



Creating better lives.

COVID-19

Learning Report

An introduction to this report

The Life Changes Trust was established by the National Lottery Community Fund in 2013 with a spend-out endowment of £50 million. The purpose of the Trust is to use that endowment to accelerate the pace of positive change in Scotland for its beneficiaries and to support transformational improvement in their quality of life, well-being, empowerment and inclusion.

The Trust has three beneficiary groups: young people with care experience, people living with dementia and unpaid carers of those with dementia.

What follows is a report based on learning which the Trust has gathered during the lockdown caused by COVID-19. It covers both the young people with care experience programme and the dementia programme.

We hope people will be able to draw on these findings - we want the learning and insights shared in this report to add further depth to the strong body of evidence being produced by our partners, award holders and other stakeholders on the importance of a local, flexible response in times of crisis and to identify what is needed to support organisations and individuals transitioning out of lockdown.

Dementia Programme

Introduction

This report has been written because the Life Changes Trust wanted to identify the particular challenges faced by people living with dementia and unpaid carers of people with dementia during lockdown, as well as the challenges experienced by the organisations who deliver services to support them. We also wanted to share how the organisations that we fund have adapted to the circumstances and the innovative ways in which they have responded to the needs of the people they support.

The information in this report has been provided through monitoring reports and feedback from projects on how they are continuing to support people with dementia and unpaid carers during lockdown. Trust staff also facilitated online discussions with representatives from Trust funded projects and other key stakeholders during May and June 2020. In some instances, we have anonymised insightful comments made during these often frank discussions.

The purpose of the report is to highlight the key learning emerging so far, in particular the flexibility and importance of a local response to need in times of crisis and to identify what is needed to support organisations and individuals transitioning out of lockdown.

The learning in this report, along with other recently published reports, has important implications for the future of local and national dementia policies and the delivery of health and social care for people living with dementia and unpaid carers in the communities to which they belong.

Key learning – main themes

Issues for people with dementia and unpaid carers

Calls to the helplines of both Age Scotland and Alzheimer Scotland increased during lockdown, with the vast majority of calls relating to COVID-19 enquiries. Alzheimer Scotland saw a 20% increase in calls without additional promotion. From the 5 April, Age Scotland witnessed an increase in calls from 70 to 700 per day, with 14 dementia-coded enquiries (calls where dementia has been explicit in the content), plus two safeguarding calls, in the six weeks to mid-April, all of which described complex situations and care/support needs. Many of the issues shared with the Life Changes Trust by these organisations largely mirror those quoted by Trust-funded organisations and are covered in this report.

Reported elsewhere was the increase in desperation reflected in people's enquiries as lockdown continued, while the ability felt by staff to offer practical advice reduced, increasing their stress levels.

The power and impact of a local response

The ability of the voluntary sector to react with speed and creativity to the COVID-19 crisis has been very clear. A recent report suggests that a *“(community) response is effective because it is delivered by people who are also local, who know the area and its needs because it is their home too and are trusted because they are not providing a service so much as supporting the place where they live”*.¹

The importance and effectiveness of this local response has been clearly stated in conversations with Trust-funded organisations. A good example is the way in which Cowal Elderly Befrienders (CEBs) in Argyll and Bute were able to quickly harness their volunteers and staff to assist with practical and supportive services while statutory efforts were being co-ordinated, ensuring that people in need were being supported as soon as possible.

¹ Local Heroes – How to Sustain Community Spirit Beyond COVID-19', May 2020, Power to Change

“We have been particularly useful to the Caring for People Helpline and those referred as we are able to act very quickly to those in urgent need e.g. collection of prescriptions near to closing time on Fridays, shopping deliveries within hours of referral having been received. CEBs was ready to assist from the inception of the Helpline with trained and experienced staff and volunteers, vehicles, an adequate supply of PPE, a network of professional and community contacts through our long-standing work in the area, and the flexibility to modify our services in response to a fast moving and ever-changing local situation.”

The importance of pre-existing relationships is also clear. Local organisations know their beneficiary group and their needs well, for example what type of support will work best for an individual, who in the community is already digitally connected and able to go online, who needs support to access the internet or food and medicine? This person-centred response has been important because, although regional and national responses have been helpful, in some cases well-meaning intentions have fallen short. A delivery of food is very welcome but may not always be suited to an individual’s food needs.

Similarly, people living and working in communities have been nimble, with an ‘all hands on deck’ approach, quickly learning and embracing new ways of providing services and activities online, and producing and hand-delivering newsletters, activity packs and small items all designed to maintain connectivity and bring joy, for example an Easter egg or cake.

Feedback from Trust-funded organisations indicates that many projects have managed to continue to deliver services with their existing volunteers. On the one hand, with many organisations experiencing a decrease in charitable donations and also forced to furlough staff, new volunteers have been greatly welcomed. On the other hand, volunteers need to be co-ordinated and, in some cases, organisations have not had the staff or resources to be able to do this. Some organisations also reported that some volunteers did not have the skills or empathy to carry out the tasks at hand, so they had to turn them down.

Temporary closure of services

Closure of day care and other services and furloughing of staff in many organisations have resulted in a loss of formal and informal support, services, and activities for people with dementia and unpaid carers. This loss of connection, peer support and routine has often resulted in feelings of isolation and a loss of confidence as well as, in some cases, a loss of mobility and cognitive decline. The loss of formal provision has also created additional caring duties for unpaid carers and put a hold on plans started before lockdown, for example home adaptations, resulting in the person with dementia being at greater risk of falling. As one person put it,

“As no-one is now seen as ‘critical’, there is a loss of support in lots of ways”.

This lack of formal support has been compounded by a lack of respite opportunities and informal support from wider family unable to visit during lockdown, and a reluctance or fear about asking for support. Some carers have had to cope with extra family responsibilities or are working from home whilst caring for their loved one with dementia. In the Carers UK April 2020 survey,²

“More than half (53%) of unpaid carers said they felt overwhelmed managing their caring responsibilities during the outbreak and worry about burning out”.

In some cases, people are being admitted to residential care earlier than anticipated because of a deterioration in their condition or carers being unable to cope with the additional hours of caring, on average ten hours extra per week.³

² Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak, April 2020 – Carers UK

³ *ibid.*

Mental health and well-being

Maintaining good mental health has been a key issue for everyone during lockdown, but for carers of people living with dementia there have been particular challenges. Carers have been concerned about alerting health and social care services if they become ill due to a fear of being taken into hospital and leaving their loved one with no-one to care for them. Carers have also been very worried about family members in residential care homes where care workers have not been tested for COVID-19, where there are inadequate supplies of PPE and where new residents, who potentially have the virus, are being admitted from hospital wards.

In many cases, carers are soldiering on and trying to manage with, as noted above, a loss of formal support structures. Carers, and those working with them, are reporting heightened levels of stress, anxiety and sheer exhaustion.

There are concerns that the lockdown measures inadvertently caused other issues that are impacting on the physical and mental health and well-being of people with dementia and unpaid carers. People with dementia are fearful of losing cognitive and physical abilities due to being restricted to the home and many worry about not being capable of going out again without support to enjoy the things that are important to them. People with dementia have also voiced fears about their right to life.

It has been difficult for organisations to support people within their own homes due to social distancing rules. At the Tagsa Uibhist project in the Outer Hebrides, staff have been categorised as key workers and, after training in the use of PPE, have been able to visit people with dementia at home, providing some respite care for unpaid carers. They have also been able to train people how to use tablets, enabling them to access information online, listen to music and remain connected to friends and family.

Where people with dementia have had to go into a care home earlier than expected, carers are trying to manage anticipatory grief without any support. Discussions with one project revealed that, after having no members go into care since the establishment of the project in 2015, during lockdown four of its members had to move into residential care due to deterioration in their condition.

Many people have died as a result of COVID-19; many loved ones are also grieving alone and without being able to say goodbye properly. In many cases the support normally provided through formal structures is being provided by voluntary and community organisations who have been under-resourced for many years. Their ability to continue to deliver excellent services under these difficult circumstances is testament to their commitment to ensuring that people with dementia and unpaid carers are not overlooked.

We have heard that reporting by the media has not always been balanced. In particular the language used about older people has influenced public understanding and impacted negatively on older people's sense of self, decreasing their self-confidence and increasing their anxiety. 'Words create worlds' – older people, and people with dementia in particular, have been portrayed as vulnerable and frail, which is not true across all older people and people with dementia.

The mental health of staff has been important for many organisations. Reassurance and support for staff and volunteers who also have caring responsibilities has been a priority. A Trust-funded project, Scottish Ballet, has worked with NHS Scotland to support the mental health of health and social care workers. They are offering online video breathing and movement exercises sessions – Energise, Rejuvenate and Relax – to support NHS and social care staff.

Scottish Government guidance

Dementia has not so far been included in the list of categories in the shielding advice. However some people with dementia and unpaid carers are self-isolating because they feel at high risk – worried about dementia, age and perhaps one or both having an underlying condition. As a result, they are not getting the support that other people who are shielding are receiving. For people with dementia and unpaid carers there is a challenge in balancing the desire to stay safe with the desire to remain connected to others. Having lost the support, services and activities they usually rely on, people are feeling more isolated than ever. The case studies below show that projects funded by the Trust have been a lifeline, ensuring that people can attend groups online and, where this is not possible, maintaining regular contact by telephone.

