

OUR BEST DAYS



C-Change Scotland
and COVID 19



At the time of writing it is already August but it feels as if the year has only just begun.

It has been the strangest of times, this COVID-19 time.

The awkwardness of it all...touching elbows...tapping feet. Standing the requisite distance apart. It was as if we had been invited to play a game at a slightly odd party.

Did you experience a chill when lockdown was announced? Some of us joked about what that would mean but we soon stopped laughing as the consequences of this time of living differently unfolded.

Loss. Separation. Illness. Anxiety. Uncertainty.

Life changing experiences, shared by us all. Experiences that will shape how we think and feel and behave into the future.

At C-Change, we are grateful to The Relationships Project whose report 'The Moment We Noticed' has inspired our own observations of this difficult time. We offer this as our Annual Report. After all, has anything else happened this year? This virus and the impact it has had might make us wonder if anything else has ever happened? Not only that, the question on our minds now is 'What will happen next?' Concern about a recession, the looming threat of a second wave of the virus...there is much to think about and plan for, however The Relationships Project made us pause and breathe on this thought.

“ There is an understandable impatience to return to normal but amidst the sadness and pain of recent weeks we have also had our best days, the moments when we’ve noticed one another, as we have seldom noticed before. There will be a short season for locking in new defaults, a season of possibility. What matters now is what we make of it. ”

The Relationships Project

2019 was our 18th birthday as an organisation. It was our ‘growing up and coming of age’ year. In that year we committed ourselves to wringing every last drop of meaning out of every story and every experience we shared. It seemed that the moment was here to consider COVID-19 and all that it had brought to us.

From the start we were encouraged to ‘not waste a crisis’ and so we were galvanised and ready to deal with whatever came our way. The machinery cranked into gear and people stepped up to the mark. We planned and organised and duly noted each step we took and decisions we made. We closed down and set up in bedrooms and at kitchen tables. We picked up the pace and worked faster, things we had discussed for months were accomplished in days and weeks. We took to the internet super highway and we Zoomed and Teamed... sometimes endlessly. Through Yammer we communicated instructions, guidelines and reliable information. In our isolation we recognised our need to create community in some other way and since we held Yammer in common throughout the organisation it became the place where everyone was invited to gather and share. We took selfies and made videos and encouraged each other.

We have had some of our best days.

Days of surprise and delight.

Some days of sadness and disappointment nevertheless rich sources of feeling and learning for us.

What follows in this report are snapshots of those days.

How we went about it

We took our lead from The Relationships Project and focussed on 3 themes:

- **The Voices Less Heard**
- **Looking for Relationships**
- **Learning for the Future**

The voices less heard

There was encouragement from The Relationships Project to intentionally seek out 'the voices which are less heard'. We gathered stories from people who didn't often speak out. We asked if we might visit and chat about their experiences and what they'd learned through lockdown. We wanted to know if there was anything about the experience that they would want to carry on as we emerged from our homes free from some of the restrictions that had been put in place.

We talked to people for whom the experience had been positive and those for whom it had been a negative, difficult experience.

We spoke to a young woman we work for and she summed up the feelings of many people when she said that, at the start, lockdown was

We talked to

People we work for.

Family members.

Colleagues with roles throughout the organisation - front line staff, Board Members and members of the Senior Management Team

“ Horrific...but it ended up a wee bit fabulous. ”

Jade

Looking for relationships

We looked to see what happened to relationships during this time.

Often when we talked to colleagues they said how, at the start of lockdown, they had real concerns about the person they worked for and their ability to cope with the restrictions lockdown placed on them. In every situation they reported that the person had amazed them with their capacity to handle the situation. When asked what they thought had made a difference for the person they would say that they gave information as straightforwardly as possible; they watched the news together and the daily briefings. It was a common experience affecting everyone and so they took the situation seriously and learned together.

It seemed as if a shift had taken place in the power and control in the relationship between people we work for and the members of their team.

The commonality of the experience and the access to information created some small space into which the person could grow and decide how they would be in the face of the facts before them. Being unable to freely venture outside affected everyone and was done for a reason. It was not a random withholding of power and agency which so often is the experience of disabled people. As with most people, when given the space to make a choice or a decision, they are more likely to make good choices for themselves and with consideration for others and this was demonstrated many times.

