ry very willing to develop these with what she has picked up along the way – Ry: caring is very specialised and you learn these things by yourself along the way – carers acquire so much knowledge and there’s nowhere to put it. Facebook groups also really helped because they’re groups of people doing the same job as you are
* Jenny Hall: peer mentoring can be so powerful
* Josh H: No one tells you that you’re a carer – you go and find out on your own – I would get behind anything that makes signposting for carers easier, especially for new carers – ‘if carers need it, they need it’ – the right help is key or caring can be very stressful – learning from Mandy Hughes’ roadmap for parent carers
* Hayley: Many RVS Companions are also carers – Powys C.C., P.T.H.B and Accessibility Powys do all have training but this project is about plugging the gaps – RVS offer essential training for volunteers when they start and then further training as they progress
* Jen: we’re aware of what’s on offer but as a carer your priority is your job and caring role, not looking for info
* Deb: I see our role as organisations as signposting and finding support – we are the first port of call when our beneficiaries require support – best case, this academy would work alongside existing organisations, build on the sector’s experience and give the sector sustainability but I am concerned about funding going to the academy rather than to independent charities because we do build up specialisms
* Ry: Macmillan have no support for the carer – you’re not in the room – they only focus on the patient. The carer is always in the background with no attention and their own health never considered – Deb: how can you care if you’re not looked after?
* Matt: lots of organisations are already doing lots of things – PAVO should be signposting so we have to ask why people are struggling to find info. Carers also won’t contact the academy if they’re not aware they’re a carer. *Action for Matt to look into info and training for carers along with the NHS.* Also to build on Owen’s point – how can a Carer find time and capacity to come? – can the cared for come with them? *Action for Jenny Hall to feed back about funding*
* Jenny H: There’s so much knowledge clearly already out there and you’re helping us to tap into that – also look at safe, informal experience sharing
* Liz B: It’s important that carers are embedded in how the academy runs so it can change and be flexible – this is not a one off consultation.
* Advocacy is important e.g. Carers Wales Employers Hub – getting out to people / small businesses through the academy
* Lives alongside and after caring – your own education, career and training
* Jen O’Hara: What about a Powys co-produced Investors in Carers project into the academy? As well as coaching support to help carers develop ideas
* Eve: Carers workshops and further groups are coming up (Carers Week 2021 and onwards)
* Owen: We need to reach out further to carers – call it ‘unpaid carers’ journey’ / ‘learning toolbox’?
* Ffion: What’s the age range for the academy? Young people have massive caring roles and information being accessible to everyone would really benefit Young Carers – it’s really hard to find what support you can get as a Young Carer – someone to show Young Carers how to administer medication would help – professionals can be dismissive and short-tempered – the academy should be somewhere friendly where you can go and ask for help
* Emily: We need more support for transitions in caring roles – support for changes but also to know the support will stay there during and after changes
* Christine: Support for the stages of dementia would help e.g. how to put on incontinence pads or training on the types/stages of dementia – your personal situation is always different to what’s in books – you need real specialist information and back up to support you because you’re so frightened if you don’t know what to do and you need practical courses like first aid
* Jenny H: Ongoing support over time is important – what about peer sharing?
* Ffion: Suggestion of a drop-in area where questions can be explained to you 1-1 – also allows the academy to be flexible so you don’t have to be free on a specific day
* Jennifer B: Individual needs for training and support are all so different so recognise and celebrate each person’s own work. Let’s nurture each person and appreciate who they are – encourage their individuality with bespoke not generic courses. How about a back up mentor service? Pathways Hub has accredited courses on e.g. assertiveness/motivation/specific skills
* Christine: resource needs to respond to changes and help you to meet people who’ve been through the same thing as you
* Mandy H: Support with caring responsibilities would be good – ‘What is a caring role?’ and ‘Is this normal?’ – the buck stops with the carer and as the carer I am the expert – hospitals and doctors close and go home but carers don’t – carers and parent carers need to be validated for the jobs they do and the best advice often comes from other carers – let’s empower them – they have learned so much but just a bit of need day-to-day advice and peer support
* Meiriona: Fears around MENCAP modern day asylums – people with learning difficulties need to be part of society – work alongside Powys People First – *action for Jen and Matt to campaign and work with MENCAP on this issue and on workshops around ‘what happens when I’m gone’*