Carers have been faced with having to make individual judgements in the best interests of the person they care for. This has meant that they sometimes feel they have to take risks and not follow COVID-19 guidance, for example not maintaining physical distance, which in turn also increases feelings of guilt and anxiety.

Added to this is anxiety about coming out of lockdown and a lack of understanding of risks. Some carers feel that social distancing is not being widely or consistently practised, so they and the person they care for are not able to go out very often. There are fears about coming back out into 'normal' life and being faced with a lack of understanding or compliance in relation to, for example, wearing face masks. There is a general feeling that Scottish Government guidance could be clearer, stressing the importance of the general public taking personal responsibility, rather than a disproportionate impact being imposed by default on the rights of some groups in the population.

Worryingly, a number of people with dementia have, over the course of the lockdown, been contacted by phone or letter by their GP practice or social care support workers to sign Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms. Some people lacked capacity to do so; others were unclear what the conversation was about and were worried by the request. In many instances there was no involvement of any person with Power of Attorney for health and welfare decisions.

The Life Changes Trust raised this matter with the Scottish Government and has worked to produce clear guidance about conversations with people living with dementia and their Power of Attorney during COVID-19, which should be published shortly.

Reduction or withdrawal of social care support

A recent report from the British Institute of Human Rights highlighted a *“lack of transparency about which social care duties have been suspended following Coronavirus Emergency powers”*. The report also highlighted *“huge concerns about the lack of clear understanding and communication about the social care legal changes in Scotland”*.⁴

A key concern for people with dementia and unpaid carers has been the reduction or withdrawal of social care packages with little or no notice due to some Health and Social Care Partnerships increasing their eligibility criteria. There are fears that, if people are not using their self-directed support budgets during lockdown, this could impact on a future assessment for self-directed support. Carers are not only worried that these packages may not be reinstated at the same level as before COVID-19 but, even if they were, whether services will still exist to support them. This fear of services closing is not unfounded.

4 BIHR Briefing: Response to the first Progress Report to the Scottish Parliament on the use of Coronavirus Emergency Powers in Scotland, June 2020 – British Institute of Human Rights

Research conducted by OSCR with 4,827 charities in May 2020 reported *“one in five (20%) Scottish charities predicted that they would be unable to do the work they were set up to do at some point in the next 12 months. The majority of these (14% of charities) foresaw this happening in the next three months, however, 8% of charities felt that they would be affected in this way as far as 12 months down the line”*.⁵

In the Trust’s discussions with projects it has become apparent that the need for support is greater than ever and, in some cases, the demand for services has increased enormously and projects are working with people that they were not previously in contact with.

Care homes

Care home residents have had their rights restricted in ways that other citizens have not. In many cases this may not have been a proportionate response and the Scottish Human Rights Commission has acknowledged that there are *“legitimate human rights concerns about what has happened in Scotland’s care homes and believes these concerns fall under Article 2 of the European Convention on Human Rights (ECHR)”*.⁶ Article 2 is the right to life.

Other ECHR rights such as the right to be free from inhuman and degrading treatment (Article 3), right to a private home and family life (Article 8), and the associated right to non-discrimination (Article 14) are also relevant to any human rights consideration of the impact of COVID-19 on care homes.⁷

⁵ COVID-19 Impact on Charities, The Scottish Charity Regulator (OSCR), June 2020 – Breaking Blue

⁶ Coronavirus pandemic: Scotland’s treatment of elderly people in care homes must be investigated by independent inquiry – Richard Leonard, The Scotsman, 29 June 2020

⁷ Commission Statement on Human Rights in Care Homes, 16 June 2020 – Scottish Human Rights Commission

Individuals have been discharged from hospitals to care homes without testing for COVID-19 and without their consent, while guidance from the Scottish Government has also prevented residents in care homes with COVID-19 from being admitted to hospital. This could be said to undermine the rights set out at s.3 of the Patient Rights (Scotland) Act 2011:

- » patient focused
- » optimum benefit to health and well-being
- » as full participation in decisions as possible
- » provision of information and support so they can participate in decision-making

Care home residents' rights may have been further impacted by an inappropriate (clinical) approach to infection control in care homes, with guidance more suited to a hospital environment than a care home. Individuals have had personal objects removed from their rooms (right to private and family life) and human rights concerns have been raised about the policy of confining people with dementia to their rooms (deprivation of liberty), causing them undue distress.

Further distress has been caused for people with dementia and their families who were unable to visit them due to high levels of infection within many care homes. For people with dementia, in particular, the absence of familiar faces, routines and physical contact is distressing. Being unable to maintain relationships has also left carers anxious that their loved one, after a considerable gap sometimes spent isolated in their room, will not recognise them when they can visit again.

One unpaid carer in Scotland has recently started an online petition, 'Before They Forget Who We Are', for one nominated family member per resident to be allowed to visit their loved one in a care home safely using PPE. The call is directed to all governments in the UK.⁸

Where a person has been admitted to a care home because a family carer has reached crisis point during lockdown, there is the added guilt and stress of feeling out of control or being unable to cope. This is made worse by the lack of support available for both the carer and the person with dementia during what is a difficult time of transition at the best of times.

These issues have also been prevalent in the wider UK context, with leading dementia charities commenting that enforced separation has caused deterioration in care home residents' mental and physical health. They also argue that family carers remain essential members of a person's care and support network whilst living in a care home, being their 'advocates, voice and memory' and keeping them connected to the wider world.

Response so far – ways in which projects/ organisations have adapted their services

As mentioned previously, responses from organisations funded by the Trust have typically been quick and person-centred, addressing the specific needs of the communities they support and many have worked quickly to put their services and activities online.

The report by OSCR looking at the impact of COVID-19 on Scottish charities revealed that *“the most common reaction from charities was to change the way in which they deliver services (84%). This included providing support remotely by phone or virtually (47%) rather than in person”*.⁹

8 Before They Forget Who We Are, A Petition to Allow One Nominated Family Member into Care Homes Using the Correct PPE Safely to See Their Loved Ones, Natasha Hamilton – https://www.change.org/p/scottish-government-allow-one-nominated-family-member-to-be-united-with-care-home-residents-during-covid?utm_source=share_petition&utm_medium=custom_url&recruited_by_id=4e2c5f20-bf6e-11ea-b502-fbf313e3fc47

9 COVID-19 Impact on Charities, The Scottish Charity Regulator (OSCR), June 2020 – Breaking Blue

These findings are certainly reflected in the experiences of the organisations that we spoke to, who are using a combination of online and traditional approaches to deliver support: from Zoom café meetings, regular telephone and video calls to music, arts and crafts, weekly newsletters and deliveries of shopping, medicine and surprise packages to cheer people up. Recognising that not everyone has access to the internet or feels comfortable participating in online activities, locally-based projects have also been ensuring that hard copy materials as well as art and craft packs are being delivered to people's homes. This has enabled people to remain connected to their communities of interest even where they are unable to connect digitally, reducing isolation and helping to maintaining a routine.

Most organisations, recognising the importance of routine for people with dementia, have tried to deliver group activities on the same day and at the same time as they would have been delivered face-to-face prior to COVID-19.

Some organisations have indicated that lockdown has provided more time to reflect on how they deliver services and has enabled organisations to create additional resources, for example, developing bespoke resources for care homes.

Here are examples of how Trust-funded projects have been delivering services during lockdown:

With their day centres closed and community groups not currently meeting, **Glasgow's Golden Generation** has found new ways to support their members. The day centre staff are regularly calling their members to ensure they have the support they need and also to provide a friendly voice at the end of the phone.

“It means our members are hearing from someone they know and trust which makes a huge difference.”

The charity is also delivering packs of essential food items and toiletries, and an activities newsletter with word searches, crosswords and more. For bingo aficionados, the GGG Facebook page live streams online bingo sessions, with bingo cards delivered in the weekly packs or available on request.

Due to the lockdown restrictions, **Shopper-Aide**, based in Campbeltown, found that its client base doubled overnight, with many over 60s now shielding and the over 70s being required to stay safe at home. The project introduced a Phone Buddy system involving a network of new and existing volunteers and staff calling clients daily, allowing for chats, reminiscence and identifying any needs that might arise. They have adapted to the large demand and are now able to deliver over 200 weekly shops to clients all over Kintyre. With their social gatherings and groups being paused, they have provided a range of activities and challenges to keep their beneficiaries connected and entertained, such as a book and jigsaws delivery service, knitting kits and adult join the dots. They are also encouraging clients, unpaid carers and families to put thought to paper with a poetry competition. This challenge was extended to the local primary schools and poetry is published on their Facebook page weekly as well as read out daily on local radio and displayed in their shop/office window. Their 'lockdown knitters' are also creating squares which will be brought together once it is safe to do so to create a magnificent blanket.