Colleagues noted that they felt the change in relationships. Natalie felt her relationship with the young man she worked for strengthened and that they became partners... **“sometimes in a dance, sometimes in crime!”**

Relationships were affected in other ways too. Dates-n-Mates is a friendship and dating project supported by C-Change. They have branches in Glasgow, Falkirk, Aberdeen and Renfrewshire. The purpose of their existence is to bring people together. One of the ways they do that is by running events; large, happy social gatherings in pubs and clubs where people laugh and talk and dance, getting to know each other and providing opportunities for people to meet. They host parties and discos and there is the chance to dress up and look your best and to see if anyone takes your fancy.

Shortly before lockdown was announced, to safeguard members from this new virus, Dates-n-Mates had taken the decision to postpone an eagerly anticipated Gala fundraising event.

Then, as of 23rd March, all social events and activities were cancelled or postponed across all branches.

At that time members were anxious and confused about what was happening and what it meant for them. The team explored ways to lessen the social isolation of the

lockdown on members by helping them keep in touch over social media. They worked hard to do the same things differently. Quizzes and karaoke and coffee and cake and comedy evenings continued online. Business not as usual – it was the same but different. As they worked to maintain the relationships that members had developed the team quickly realised that not everyone had been able to connect with them on social media. They undertook a telephone survey of members to establish who was able or unable to get online. The survey showed that 25% of the membership were digitally excluded, either through lack of equipment, access to the internet at home or lack of knowledge. While technology has been the saviour of many during this time it has highlighted the inequalities that exist for some.



Learning for the Future

One of the questions asked of everyone was what they would take out of their lockdown experience and carry forward into life in 'the new normal'.

One of our Board Members, Mole Chapman has encouraged us to see how the experience is proving that 'warehousing' people in congregate settings is not safe and discriminates and disadvantages the life chances of disabled people. She asks us to be alert to the implications of this as discussions around funding for Social Care begin and questions are asked about 'the model' of providing care and support.

There is much to learn about how we think about the potential of a person. Holding a strong belief that 'Better is Possible', in situations where people

are 'doing well' supports a continuous striving for the best. It honours the potential of people to grow and develop.

The situations where we have expressed surprise at how well people have dealt with lockdown suggests that we may have become complacent and stopped asking what better might look like for the person we're working with.

There is more listening to be done. At this time there are signposts everywhere and all of them point to other, deeper questions. We welcome the opportunity to work with Professor Dave McKay of Strathclyde University Business School on our Strategic Plan and to do that with the people we work for.

Some observations

The past few months have revealed that C-Change as an organisation has been able to do hard things. We have worked faster, harder and still managed to be innovative and creative.

Colleagues have developed different working patterns to minimise the numbers of people going in and out of a person's home. This was to safeguard the person they work for as well as themselves and their family.

We realised that where trust and respect are present the urgency of a situation can have a 'microwave' effect, creating the opportunity for everyone in the relationship to grow.

We became quick and agile, making changes that had been under consideration, sometimes for a few years.

A Virtual Communications Team was established which has increased engagement with Yammer, our internal communication community. The team has successfully produced short videos to inform on a wide range of issues.

Our imagination was awakened and we found creative solutions to issues that had been longstanding.

People are stepping up and becoming... the environment allows the space and time for people to be their best selves. What is in the person has found the space to flourish.



Some undercurrents that need further exploration

“The shifting attitudes and behaviours that could pre-figure more profound change.”

‘The first time we noticed...’ The Relationships Project

Know what’s important and keep it safe

As the recession bites and funders begin to balance their books it seems likely that the funding of Social Care will be under scrutiny and discussion. Mole Chapman’s piece highlights the issues and makes the case for Supported Living as the most effective model, upholding the human rights of Disabled People and delivering services that cost less and offer better quality of life than traditional congregate models.

We have seen the fraying of the edge that keeps people on just the right side of humanity. From that fraying there is only a short fall to being treated as a commodity. When your humanity is devalued in this way there are consequences. Wolf Wolfensberger describes people’s experience as ‘having a wasted life and an early death.’

Over the past 20 years or so the changes in Social Care have gone some way to repair the frayed edge. The focus on a Human Rights approach, the emphasis on Person Centred working, legislation such as the Social Care (Self-directed Support) (Scotland) Act 2013 could be undermined as the extent of the economic impact of the pandemic is understood. It would be easy to find ourselves cast back into the old ways, the old models that brought out the best in no-one.

In his poem, A Ritual to Read to Each Other, William E Stafford offers this wisdom:

For it is important that awake
people be awake,
or a breaking line may
discourage them back to
sleep;
the signals we give — yes or
no, or maybe —
should be clear: the darkness
around us is deep.