* Josh L: Social Services and Wellbeing Act 2014 was all about working with not for families – this is a step backwards and a serious concern if families are not getting basic rights like visitations – a collective group of carers’ voices can make huge changes and AWF are right behind Meiriona with her concerns. In terms of the school, it needs to give families ongoing support around what they want to achieve with their lives
* Mandy: What happens to my daughter when I die is definitely something that concerns me too – always remember we’re not on our own with these feelings and you have to be able to air them in a safe space
* Owen: shocked at Meiriona’s story. Carers need practical support because they don’t know anything when they first go into a caring role – physical, mental and emotional support and keeping the carer and cared for safe – respite to keep a carer caring in the way they would like. Is there scope for the academy to get involved in carers assessments? All carers have a right to one so this could be a platform of services and training to help carers in their journeys
* Becky: What Owen’s said here is key – linking to points in statutory services’ lives where they can refer or support – they are trying to be person-centred but do still want a menu of options. Meiriona’s mention of what happens after I die has been on my mind too. Carers’ expertise and understanding is similar to ASD peer support work recently and I would put parent carers at the top of all collaborative work. Most exciting thing about the ‘school’ is peer support and carers sharing their skills! Education within schools and the community (as Ffion mentioned) would be great
* Ffion: For parents it’s about when they die but for Young Carers it’s about when they move away or leave school or aren’t at home – Jen: coaching support may help here? Ffion: younger generation treats people just as badly – they make jokes about disabilities and teachers won’t step in unless it’s directed at someone specific
* **\*Real theme of support with all transitions for all ages\***
* Meiriona: Carers are powerful – Credu has come up from the dust
* Heather: Also shocked at Meiriona’s story. Found Whatsapp groups for paid carers to talk out of hours really useful as there is a big knowledge base in the network
* Josh L: It’s really important to have pathways into social care but also to support all networks for carers (‘find your tribe!’) – we need options out there for carers that are flexible – online and offline etc. and we need potential for carers to be at the heart of this process. Many carers don’t want professionals to come in and tell them what to do because they are the experts – instead, bring together peer groups and friendship groups. Let’s look at what’s already there and push people to work together
* **\*Key theme of flexibility being important\***
* Kev H: Let’s acknowledge all the carers who spoke and said it how it is. It looks like we need physical, mobile and peer/online support. ‘Tribes’ within the school could include: self-development and growth, practical core caring support with the carers as the experts and aspirations – careers and transitions
* Sally: Carers need to know their rights and have education around that and also around what we can do about things that are going on in reality / how we can change them. Carers want to support each other – they know how it feels and they want to inspire each other
* Anne J: I feel so emotional and I love the idea of it being a ‘hub’ – carers need to feel they have ownership over this and peer support needs to be there with people who won’t judge but will share and support each other
* Blue: this was so inspiring – knowledge is power. People need to understand the skills you build as a Young Carer make you resilient and should be aware just how important those skills are.
* \*Key theme of respect\*
* Eve: Mention of groups to start thinking about research on 23rd and/or 24th June and carers can report back with Liz, Jenny and their team?
* *Matt: How can we support carers to help with this project as they already give so much?*

**Hayley Pugh:** I would be very interested in learning about tech skills - how to navigate zoom/ Tech and calendars and organisation on a laptop/computer/ phone - things like hospital documentation sharing pdfs and accessing documents the easy way - I'm dyslexic and struggle remembering certain things. I'm struggling with zoom land and organizing the links everyone sends me - I end up missing most of them because I can't find them so I suppose I'm looking for a digital diary/ Calendar - any easier way to organize and access things

**Anne John:** So much information and sharing of views. Carers have so much knowledge and I know we will use that to their best advantage. I love the Hub idea and also a travelling bus. I think I see this as a ‘pick and mix’ for folks to dip into when it’s right for them. This could be the start of a whole new way of learning.

**Blue:** I think the sharing hub / or carers school needs loads of FIND your TRIBE space and lots of that is a creative section about great organisations and people who really fight for youth voice and support you as you grow up like MPYT and IMPELO, Night Out Scheme for kids and small communities.... and loads more around powys and wales - you need an outlet - libraries and leisure centres run so many free wellbeing sessions too.