The **Eric Liddell Centre** in Edinburgh is working hard to make sure that their Day Care service users and carers remain engaged and connected during the coronavirus crisis. They have secured food donations for their Lunch Programme, as well as books, knitting kits, and some Kindle Fires from investment firm Baillie Gifford, in order to ensure that their clients are able to access lots of fun activities and online information. Their Facebook page has regular challenges and activities such as quizzes, recipes, and even a stained-glass window tour.

The centre transferred all face-to-face befriending to telephone befriending and introduced an element of intergenerational befriending as well. They have also developed a weekly publication called 'The Isolation Times' which is either posted or emailed to carers and people living with dementia to help keep people feeling connected. Each issue is themed and includes photos, activity and creativity suggestions, and welcomes contributions from readers.

The **Cuimhne Project** at Tagsa Uibhist is working hard to ensure that social distancing doesn't mean isolation for its members scattered across the southern isles of the Outer Hebrides. Its very active Facebook page regularly showcases photos and videos of members and staff at home, keeping everyone updated with what they have been up to. They have organised for six of their members to receive tablet devices with funding from the local housing association and provided support in how to use them.

Staff also help with shopping deliveries. They have set up several community message walls in local shops for people to leave messages of support to the locals. Over the last two years, in collaboration with UistFilm and people in the community, they have been recording some reminiscence podcasts and the first ones are now on their website for people to enjoy.

Heart for Art is supporting care home residents to stay engaged in creative activities. They are delivering hand drawn canvases with visual aids for care staff to support residents in painting. They aim to provide every CrossReach care home with ten drawings, ten visual resources as well as resealable paint pots and brushes. They also support their artists in the community by sending art packs directly to their homes, with two hand drawn images, two visual resources and hints and tips for families and carers to support their loved ones make art. Heart for Art has set up a closed Facebook group for their members, where they can showcase their artworks, and aim to provide an online exhibition of the work produced during the lockdown.

Befrienders Highland made a new link with The Highland Archive Centre, who produced storyboards with information and old photographs from their files. This resource was sent out to unpaid carers and care homes to use as a reminiscence tool, and was shared with the Memory friends and their volunteers, to help stimulate topics of conversation during the social distancing restrictions. This proved to be a really useful resource, as evidenced by feedback from one of their Memory friendship volunteers who had been struggling to engage their friend in conversation. The storyboards were posted to the volunteer and to the friend.

“I want to thank you very much for the Highland Archive materials. We had the most wonderful, animated chat together ever today. We spoke on the phone for over 30 minutes and both really enjoyed the pictures and stories. A wonderful resource and I can’t wait to phone next week.”

Befrienders Highland have posted information packs to unpaid carers which include hints and tips for activities at home, a carer journal, hand washing signs and day wall planners.

Badenoch Shinty Memories, also based in Highland, has created a pack of 100 Shinty related reminiscence cards in English and Gaelic. The cards are released regularly on their social media pages and will be printed and produced as a boxset. The packs are distributed (along with USB sticks containing videos of all Shinty matches) to care homes and individuals in order to keep them engaged. Also in the field of sport reminiscence, **Sporting Memories Scotland** have released their digital Sporting Pink newspaper, featuring articles and stories of past sporting events, have turned their weekly clubs into online clubs, and organise weekly phone catch ups.

Scottish Ballet are using Facebook Live to stream a new workshop every week. Time to Dance, the workshop dedicated to people with dementia, streams every Wednesday at 11.30am for the duration of the quarantine. People can follow the class and do the exercises comfortably from home. By developing communication, expression, coordination, balance, creativity and social interaction, dancing engages the brain and enhances quality of life as well as being lots of fun. They have worked with Bishopton Primary School and Erskine Care Home to develop an intergenerational resource and are developing a programme of online classes exclusively for care home settings.

Playlist for Life recognised how many older people are becoming more isolated due to their not being online. They have worked to produce a workbook in paper version, distributed to Help Points across the country for delivery to care homes and individuals, to assist people in making their own playlists.

Kirrie Connections in Kirriemuir has been holding a range of groups on Zoom since their high street hub closed, including one for carers and a session for both people with dementia and carers. Their choir, Kirrie's Singin, has gone online too. One-to-one contact is being made on Zoom or by telephone. Their new weekly newsletter is increasingly written by members and carers including input from the Farming Memories Group, and a weekly pack of song sheets and craft activities with seasonal poems is delivered to members' homes. The community garden is used for one-to-one meetings and, to do more even if the weather is bad, a pop-up gazebo is being considered.

Dementia Friendly Dunblane in partnership with Dunblane Development Trust volunteers provide a range of activities to local people isolating or shielding, including a Telephone Tree friendship service, shopping and prescription collections. A 'Soup and Cake Run' is made twice weekly and a call to the membership of local Boys Brigade has resulted in young people sending a letter to an older person via a drop-off box in supermarkets. The group has experienced a huge increase in the number of people who need support (from just over 20 to approximately 100) and have also been receiving referrals from Stirling Council services.

Capital Theatres' Dementia Friendly Community in Edinburgh were initially keeping in touch with participants by telephone until it quickly became clear that people wanted ongoing access to arts-based activities. An online programme of dementia friendly events was launched as part of Capital Theatres' Raise the Curtain project, engaging with people digitally during lockdown. It includes monthly Contactless Afternoon Tea Parties, with cake etc. delivered to Edinburgh residents to enjoy while watching a pre-recorded performance online; A Brew and A Blether, an online drop-in chat twice a month, *'to just be together and see some friendly faces'*. They also run Tea & Jam sessions, which are monthly music making sessions, with people encouraged to join the 'jam' session with their own instruments, voices and dance moves. Sessions are available by Zoom to care homes and people in their own homes.

A new project, **Joy to the Moment**, was inspired by a young person worried about people isolating and who wanted to find a way to entertain them. Anyone wanting to get involved was invited to record themselves doing something creative outdoors, given the films are specifically to share with people who have to stay indoors, shielding in their own homes or in their rooms in care homes. These mini-performances, by professional artists and members of the public, have been edited into a series of films and are available on YouTube. Care homes will receive a DVD allowing multiple showings.

Tide (Together in Dementia Everyday), the UK-wide carers involvement network, has been hosting regular Zoom coffee mornings for carers of people with dementia – at local, regional and UK levels – along with some UK-wide focus groups bringing together carers experiencing a similar situation now or in the past. The first focus group featured carers of people with early onset dementia. **Tide** held a Big Coffee Morning online to celebrate Carers Week in June, when the theme of conversation was Making Caring Visible.

Glasgow Life's plans to roll out 13 dementia friendly hubs across Glasgow changed instead to the creation of 3 virtual hubs covering the north, west and south of the city. The organisation is aiming to quickly digitalise all their services, for example, libraries' memory boxes and place-based photos, interactive tutor-led sessions such as Muse Through the Years sing-a-long, sports-based activities such as Armchair Aerobics, Yoga and Mindfulness.

Challenges and opportunities arising from COVID-19

It is no exaggeration to say that the challenges have been and will continue to be considerable, with untold stress, loss and grief experienced by individuals and families. At the same time, there has been a huge amount of good work that has continued during lockdown, including greater reach and better and new ways of working. Some of these challenges and opportunities are discussed below.

Funding / resources

Many of the organisations funded by the Trust also rely on charitable donations to deliver specific support work. As with most charities, they have experienced a huge reduction in donations, in some cases as much as a 90% decrease in April. This will have long-term implications for supporting people with dementia and unpaid carers.

A recent report suggested three ways in which communities can be supported to continue to meet public need post COVID-19. Among these was the establishment of a Community Heroes Fund to fund new mutual aid groups that want to become formal, sustainable organisations and the development of new legislation to put community organisations directly in charge of local budgets.¹⁰ The report recognises what we know to be true through the Trust's funding of locally focussed grassroots work and the Trust's involvement in the development of local dementia strategies: that strong trusted community groups are best placed to meet the needs of their local communities but they need to be resourced properly and have a seat at the table in order to achieve this successfully.

¹⁰ Local Heroes – How to Sustain Community Spirit Beyond COVID-19', May 2020, Power to Change

Delivering support online / new ways of working

The impetus to fast track delivering support, services and activities online has provided greater access to people who are no longer mobile and/ or who live in rural areas and remote communities. This has created opportunities for people to connect in new ways – their networks are no longer only local. Many projects have increased the number of people that they can support and, in some cases, projects are welcoming new members who they have not been in contact with before.

Organisations see new or adapted activities as an opportunity, to be incorporated into their ongoing core provision. However it is important not to make assumptions about the wholesale use of technology – *“a blended approach will be needed”*.

In our discussions, someone commented that *“the digital divide is greater than ever”*. Online provision presents barriers since not everyone wants to, or has access to, the internet. Not everyone has the necessary equipment and ability and support to use technology. Many older people in rural and island communities do not have access to mobile phones or laptops and it is not an easy task to provide technical support or training virtually. Glasgow Life has recruited ‘digi volunteers’ who, during lockdown, are training carers and people with dementia over the phone and online.

Data security is also a challenge, ensuring online provision is not only accessible but that systems are secure for those using an organisations’ online services and activities.

For those facilitating online interactions, with people talking about difficult issues, it can be challenging to offer support remotely to help manage emotions when it is not possible to offer someone a hug.