The value of inclusion - the cost of exclusion

“...without Zoom, I don't know if I'd be here now.”

The digital exclusion of members of our communities needs to be urgently addressed as we enter a time when we are depending more and more on technology for our work and socialising. To quote John from dates-n-mates for whom the online activities were a lifeline, “... without Zoom, I don't know if I'd be here now.”

In our 'new normal' being 'online' is a necessity that enables everyday tasks like paying bills, shopping and learning. Technology is also a way to connect... Facebook... Twitter... TikTok. As we become more physically distanced we all need the means to draw

closer in any way we can. The skills to use technology are increasingly important. The means to access it - phones, tablets, laptops, internet connection - requires the ability to afford it. These are becoming essentials for people to live well and contribute as equal citizens in our 21st century world. For those of our citizens who are impoverished and marginalised they are difficult to achieve. What would it take to change that?



In conclusion (but not the end)

At this time, when we have experienced some of our best days as a society, while staring down the barrel of some of our worst times, we need to maintain our active concern for our communities and fight to continue to appreciate the gift of difference in our lives. The stories we have gathered from lockdown highlight the potential of individuals. They do not provide earthshattering insights but it may be true to say that when the stories are heard by open, soft hearts then the room may judder slightly.

For everyone interviewed the stories have an element of 'becoming' or 'realising'.

For Jade and Kurt and Peter and Ian and the teams around them who, when the time came, showed us who they are and what is in them... strength, trust, decency and love.

For Mrs Laird, the work of moving from being her son's carer to becoming his Mum again continues. She sees that he can manage the separation and the distance and, although occasionally yearning for 'her boy', she is becoming delighted in his success and her freedom.

For the colleague who spent the time shielding for the sake of his health he realises that he is a valued member of the organisation...and we are realising the need to be more careful of our colleagues and, in the busy-ness of the work, not overlook them as we strive to complete the task.

For Margaret who, in the middle of trying times, discovered new skills and talents.

For Aimee, who quietly gets on with things and realises the importance of the times she's living through and understands that she could take pride in the work she's done.

At a time when it would have been easy to have become lost, our experience has been that many people have been surprised by what they found.

The aim of this report is to capture the energy, resilience and creativity that dealing with the virus has produced...Our best days.

Our best days tell stories of who we are and what we are striving to become. There can be nothing wasted in this crisis. We cannot throw some people away, careless of their contribution and potential. We need to ask people what will help them thrive and work to create and maintain the conditions where they can flourish.

It seems important not just to document the time of Corona but to capture something of what we became so that we don't lose it.

From the things that people have told us, here are some seeds we might plant and watch grow.

Expect the best of people

Trust them with the truth

Involve them in the adventure

Stay awake!

Know the difference between value and cost

This document is just the beginning. There is more to be learned and more to be done.

C-Change Scotland
August 2020

Financial information

Incoming resources totalled £5,530,269 (2019 £5,280,205)

Outgoing resources totalled £5,464,869 (2019 £5,232,099)

There was an overall increase in the funds of the charity of £65,400 (2019 increase of £48,106)

There is a surplus in the unrestricted general fund of £869,278 at 31 March 2020

Sharing people's stories

Love in the time of Corona

A story about a big man and a wee dug.

The big man's life hadn't always been easy. He'd suffered. He'd been misunderstood. Yet all the time his heart had beat solid gold. Kindness and gentleness; humour and grace were shyly revealed to those who stood with the big man as he unfurled into himself.

Not much was known about the wee dug. He came from a rescue centre and so there was surely some sadness in his story.

The week before the world ground to a slowing halt; when the doors and windows were shut and the people stayed inside and they closed the parks and the shops were chaos and families loved each other through the windows at a social distance: in that week of all weeks, the big man and the wee dug met.

Who could resist the sad eyes of a wee dug? What wee dug could resist the soft heart of a big man?

And so they went home together and the love affair began... the wee dug lying snoring on the sofa beside the big man sleeping soundly. In love and in comfortable companionship with each other. Staying in together. Going out with purpose.

Wee dug...big man...the journey has only just begun.

A lesson worth learning

The man sounded weary when I talked to him on the phone. As his story unfolded it became clear that the weeks he had spent shielding had taken it out of him. When preparing to speak to him I had imagined that I knew what the experience had been like. I had anticipated his responses...a bit lonely...a bit frustrating...a little bit frightening. And while I thought I knew how he felt I was not prepared for the depth of it.