However, lockdown has offered the opportunity to innovate, knowing that something might not work – something that has to be recognised as invaluable and not to be lost going forward. It also has prompted reflection, with time to create additional resources such as online training.

Evidencing impact

Evidencing the impact of alternative online work, not least during a difficult and busy time, is challenging for staff and organisations, with the need for funders to be flexible regarding the monitoring of grants. At the same time, it is important to capture people's thoughts, feelings and memories stirred by lockdown, to gain their insights about the impact of COVID-19 on their lives so the learning can be applied in the future.

The COVID-19 pandemic has resulted in many national and international conferences being transferred to online events. This presents an opportunity for many organisations, who would have been unable to attend these conferences in person, to share the learning from their work and learn from others, both in Scotland and the rest of the world. Equally, it may allow people with dementia and unpaid carers more scope to participate in events, notwithstanding barriers previously mentioned around digital access and cost. The Trust has recently launched another round of Conference Bursaries to assist people with dementia and unpaid carers to attend conferences.

Unmet need

Due to being unable to access health services in the normal way, people have experienced delays in getting a diagnosis of dementia and the subsequent post-diagnostic support that they would be entitled to. With no clear diagnosis, it has been difficult to signpost people to relevant services. Similarly, many people with dementia who have other long-term conditions are unable to access treatment at the moment; care and locally available support are becoming increasingly important in helping to mitigate stress and anxiety related to deteriorating health during the pandemic.

Moving forward – what is needed to support projects, organisations and the people they support?

We must listen

It is important that we hear first-hand from people living with dementia and unpaid carers of people with dementia about their experiences of lockdown and their support needs in transitioning out of lockdown. People working with people with dementia and carers have told us they are wondering if restrictions have been causing more harm than good.

Measures must be taken to continue to manage and minimise the risk of infection, but we must also guard against the risk of taking a step back to a medical model of dementia. We need to ask people with dementia and carers about their views about risk and what they think is the balance to be struck between not getting COVID-19 versus people becoming more ill if they do not have social contact. As one person commented, *“it is easier to go into lockdown, much harder to come out of it”*.

We must protect human rights

People living with dementia and unpaid carers of people with dementia have, without a shadow of a doubt, been disproportionately impacted by COVID-19. There should be a grassroots-led, human-rights-based examination of the experiences of people with dementia and unpaid carers of people with dementia during COVID-19 so that lessons can be learned.

We need to return to activities and social interaction

People need direct contact, familiarity and trust. Access to online support, services and activities is good but, for many people, this cannot replace human contact. Equally, one-to-one support and activities cannot substitute for group-based interactions and peer to peer support. It is important not to let the pendulum swing too much towards online and individual responses.

When so much of the support, services and activities which people with dementia need are based around socialisation, there is an urgent need to get back to albeit shorter smaller groups, importantly, also giving carers some regular respite.

Providing face to face activities on a smaller scale means running extra sessions to reach more people which in turn requires more funding to cover extra costs. Funding also needs to include small, flexible grants for additional expenses, for example, the regular deep clean of a community bus.

Carers need respite

Given the extra responsibilities and stresses that carers have experienced during lockdown, the need to offer carers community-based respite options and provision that is innovative, flexible and available quickly and at scale, is critical. The Trust has been told that *“a huge rush for respite is anticipated as carers of people with dementia will be on their knees [following lockdown]”*.

Respite, at the best of times, for unpaid carers is a vital lifeline – as indeed it is by extension for the person they care for and their families and, equally, for society and the public purse. It is well-established that caring for a loved one comes at a significant personal cost for carers. Aside from often having to reduce working hours or give up paid work and the financial hardship that may follow, it has a detrimental effect on carers’ own physical and mental well-being.

Caring can be physically demanding, for example, involving moving and lifting (without the essential training paid staff access) and a regular lack of sleep. Many carers are older and may have an underlying health condition which can be exacerbated as the number of hours they care per week increases. Caring puts a strain on other personal relationships – with a partner, other family or friends. Carers report higher than average levels of anxiety and lower than average levels of happiness.

Recent figures released for Carers Week 2020 show that ***‘In Scotland 16% of the adult population said they were already providing care before the coronavirus outbreak (...) and a further 9% said they have started caring since the coronavirus outbreak (...). This suggests there are currently as many as 1.1 million unpaid carers in Scotland’***¹¹

Our health and social care system relies significantly on the contribution of unpaid carers and will continue to do so. Carers reaching crisis point is not only hugely distressing for individual families but, occurring in large numbers, will likewise impact on our health and social care system and public finances. The economic value of the contribution made by unpaid carers in Scotland was estimated in 2015 to be £10.8 billion.¹²

People need access to technology and support in how to use it

To prepare now for greater resilience in the future means that resources need to be re-directed to ensure equitable access to the technology necessary in what will probably be a physically-distanced world for a considerable time to come; support and training in how to use it is equally important.

11 Carers Week 2020 research report, The Rise in the Number of Unpaid Carers During the Coronavirus (COVID-19) Outbreak, June 2020, Carers UK – <https://www.carersuk.org/scotland/policy/policy-library/carers-week-2020-research-report>

12 Valuing Carers 2015: The Rising Value of Carers’ Support, Nov 2015, Sue Yeandle and Lisa Buckner, Carers UK – <https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

Information and guidance need to be clearer

Any change in the status of dementia in relation to shielding has to be nuanced and accompanied by clear guidance and, importantly, support for carers who fear adding dementia to the list could result in carers becoming even more isolated and lacking in support.

People in situations of vulnerability who need to continue self-isolating, including those not classed as shielding, must have an ongoing offer of support. The five National Carers Organisations in Scotland make a similar call:

“...for those for whom lockdown will remain a reality for much longer than the rest of the population, a range of services and supports must be introduced to provide holistic support that encompasses (...) all aspects of their lives (wraparound support). This must go beyond those who are shielding and include those who are at higher risk and their unpaid carers. This should be developed with those affected”.

Guidance must be clear, with information available in a variety of accessible formats, and not only digitally. It must include information which assists unpaid carers when they have to make difficult judgements about the balance of risks and harm, for both the person they care for and themselves.

This is an opportunity to use self-directed support to its maximum potential

The problems experienced under lockdown are not new – the COVID-19 pandemic shines a spotlight on issues that existed before the virus did. New and diverse ways of providing social care are required, using existing self-directed support legislation properly, as well as taking into account learning from how people have reacted to COVID-19.

An evaluation of the Trust's Individual Awards Scheme demonstrated the positive impact that a small personal budget can have on the physical and mental health and well-being of people living with dementia and unpaid carers. It enables them to keep an absolute focus on their personal outcomes rather than on how resources are used. Not only was immediate impact evident, but there were wider ripple effects which could be wide-ranging and long-lasting. The benefit was ongoing for many months after the initial spend, potentially avoiding or delaying a need for more costly support and having a positive impact on the wider family or carers. The process of accessing an individual award also connected people with other forms of support.

The Individual Awards Scheme report¹³ underlines the essential elements that are necessary to really unlock the potential of individuals directing their own support, in particular the flexibility to spend the budget on anything that matters to and/or will make a difference to them. This flexibility provides a sense of control over the process of applying for self-directed support and decision-making around spend.

People living with dementia and unpaid carers must be trusted to make decisions about what their budgets can be spent on, based on their individual circumstances rather than what might be 'allowed' within the parameters of eligibility criteria. In order for self-directed support to be effective, it must be flexible and include the option to adjust decisions on spend when people's circumstances change.

13 <https://www.lifechangestrust.org.uk/publications>

The response to this crisis, and effective ways of working in the future, is a community-driven, government supported approach

Trust-funded projects have demonstrated the effectiveness of voluntary organisations and local communities in their response to COVID-19, continuing to support people with dementia and unpaid carers in their communities, whether of place or of interest, whether independently or in collaboration with others in the voluntary and statutory sector. The power of this response is surely an opportunity to be built on.

We cannot assume that the COVID-19 pandemic is on the way out. There may be another viral spike or another virus in the future may cause a similar public health and economic crisis. In terms of how we move forward, a key question being asked elsewhere is:

“If the community response to the crisis has been central to ensuring people’s well-being, what does that mean for how we think about the economy, and public services?”¹⁴

Cormac Russell, in the same report, argues that:

“...we have learned that the only credible response to significant public health crises is a community-driven one. The Covid-19 pandemic is no different, it will not be unilaterally addressed by a top-down deficit-based agency response nor will it succumb to volunteer drives to target the most vulnerable. There is only one credible, evidence-based, tried and tested response to the current challenge, that’s the one that puts communities in the driving seat, with institutions in a strong support role.”¹⁵

¹⁴ Local Heroes – how to Sustain Community Spirit Beyond COVID-19, May 2020, Power to Change

¹⁵ *ibid*, page 13

Central to that is the active involvement of people with dementia and unpaid carers in relating their experiences and what could/should have been done differently.

This has been an intense and testing period, full of challenge but also ingenuity and innovation. We need to create opportunities to reflect, share and discuss learning about what has worked well and what can be applied in the future.

This includes, for example, hearing more from care homes where there have been no cases of COVID-19 at all (neither symptomatic nor asymptomatic).

Sharing further evidence and learning

There will be many opportunities to take part in the sharing of learning and evidence from the work of the Trust over the coming months through webinars, conferences and learning events. The Trust recently launched '[Dementia: A Whole Life Approach](#)' which outlines existing evidence about the importance of a local person-centred response to the needs of people living with dementia and unpaid carers through the work of dementia friendly communities, peer support projects and other grassroots, citizenship and rights-based approaches. The resource has five volumes:

- » Human rights and dementia
- » Community and dementia
- » Independence, confidence and support
- » Peer support
- » Information, awareness, training and education

The Trust will contribute to the transition out of lockdown through the provision of small, flexible grants aimed at individuals and smaller local organisations. Two of these funds have already been launched (Peer-to-Peer Resources Funding for People with Dementia and Peer-to-Peer Resources Funding for Unpaid Carers of People with Dementia). Further Creating Better Lives grants (small, and area-based) will be announced over the coming months.

Many of the Trust's projects have also developed bespoke and online training, for example Age Scotland's Human Rights for Unpaid Carers course. You can learn more about this and other training opportunities on Twitter and through our news bulletin <https://www.lifechangestrust.org.uk/newsletter/signup>.

We are in the process of evaluating almost all Trust-funded projects and programmes and these reports will be available on our website <https://www.lifechangestrust.org.uk/publications>. To further embed the learning from these evaluations we will be working with key stakeholders to organise learning events which will be open to everyone and will also be publicised through our news bulletin and through our existing networks.

Appendix – useful reports

- » **Covid-19 Impact on Charities**, OSCR, June 2020 – Breaking Blue <https://www.oscr.org.uk/news/charities-active-in-counteracting-the-impact-of-COVID-19/>
- » **The Third Sector and COVID-19: Evidence Session**, 26 June 2020 – Local Government and Communities Committee, Scottish Parliament <http://www.parliament.scot/parliamentarybusiness/report.aspx?r=12726>
- » **Dementia, Human Rights and COVID-19**, 3 June 2020 – Anna Buchanan, CEO, Life Changes Trust <https://lifechangestrustblog.wordpress.com/2020/06/03/dementia-human-rights-and-COVID-19/>
- » **The Need for a Human Rights Inquiry – Coronavirus and Older People**, 13 June 2020 – Donald Macaskill, CEO, Scottish Care <https://scottishcare.org/the-need-for-a-human-rights-inquiry-coronavirus-and-older-people/>
- » **Response to Scottish Parliament COVID-19 Committee Call for Evidence**, May 2020 – About Dementia, Age Scotland https://www.parliament.scot/General%20Documents/About_Dementia.pdf
- » **Response to Scottish Government Stakeholder Inquiry on Shielding**, May 2020 – About Dementia, Age Scotland <https://mailchi.mp/e5c9c822ad9a/about-dementia-july-newsletter>
- » **Effective, practical care and support of people living with dementia in care homes during and after the COVID-19 pandemic** – webinar, 27 May 2020 – Journal of Dementia Care <https://www.ipevents.net/journal-of-dementia-care-webinars/effective-practical-care-and-support-of-people-living-with-dementia-in-care-homes-during-and-after-the-COVID-19-pandemic/>

- » **Caring Behind Closed Doors – Forgotten Families in the Coronavirus Outbreak**, April 2020 – Carers UK https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf
- » **Discussion Paper on Life Leaving Lockdown**, May 2020 – National Carer Organisations <https://carers.org/downloads/scotland-pdfs/moving-out-of-lockdown-final.pdf>
- » **Local Heroes – how to Sustain Community Spirit Beyond COVID-19**, May 2020 – Power to Change <https://www.powertochange.org.uk/blog/local-heroes-sustain-community-spirit-beyond-COVID-19/>

Young People with Care Experience Programme

Introduction

Since the beginning of lockdown, the Life Changes Trust has been learning directly from young people with care experience¹ and those who support them about the impact of COVID-19.

When public health measures first emerged to deal with the pandemic in March 2020, the Trust and our Advisory Group (voluntary advisors who each have their own experience of the care system) quickly recognised the acute impact that social isolation and societal disruption was likely to have. By April 2020, we had coproduced and launched an individual grants initiative called the Keep Well Fund to support the well-being of young people with care experience during lockdown.

The rich data we have gathered from the testimony of hundreds of young people who applied to the Keep Well Fund is the main focus of this report. This data has offered us a unique lens in terms of understanding the impact of the global pandemic on young people with care experience. The report also draws in learning from Trust-funded organisations.

Providing reassurance, flexibility and opportunities for peer support so that funded organisations can prioritise relationships and stay focused on their mission has been a priority for the Trust through lockdown.

This report will touch on the experiences of projects who have struggled to maintain engagement with young people and/or key partners through lockdown and share insights from those who have quickly adapted to difficult circumstances. Many have developed creative and effective ways to respond to young people's needs, often through relationship-based and participative practice.

¹ The Trust focuses on young people who are currently experiencing or have previously experienced formal care arrangements such as residential care, foster care, kinship care, care at home (Supervision Order) or secure care. Our funding targets those in the 14-30 age range.

The information provided has been drawn from application forms, self-evaluation reports, stakeholder conversations and facilitated workshops/group discussions with Trust-funded projects. We want the learning and insights shared in this report to add further depth to the strong body of evidence being produced by our partners, including CELCIS, the Centre for Youth and Criminal Justice, Staf and Who Cares? Scotland, to inform and shape policy and practice. This is vital as the public, voluntary and community sectors begin to support young people to transition out of lockdown.

The Keep Well Fund

At the Life Changes Trust we believe that young people with care experience are all individuals with unique talents, skills, ambitions and potential. We also know that, as a group, they face significant challenges. The Trust and the members of our Advisory Group co-produced the Keep Well Fund because we understood that lockdown would potentially deepen inequalities and amplify existing issues, particularly around poverty, mental health, physical well-being and loneliness.

This initiative offered up to £250 to young people with care experience to improve their physical and/or mental well-being. Investing directly in young people through individual funding awards is an important aspect of the Trust's overall approach to creating lasting positive change. The Keep Well Fund gave young people (sometimes with the support of their key worker) the space to express themselves and tell us in their own words what would help them to stay well.

The input, leadership, challenge and reassurance offered by the Advisory Group at every stage of the Keep Well Fund process was invaluable. Despite the challenges around time and physical distancing, the Trust remained committed to the principles of co-production, and this ensured that we launched an initiative that young people with care experience (and their support workers) could easily engage with.

The response was overwhelming, and as we read through each application it was sobering to see the confirmation of much of what we already know – that young people with experience of the care system are affected by inequalities in relation to health, income, digital access, housing and other areas of life.

The Trust was heartened by the response of the funding community when we reached out and asked for further support to enable us to provide more grants. Donations from the Esmee Fairbairn Foundation, the William Grant Foundation, the Cattnach Trust, Cycling Scotland and Inspiring Scotland were all vital in expanding the reach of the Keep Well Fund.

The timing and reach of the Keep Well Fund gave us a much clearer picture of the circumstances of young people with care experience during lockdown, and it has been a privilege to be able to support the creativity, ambition, determination and kindness of young people amidst the unprecedented challenge of the global COVID-19 pandemic.

The Keep Well Fund in numbers

Number of Applications Received: 817 (these included ineligible applications due to age, applications referred to Emergency Funding providers and duplicate applications)

Number of Applications Assessed: 712

Number of Award Offers: 691 (two of these turned down the funding as they felt it was no longer necessary)

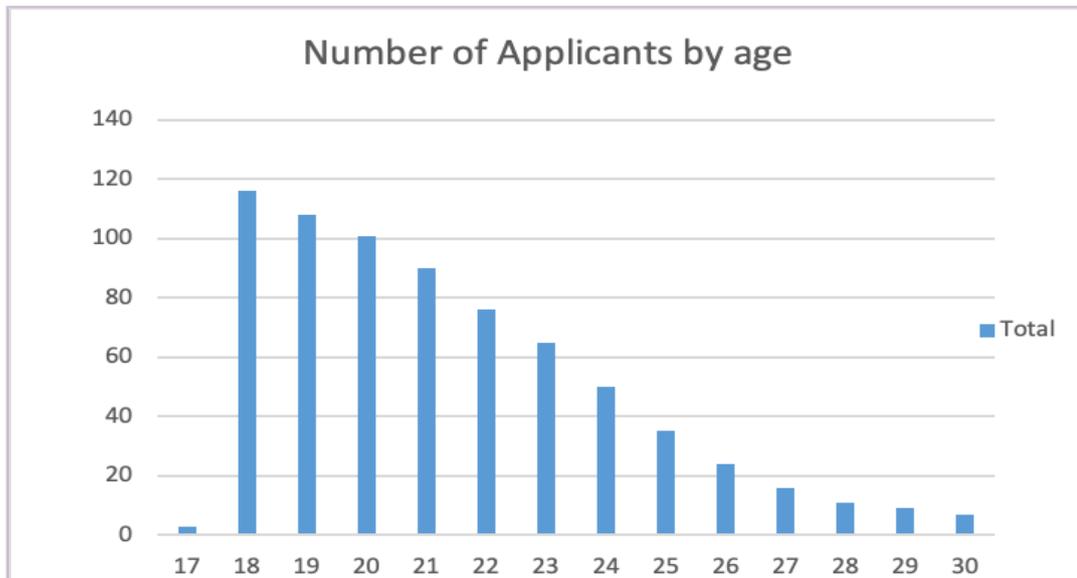
Number of Applications referred to Emergency Funding partners (including those which were partially funded through KWF): **119**

Average award: £199

Total amount awarded through KWF: £138,272

Demographic information

Age



Note: Two of the 17 year-olds were ineligible due to age; the third would have turned 18 by the time the application was assessed so was considered eligible.