I really didn't understand how it was. To be at home...at all times...for 12 weeks...to be alerted again to your extreme vulnerability when all you've tried to do is live as ordinarily as you can...to live with the threat of dire consequences hanging over your head, never mind the financial and practical worries that accompany the act...

Really, what did I know?

Our conversation continued and the man spoke of his relief and his appreciation that the organisation had made sure that he was not disadvantaged by the situation, financially he would be just fine. When I asked how we had been in all of this he spoke of his appreciation of the way that one of the Directors had kept in touch with him, keeping him up to date and asking he how he was...how was his wife?...what about the rest of his family? You must be missing them. Keep your spirits up.

Was he doing OK?

As we talked the man said several times that he had appreciated the sincere and understanding way she had

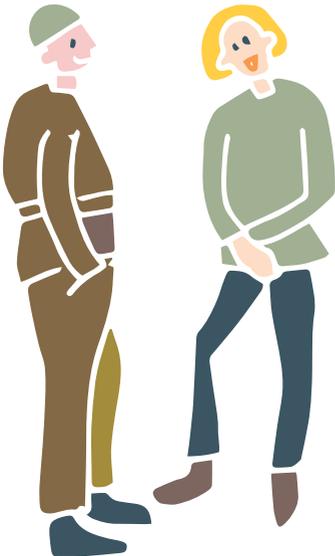
communicated with him. No praise was high enough for her... her sincerity...her understanding during that time. He said it several times and it prompted the question from me, 'If our conversations with you have been sincere and understanding at this time, what were they like before?'

He said that before, most of the contact he had with us had been about getting him to cover shifts. That it didn't seem as if he mattered, That no-one paid attention to the impact of extra work on his family life. What was important was getting the shift covered. This time was different.

The difference was night and day.

It seems to me that in this work it is too easy for people to become commodities. People can become numbers. Funding. Shifts. Cover. They become what is easy to count and quantify. This man was a reminder that this work requires a beating heart. It requires connection. It thrives on compassion.

It is damaged by counting...it is healed by sincerity and understanding. As we move forward from these, our best days, we must not leave behind our best selves.



Aimee

If you ever wanted someone to rely on, Aimee's the woman for you. When you meet her you just know that she'll do what she says she'll do. She won't be late. She won't let you down, She won't mess you about. You can trust Aimee.

Over the 3 years that she's worked as part of Ross' team she's proven her worth. A collaborator with Ross and his family. A go-between with the other team members. That's Aimee.

She talks enthusiastically about how 'everything was about Ross' How the team explained things as they went along; drove past favourite restaurants to help him understand that it was closed, tried arts and crafts, word searches, films. Whatever it took for Ross to be happy.

Aimee admitted that it sometimes felt like they were making progress and then it would be 'one step forwards and a good couple back' but when I spoke with her she talked about the need to value the small things, being clear about the detail. She said that she's learned not to take anything for granted... that things can change quickly and so can people.

I asked Aimee what she's going to take away from this lockdown experience. She thought about it long and hard and then she lifted up her chin and said

'When the country's been at a standstill

I've been there...I done that

I'm proud...'



Cometh the hour, cometh the man



He wasn't a man you could rely on to make good choices for his life. That's not to say that he was always getting it wrong. Far from it. But he lived in the moment and he made his decisions that way.



He'd been struggling a bit with the restrictions that social distancing had placed on his life. To be 'locked down' for all these days threatened to cramp and constrain him. The great hole of history opened up and reminded him of more difficult times when being free had not always been an option. The difference in these days was that good people worked with this man. They explained and listened. They knew that he would make his own decisions in his own way. They deeply respected his right to choose and more than that, some of them even seemed to love him.

And so they kept faith in the man and they took each day as it came and everyone lived moment to moment.

One of the top spots in his week was a catch up and lunch with a friend. But he'd been worried. He hadn't been able to contact his friend for a good few weeks. At last, his friend made contact. He'd been in hospital but was home and eager to connect. Let's have lunch! Let's meet up! A choice was presented. A decision had to be made.

And the man stepped up...he told his friend about Government Guidelines and lockdowns and social distancing and he said No...or at least, Not yet...

It took courage for the man to decide...he missed his friend yet he understood that there was more at stake than lunch and a catch up.

It took courage for the good people around him to trust in their work and not try to tell him what to do.

Deep respect to those people.

Cometh the hour, cometh the man.

Deep respect to the man.