Gender

Gender	Num. of Applicants	Percentage of Total Applicants
Female	394	55.3%
Male	305	42.8%
Other	4	0.6%

N=703

Ethnicity

	Number of Applicants	Percent of Total Applications
White	625	87.8%
BAME	79	11.1%

N=704

Care Background

Category	Num. of responses	Percentage of Total Applicants
Foster care	335	47.1%
Residential home/school	341	47.9%
At home (e.g. supervision order)	129	18.1%
Other family/friends (kinship care)	182	25.6%
Secure care	71	10.0%
Unaccompanied asylum seeker	23	3.2%
Other	3	0.4%

Education/Employment

Category	Num. of responses	Percentage of Total Applicants
Unemployed	299	42.0%
In full time education	230	32.3%
Stay at home parent	69	9.7%
In part-time employment	53	7.4%
In full-time employment	42	5.9%
In part-time education	25	3.5%
Other	20	2.8%

Scottish Index of Multiple Deprivation

SIMD Percentile	Num. of applicants	Percentage of Total Applicants
1 (Most deprived)	169	23.7%
2	123	17.3%
3	96	13.5%
4	85	11.9%
5	50	7.0%
6	40	5.6%
7	45	6.3%
8	21	2.9%
9	18	2.5%
10 (Least deprived)	21	2.9%

N=668; Total Applicants = 712

Funding Requests

Category	Num. of requests	Percentage of Total Applicants
Technology for entertainment	246	35%
Technology for connection	245	34%
Gym and exercise equipment	165	23%
Art supplies and equipment	114	16%
Educational materials or tech for applicant	111	16%
Family activities	70	10%
Bikes	57	8%
Other hobbies	36	5%
Cooking and Baking	33	5%
Musical instruments and equipment	24	3%
Gardening	23	3%
Home items and decorating	18	3%
Educational materials or tech for child	13	2%
Beauty supplies and training	8	1%
Other purpose	31	4%

N=711

Key Messages from the Keep Well Fund Applications

Analysis of the data from the Keep Well Fund has identified challenges for young people with care experience around three main themes:

- » Isolation and loneliness
- » Mental Health
- » Poverty

As we would expect, these themes are interlinked, reflecting the whole life perspective offered by young people. As well as identifying fundamental challenges, our analysis has also highlighted evidence of the determination of young people to take control of their circumstances in ways that promote their well-being. This chimes with the insight shared by funded projects, who have also found that for some young people there have been benefits to the consistency and structure provided by lockdown, whilst for others existing challenges in their lives have been exacerbated.

The Trust believes placing young people at the heart of all efforts to transform the care system is vital if we are to achieve lasting change. This includes listening closely to what young people tell us and building on this intelligence, creating opportunities to work alongside young people themselves to design the services and supports of the future.

We have incorporated the voices of young people and the supportive adults around them into this report through the inclusion of anonymised excerpts from applications. These excerpts bring to life the data we are sharing and highlight the stark challenges facing young people with care experience during lockdown. However, within the Keep Well Fund data and through the learning shared by funded projects, we can also begin to see protective factors and potential solutions emerging.

Isolation and loneliness

- ⇒ Fifty-two percent (52%) of young people with care experience who applied to the Keep Well Fund either lived by themselves or were single parents who were the only adult in their household.
- ⇒ Young people who came to Scotland as unaccompanied asylum seekers and young people living in homeless accommodation evidenced particularly concerning levels of isolation

We know that young people with care experience are disproportionately affected by vulnerability factors associated with isolation and loneliness, including weakened family connections, stigma, disrupted friendships, sibling separation and contact, leaving care, homelessness and more². Over half of the applicants to the Keep Well Fund lived entirely alone or were lone parents. The data from these applications highlights that young people with care experience often do not have the extended networks of family and community that many of us rely on. It is also clear that the lockdown measures have reinforced vulnerabilities and exposed the fragility of some support networks for young people with care experience.

“I moved out of my residential children’s unit last year into my own accommodation. Prior to the COVID-19 outbreak I was struggling with loneliness and feeling isolated, however was making positive steps to try and improve that, this has drastically changed now. I am now expected to work alone in my house, which I already felt lonely in, and have not had the interaction which I need to thrive...”

Keep Well Fund Applicant

² Morton, L. (2018) [Joint response to Scottish Government consultation on ‘A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections’](#)

The immediacy of concerns around isolation and loneliness were also clear for young people who had successfully built positive support networks and routines that were abruptly disrupted by lockdown. In particular, applicants highlighted disruption to education, early years provision, third sector projects, social work services and family relationships with people who are in the 'at risk' category (particularly elderly relatives and people with existing health conditions).

“I am a single parent and live with my daughter. Before the outbreak I had a routine of taking my daughter to nursery and then visiting my friend who has a toddler. We would go for a walk and shopping together. We are close friends and give each other a lot of support. (...) The days are running into each other and are very long when you are worried about the situation, your anxiety is raised and you are trying to entertain a young child who is used to the busy routine and activities offered by the nursery.”

Keep Well Fund Applicant

For those young people who had recently come to Scotland as unaccompanied asylum seekers, their sense of isolation was even further compounded. Many were struggling with the trauma of their pasts, with several young people seeking asylum specifically mentioning the challenge of being alone with their thoughts. While this number of applicants was small (23 in total), we know that there are many more young people in similar situations. In 2018/19, the Scottish Refugee Council, in conjunction with Aberlour's Scottish Guardianship Service, helped 200 newly arrived young people, nearly half of whom had been trafficked or suffered exploitation.

“I arrived in Scotland in 2019 and am asking for asylum here. I didn’t know anyone when I arrived here but I started college last year and have met friends there. I am now on my own and feel alone with my thoughts. The only thing that I used to do, as I am new to the UK, is the [group activity] and college - sometimes I walk around the shopping centre. But now I have to stay at my home... This has been really hard for me. My home is also very basic with little in it so I stay in my bedroom and sleep most of the time.”

Keep Well Fund Applicant

Young people living in homeless accommodation, some of whom had recent experience of the justice system, also seemed to be particularly badly affected by loneliness and isolation. For some of these young people, their only relationships prior to lockdown were with staff members, and this contact was disrupted due to little or no access to digital technology.

“Live alone in a temp accommodation provided to me by the Council... I only have a sofa and a coffee table, no tv no tablet etc. Very lonely and isolated in every meaning of the word.”

Keep Well Fund Applicant

Mental Health

- ⇒ A majority (52.9%) of young people with care experience who applied to the Keep Well Fund disclosed an ongoing mental health issue – i.e. a mental health condition that pre-dated lockdown.
- ⇒ Applicants most commonly highlighted anxiety and depression, although just over 10% highlighted other mental health conditions such as personality disorders, bipolar disorder, or PTSD/trauma.
- ⇒ Young people with care experience evidenced a range of coping strategies relating to their mental health issues such as connecting with others online, exercise, gaming and artistic and musical pursuits.

For over half of our Keep Well Fund applicants, the stress and uncertainty of lockdown only added to pre-existing anxiety, depression, and other mental ill-health challenges. Evidence from the Fund around the particular challenges lockdown has presented to young people with pre-existing mental health conditions chimes with the findings from the UK-wide data collected by the Centre for Youth Impact³.

Applicants reported being cut off from their support networks and other coping strategies due to lockdown. Young people missed contact with important people in their lives and this was having a detrimental effect on their mental state. As a result, thirty-four percent (34%) of applicants requested funding for mobiles, laptops, and tablets specifically so they could keep in touch with those they relied on most for support (young people also requested funding for digital devices for entertainment purposes and many young people highlighted the benefits of these digital devices for both keeping in contact with family/friends and keeping occupied).

³ The Centre for Youth Impact (2020) [‘Diving into COVID survey data, part 1’](#)

“My mental health is poor, and my anxiety is high. I have a cheap mobile phone which is my only contact with my family and friends. Before this I would be out every day and visiting family and friends. I would take my [child] to various groups. I would attend mental health support groups. I had a befriender who would take us out. I don’t do well on my own...”

I would like to apply for a laptop. This would allow me to contact my family and friends and see them at the same time. I could also access mental health support online much easier than on my phone. I could look for things to do with my [child] and access media for myself as it is hopeless on my phone. This would help me a lot by seeing other people and having something to do when the wean is sleeping.”

Keep Well Fund Applicant

Young people also highlighted that access to other coping strategies such as physical or creative activities was severely limited by lockdown.

For example, the Keep Well Fund received a high proportion of requests for gym and exercise equipment (24% of all applications) and exercise was cited as a key strategy for managing mental health issues. With public gyms and swimming pools closed and team sports paused, young people sought funding for bicycles, free weights, benches, running shoes and other equipment that can be used either at home or outdoors.

“One young person was absolutely delighted to get the award. He bought exercise equipment and was in a really bad place. He is using it once a day, but that was really all he had to do each day.”

Key Worker

Additionally, young people described creative pursuits as playing an important role in maintaining or improving mental well-being.

The applications in this category were varied and included materials for small decorating/upcycling projects, drawing and crafts materials, journals for creative writing, paints and colouring books. Almost one-fifth of all applications (19%) requested funding to support this type of activity.

“Drawing and writing have been a really important way for me to relax, and take myself out of the anxiety and depression that I struggle with. Sometimes it is the only thing that keeps me going. I would like to do my own drawings, to express my feelings - but also to have colouring in characters for complete relaxation, with no pressure to judge my own skills... At the moment I don’t have any proper art materials, and it is very frustrating. I think it would make a lot of difference to me to be able to do drawing and colouring in, and also to start a journal to help when my feelings overwhelm me. When I color it stops me thinking negative thoughts, keeps me distracted and relaxes me. “

Keep Well Fund Applicant

Poverty

- ⇒ Nearly a quarter (23.7%) of the young people with care experience who applied to the Keep Well Fund came from the most deprived areas of Scotland (according to SIMD data).
- ⇒ Almost three-quarters (73.5%) of applicants came from the top five most deprived areas.
- ⇒ Forty-two percent (42%) of the young people who applied were unemployed.

It is increasingly well-documented that young people with care experience are disproportionately affected by poverty in all its forms⁴. The financial pressures (and related challenges of food poverty and digital exclusion) that many face have been amplified during the pandemic. The Keep Well Fund data provides a distinctive insight into the pervasiveness of poverty amongst young people with care experience.

Over forty percent (42%) of applicants to the Keep Well Fund were unemployed. Furthermore, applicants who were in employment often expressed concerns about the security of their jobs and/or stated that they were still experiencing financial shortfalls (in-work poverty). The Keep Well Fund was designed to be distinct from crisis funding available to young people (although the Trust did make contributions to the emergency funding initiatives administered by Who Cares? Scotland and Aberlour). Nonetheless, we made over 100 referrals to emergency support for young people who were struggling to pay essential bills and/or buy food and necessities.

4 Staf (2020) [#WeLove: sharing COVID-19 best practice](#)

“The kids being off nursery and school the days are getting harder to fill with activities for us as a family. I am not in a position financially to invest in crafts or games to keep the household fulfilled, active and as normal as possible at such uncertain times. Basic household supplies such as food, toiletries are running low which is adding more stress to our situation. I am currently still working full time nightshift and trying to keep on top of everything. It definitely feels like a mountain sometimes.”

Keep Well Fund Applicant

Financial hardship was a recurring theme across almost all applicants, but as we found in relation to loneliness and isolation, some young people such as those who have experienced homelessness and young people seeking asylum, appear to be particularly exposed.

“I currently live on my own having just moved into a homeless network flat. (...) Having had my own tenancy previously, I have used all of my leaving care grant and there are no funds available to buy another TV. (...) I have ADHD and struggle when I do not have things to do and having a television would provide me with something to occupy my time and hopefully take away some of the boredom of living on my own which has historically been a problem for me.”

Keep Well Fund Applicant

It is also clear from applications that technology and data poverty remain highly prevalent, and digital exclusion often prevents young people from receiving support and engaging in activities that not only promote their well-being, but also have the potential to radically improve their life chances such as further/higher education.

“[Organisation] would normally give me access to their residential project where I can access Wi-Fi and a laptop. But due to the strict social distancing measures and the fact that the college is closed I have no functional means of study and access [to learning pages and notes]. (...) I am doing this purely by a small mobile phone.”

Keep Well Fund Applicant

Digital exclusion is particularly concerning as essential public services are increasingly being delivered online. With libraries, education institutions and community/group spaces closed, digitally excluded young people have been cut off from opportunities to connect virtually with important people, complete applications to access financial support, pay bills, access online information and platforms (for education, entertainment or otherwise), shop online (particularly if shielding), and much more.

“[Young person] can only communicate by email as he can't afford a phone or credit. He has been working with the Team who confirmed he doesn't have any disposable income. These restrictions [lockdown] have had a negative impact on him and he would benefit from having access to a mobile so he can contact his supports and peers as required and also for us as professionals to be able to offer on-hand communication and be able to make regular welfare check-ins with him. “

Key Worker to Keep Well Fund Applicant

Over half of the grants made by the Trust (58%) supported the purchase of mobiles, laptops, tablets and other forms of digital technology.

Keep Well Fund: Impact and Learning

The Trust has gathered some light-touch feedback from young people and key workers regarding their experience of the Keep Well Fund and we have combined this with our own analysis of some key learning points around the following topics:

- » Individual grants/flexible budgets
- » Co-production
- » Corporate Parenting

These topics are interlinked and all of them are underpinned by the need to develop stronger foundations for relationship-based practice to thrive.

Individual Grants/Flexible Budgets

As we have seen with other individual grants programmes, young people often value the fact that someone is willing to reach out and offer a small funding award as much as the practical benefits the money itself can bring.

“Thank you ever so much for awarding me the grant money. Myself and my family are completely over the moon... This really does mean so much to us.”

Keep Well Fund Awardee

“Honestly thank you so much again, my children have had an absolute blast today and I’m sure will continue to do so for the next few months. What you guys do is truly amazing and I have two very happy children.”

Keep Well Fund Awardee

Key workers appreciated the simple, straightforward process and the quick response from the Trust. They also commented on the immediate positive effect on young people of having a small budget that they can direct.

“We supported young people through telephone calls and we completed the applications whilst on the phone... It was all very quick. A lot of other grants take a while, but it was great to get this one through lockdown. It’s really isolating in temporary accommodation and the things they bought had an instant impact.”

Key Worker

Simple, accessible individual grants providing small amounts of money in a timely manner can play a key role in offering more choice and control to young people.

“The Keep Well Fund has been really valuable. It was much more open than other funds, young people got to ask for what they wanted and they got to own the things that they bought.”

Key Worker

Despite the straightforward application process, many young people were supported to apply with the help of social workers, project staff and guardians. Trusted adults built on existing relationships to support young people who lacked the technology to apply, who may have struggled to articulate what they really wanted to apply for, or whose lives are so complex that they may have missed the deadline.

“The application was straightforward from a professional point of view. We did provide support through the process though as some young asylum seekers would have struggled with language and/or comprehension.”

Key Worker

The importance of these relationships reinforces concerns that young people who are not being reached by support services and funders are more likely to be further disadvantaged during the current global pandemic.

Co-production

The Trust had to adapt its usual approach to co-production in light of lockdown, but we still worked closely with our Advisory Group to create the Keep Well Fund, and this was central to making sure the Fund could reach out widely to young people with care experience across Scotland.

The level of demand for the Keep Well Fund was well beyond what we originally anticipated and this meant that the approach to working with the Group had to be adjusted – for example, it quickly became clear that they would not be able to assess all of the applications. However, the Group identified their own solutions in relation to running a sample panel, making decisions on priorities and benchmarking costs. This enabled the Trust to continue to work to co-production principles whilst processing applications efficiently.

Corporate Parenting

Finally, our learning analysis has highlighted areas for attention in relation to Corporate Parenting. These gap areas highlight again the importance of taking a whole life approach, as young people have multiple identities beyond having experience of care. In the data from our Keep Well Fund applications, three identities emerged strongly: those who declared themselves as having a disability, part or full-time students, and parents or those expecting children.

Half of the young people with care experience who applied to the Keep Well Fund self-identified as having a disability. The vast majority of those had mental health conditions (38% of applicants), with others living with learning disabilities (13% of applicants), physical disabilities (10% of applicants), and neurological conditions (4% of applicants). This raises questions about the level of support currently offered through Local Authority Continuing Care and Aftercare arrangements - it is not clear if the needs of young people are being fully assessed prior to leaving care.

A quarter of our applicants were young people with care experience who are parents or expecting a child. Many applicants described the access they usually had to child care, early years services, local community groups and free or reduced-cost activities such as parks and playgrounds and other outdoor activities. It was clear that for this group of young people with care experience, those supports are lifelines, and their removal made an already challenging time even more difficult.

“I had previously felt like a failure as a single mother. I can’t possibly put into words how good it felt to be able to buy my toddler toys for the garden.”

Keep Well Fund Awardee

This finding strengthens the argument for greater engagement at local level of all agencies and services which have Corporate Parenting responsibilities; Champions Boards across Scotland provide a platform for this engagement. If another lockdown arises, Corporate Parents should think widely about their responsibilities towards young people and consider “care proofing” their decisions, particularly those relating to early years provision. In addition, for many young people, community-based projects run by the Third Sector are vital sources of family support. Funders can play a key role in providing more financial sustainability for projects such as these, through more provision of core funding and longer-term funding agreements.