Jade and the pink palace

The young woman's house is a palace of pink where unicorns run wild and free. Crystals sparkle and shimmer on the windows. Walking through the door you feel that magic might happen and perhaps it has.

The harsh reality of the lockdown threatened to disturb this place. There were fears that the young woman would find it too difficult...would react badly. The worst thing was that she couldn't go out and she couldn't see her family. There were worries that the pink palace might turn into a prison.

She said that the lockdown was 'horrendous' but as we talked she described achievements and laughs and relationships that flourished. She talked about watching the news every night and how the scariness of the daily announcements about the virus was made less scary as people she knew and trusted, the people in her team, explained it to her and reassured her that she had this, they would be with her and it would be alright.

Things changed of course. Gym visits became craft days. Eating out became culinary adventures with a slow cooker. Meals were full of health and goodness. A holiday was planned far into the future...far enough away to feel that there was a good chance that it would happen and as the time passed, 2 dress sizes were dropped and new clothes were bought for the holiday. By the end of our conversation the lockdown had become 'horrendous but also a little bit fabulous.'

All the time, the drip, drip, drip of safe and true information. The young woman was reassured and as the reassurance found a settled place in her, confidence grew.

She had this...they would be with her.

And they were. And she did.

And the magic worked...but it wasn't unicorns and crystals and the magic of pink.

A deeper magic was at work...trust, honesty, loyalty, belief and maybe a bit of love thrown into the mix.



Mrs Laird's boy

Lockdown has been hard on her. She had to shield and couldn't do the job she loved. Her contact with the dear people she worked for was only through Facetime. She didn't love the technology but it was a way for her to keep in touch. Her husband was shielding too so the two of them rattled around in the house together, alternately supporting each other and driving the other mad. The only relief was walking the dog.

At least she hadn't had to worry about her boy. She had worried at the start. Would he cope? How would he be? Would it all be too much...too different? She been through it all before with him. Incidents and accidents. And if it happened again she couldn't do anything about it because she was shielding. But not to worry, the team had got him through it before.

Turns out that she needn't have worried. The team around her lovely boy changed and adapted. They worked longer hours in order to cut down on the comings and goings...so that they could keep themselves and her boy safe. She knew that they could do it...they had done it before.

There was a time when Mrs Laird hardly knew who she was. Her life was with her husband and her son: her day to day was spent as her son's carer with all the love and turbulence that involved. The love never wavered but the turbulence wore her out. She's almost forgotten what it meant to Just. Be. His. Mum.

This team had changed that for her. They had made it possible for her to be his Mum. And it was happening again. In the midst of all this lockdown and COVID-19 they were making it possible for her to be the Mum of the grown up who was still her Boy.



Margaret's story – in her own words

My story started around 5 weeks into the pandemic when I received a shielding letter. I was finishing my work on the morning of Friday 1st May and my husband picked me up and I noticed something was wrong!

Finding out that our beautiful furbaby, Sasha our dog, was rushed to the Emergency Vet suffering from recurrent seizures earlier that morning...My world collapsed.

Phone calls and updates as well as a multitude of prayers continued along with tears!

Saturday 2nd things looked promising however by 7pm she took a turn for the worse and we were asked to go up to say goodbye! We were told that only one person would be allowed in and this was devastating.

But for whatever reason the vet allowed us both to be with her for some time then we said our goodbyes....

Monday 4th I was due back to work. I received the shielding letter and a call from my GP explaining that I had to stay indoors. It was already a very emotional time and now this! I didn't think it could get any worse...but it did. A few days later I heard that a fellow team member had collapsed at work and was in a serious condition. He passed away the next day.

We used Zoom and met as a team. Through the video link I could see that everyone was devastated. Our priority was to keep everything as normal as possible for the person we worked for. I would have helped in a heartbeat but I was



reminded that my shielding meant that I just couldn't risk it. My frustration was high. I wanted to help but I just couldn't.

SOOOO...How to be helpful in these new circumstances, with the constant changes being thrown at me. I know my job. I know how to keep a team running smoothly...I'm straightforward and honest about the work we do. How could I do the same but do it differently?

I found myself being asked to join Microsoft Teams, Zoom meetings, Interviews and give feedback from my notes. I offered Peer support to new Personal Development Workers. I set up interviews and use outlook calendar to book new events for myself and the new Support Advisor and lately I've been doing the Quarterly Medication Audits for Glasgow.

So yes...BIG changes in my Story...

What next? Well I'll return to work with the team on the 2nd August covering heaps of annual leave as my fellow team mates deserve a break.

For me? Well I need to get used to being around people outside my own household...Zoom and Teams Video have been great. I have enjoyed learning and can use the skills I've developed to help out if needed again. It's a far cry from being a Personal Development Worker with daily routines, cooking, cleaning and personal care as well as following a strict COVID-19 regime.

But...I miss that personal touch, it's the bit I signed up for as a Direct Support Worker.

Heart, mind and soul by Mole Chapman

I'd literally finished my PhD corrections when the lockdown came! The first glimpse of freedom in years... We were planning a trip to Florence which was cancelled. I went back to work... a few days later I was ill, COVID presumably! The story gets a bit foggy... but I remember a conversation early April about colleagues struggling with the implications of deaths in care institutions and disabled friends receiving DNR latter through the post.

Having explored the lack of voice of Disabled people in research, which meant they were practically silenced in matters of global concern, the state of the nation wasn't too surprising. Sadly, I didn't want proof that my ideas were spot on. When you've spent 6 years delving into the dark side, you'd rather turn to the light!

A large part of the research work was turning the life within an organisation into a story. Once written, the tale provided a text from which ideas appeared, these were then linked to theory. I watched and recorded the goings on of an organisation providing support for people defined as needing help. It was important for the research that workers were so familiar with matters of disability they had become unremarkable, because research suggests that experience trumps stereotypes when it comes to bias.

My exploration of a disability-positive culture was unsurprisingly a good news story. It seems that support provided to disabled people in ways that keep their needs, wants and wishes central to every decision, requires a way of accounting that is highly unusual. In simple terms the 'clients' hold most of the money, their budget, and paid the organisational a percentage. This critically means that the money is never lumped together to be divided, but is spent by each individual according to choice, preference and with a long-term goal in mind. This system of money flow has an informal name, I called it a pot structure!!

When the pandemic struck things went remarkably well it seems for the people supported by the organisation. As their homes were in localities they went on receiving help in lockdown similarly to usual. Workers found ways to bring

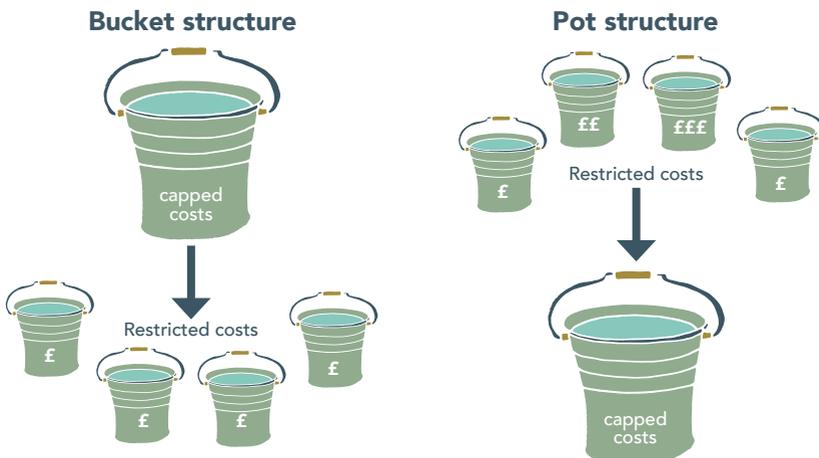
in what was wanted and what was needed. Not surprisingly there was a surge in the use of technology, and creativity was needed to help people feel as connected as possible by putting time into new ways of staying in touch.

Months on there have been no fatal cases, although a couple of people have been tested. Compared to the national picture, where two thirds of deaths have been linked to 'an underlying health condition', the result is amazing. It seems that treating people with respect, dignity and compassion not only keeps them safe and well, long-term it's positively life enhancing. Go figure! Reality does mirror the felled forests of well-being literature.

Doing things in ways that counter old orders can unlock a little happiness it seems. As long as we can keep new ways of seeing things in our vision. Slow thinking is hard, it requires energy, you can't counter existing orthodoxy lightly. In addition, well-being doesn't ensure health, it makes it more likely ... however, importantly, sufficiently more likely to avoid Human Rights abuse.

The cost, I hear you ask, the same as institutional living to begin with ... years on, possibly far less, and sometimes nothing. That's right = some people are so well supported, in time they regain the strength to run their own life with relationships in place we all rely on.

Life affirming seems to be the minimum, the bottom line, the healthiest of all options.





C-CHANGE Scotland

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