Another area for attention relates to young people in full or part-time education. Thirty-six percent (36%) of applicants fell into this category, and around one third of this group requested funds for simple digital devices. Many young people described trying to write essays on their phones, or sharing their tablet with their child so they could keep up with home-schooling, which meant they themselves could not keep up with their own studies. Given the role of Further and Higher Education institutions as Corporate Parents, more needs to be done to ensure that young people with care experience who are students have the equipment (particularly digital devices) they need to learn.

Funded Projects: Impact and Learning

The key insights gathered from the Keep Well Fund align closely with the learning shared by Trust-funded projects who have been supporting young people with care experience throughout the pandemic. Project workers have highlighted the challenges of supporting young people in managing their mental health, concerns about financial vulnerability and the difficulties some young people face getting online access, whether due to data poverty, digital poverty or a living situation where they cannot easily participate in online activities due to lack of space or privacy.

Trust-funded projects miss face-to-face interaction with young people. This is particularly the case for projects who are in the early stages of building relationships and forming a cohesive group of young people to shape and steer project activities.

However, as well as being privileged to support the determination and creativity shown by young people through the Keep Well Fund, the Trust is also proud to work with organisations who have responded to this crisis with speed, creativity, flexibility and a continued commitment to putting young people at the heart of their work.

Projects funded across all of the initiatives within the Trust's Young People with Care Experience Programme have shared a range of positive experiences of delivering their work in new ways, reaching new participants, strengthening collaboration and making time for valuable peer support.

“Using different ways to build and maintain relationships, such as taking advantage of more one-to-one time on virtual calls or socially distanced walks, are helping project staff to engage with their young people and ensure current circumstances don’t lead to further isolation.”

Project Worker

Many projects have highlighted advantages to virtual engagement and delivery. These include:

- » online delivery allowing them to reach and/or spend more time with young people in remote locations
- » some young people flourishing as a result of online engagement, particularly those who generally struggle to take part in group activities
- » more time freed up to spend with young people or to engage in learning/collaboration work with their peers due to less travel commitments

Most of the organisations who have adapted in response to the pandemic plan to offer a mixture of physical and virtual opportunities going forward.

Organisations who already had strong relationships with a core group of young people have found interesting ways to continue to maintain engagement. A small selection of the experiences and learning shared by projects is provided below.

Champions Boards

- ⇒ Delivering food parcels and care packages, distributing technology and data and organising regular phone check-ins are just some of the ways that Champions Boards have supported young people through lockdown.
- ⇒ Champions Boards have also developed an interactive and varied programme of activities with and for young people in their area, from virtual quizzes, treasure hunts, fitness classes and online cooking sessions, to creative tasks that young people could do in their own time, such as collecting content for a time capsule or writing a letter to share with a resident as part of an initiative with a local care home.

Creative and Active Lives/Home and Belonging

- ⇒ Projects funded by the Trust have also developed a range of creative ways for young people to deal directly or indirectly with mental health issues.
- ⇒ Organisations such as Moniak Mhor and the University of Highlands and Islands have worked with participants to use creative writing as a way of expressing and processing their feelings during lockdown.
- ⇒ Impact Arts 'Make it Your Own' project has produced videos and tutorials to support young people to make their space into a home.
- ⇒ Scottish Dance Theatre has been supporting participants to engage with high-quality performance work that has been made available online for free during lockdown. Generally, this material would not be accessible to their participants due to cost and/or location.

Workforce Development

- ⇒ Young people involved in Staf's Project Return have continued to engage in creative methods of participation throughout the pandemic, from taking part in 'self-care evenings' to support their own well-being, to developing and distributing their 'Seeds for Change' indoor plant-growing kits to 'bring nature and nurture into the homes of both care leavers and workers'⁵.

Educational Mentoring

- ⇒ MCR Pathways' school-based mentoring programme quickly adapted and found new ways to provide support to young people. The team developed virtual mentoring options which allow young people to meet their mentors via video, audio calls and live chats, while maintaining safeguarding guidelines. The new options helped MCR's mentors to reach out to their young person, and offer renewed contact and a sense of normality.

A number of Trust-funded projects have also been highlighted in Staf's #We Love report⁶, which celebrates and reflects on the inspirational work that has taken place across Scotland to support young people with care experience during lockdown.

We can see from the Keep Well Fund data and from the good practice shared by projects that maintaining strong relationships and connectivity has been central to supporting young people throughout lockdown.

Organisations, including those with Corporate Parenting responsibilities and funders, have an important role to play in creating the right culture and context for relationship-based practice to flourish. These are

⁵ Staf (2020) '[#WeLove: sharing COVID-19 best practice](#)'

⁶ Staf (2020) '[#WeLove: sharing COVID-19 best practice](#)'

challenging times, but responding to the immediate crisis whilst keeping a focus on medium and long-term goals will be crucial for maintaining positive relationships, good staff morale and, ultimately, positive outcomes for young people. Some projects have shared frustrations around the impact of risk-based policies and decision-making that often does not serve the needs of young people. Rigid policies around ICT use and prohibited digital engagement platforms have stymied the efforts of skilled professionals to engage with young people in the right way and at the right time.

Project staff have valued the Trust's investment in regular network meetings and peer learning workshops. These events have been well-attended and have provided practitioners with a safe space to share what has and has not worked in project delivery. Beyond this, the events have also explored important issues such as emotional and physical burnout, self-care and how to handle difficult conversations. The Trust would like to encourage all funders to invest in these opportunities for projects and to let practitioners steer the structure and content of sessions in a way that ensures their relevance but avoids over-burdening people with additional work.

Moving Forward

⇒ **National and local government, Third Sector organisations, sectoral bodies and funders should prioritise working collectively**

The experience of the Keep Well Fund and of Trust-funded organisations is that the COVID-19 pandemic has intensified the challenges already facing young people with care experience particularly around poverty, mental health, physical well-being and loneliness. These challenges relate to the complete life circumstances of young people and require a cross-sectoral response, guided by lived experience.

⇒ **The Scottish Government should address the digital exclusion experienced by many young people with care experience**

The Trust supports the call from CELCIS to close the digital divide for care leavers⁷. We particularly call for the expansion of the Connecting Scotland project to develop a specific funding offer for young people with care experience. Over half of the grants made by the Keep Well Fund (58%) supported the purchase of various forms of digital technology and Trust-funded projects have reported concerns about digital/data poverty. It is clear that a significant proportion of young people lack basic digital equipment and/or data to stay connected to important people, services and forms of entertainment, deepening the inequalities they already face.

⁷ McGhee, K. and Roesch-Marsh, Dr. A. (2020) [‘Bridging the digital divide for care experienced young people in Scotland: If not now, when?’](#)

⇒ **The Scottish Government should increase the Care Experienced Bursary so it supports students with care experience for the full twelve months of the year**

This call is already being led by Staf and the Trust is adding its support to that of CELCIS, Who Cares? Scotland and the Hub for Success⁸. Financial hardship was a recurring theme amongst young people who applied to the Keep Well Fund and over one-third of applicants (36%) were in full or part-time education. The extension of the Bursary will provide young people with a foundational annual income, providing mitigation against financial hardship. Given the impact of the pandemic on the economy and jobs, it is highly likely that young people will not be able to rely on part-time, seasonal or casual work to top up their Bursary, strengthening the argument for year-round support for students who are care experienced.

⇒ **Further and Higher Education institutions should introduce a consistent approach to making sure all students with care experience have access to the equipment and support they need to study at home**

Through the Keep Well Fund, the Trust has heard directly from young people about the challenges of trying to study from home during lockdown without appropriate digital equipment and/or data packages. Added to this is the anxiety about studying without face-to-face support and concerns about falling behind. There is a clear link here with digital/data poverty for care leavers, but for young people in full or part-time education there is the additional element of the absolute necessity of having digital devices and data packages which can meet the demands of whichever online system(s) their institution requires them to use. We know that generally young people with care experience are at greater risk of dropping out of further and higher education so the provision of equipment and support is a key preventative measure.

8 Staf (2020) '[Staf leads call for Care Experienced Bursary extension](#)'

⇒ **Schools should prioritise the provision of educational mentoring for young people with care experience and those on the edges of care**

Data collected from over 1,000 young people engaged in the MCR Pathways mentoring programme found that sixty-eight percent (68%) reported doing no school work during lockdown, citing challenges with the materials provided, stress and anxiety and the pull of caring responsibilities. Although statistics have improved in recent years, it is still the case that young people with care experience tend to leave school at the earliest possible point and with lower levels of qualifications than their peers⁹. To prevent lockdown from exacerbating this situation, it is crucial that young people can get back to school and are supported to resume their learning effectively. Over eighty-two percent (82%) of young people stated that meeting their mentor would make it easier to get back to school.

⇒ **Local Authorities and Health Boards (as Corporate Parents) should consider the mental health needs of young people within the design of Continuing Care and Aftercare supports**

Evidence from the Keep Well Fund and Trust-funded projects shows that community-based supports, such as volunteer befrienders, Third Sector family support services and creative activities which have light-touch therapeutic benefits are highly valued by young people. Many of these supports ceased or became much more difficult to access during lockdown, leaving young people with care experience, who do not tend to have access to the same extended family networks that most of us draw on for support, particularly exposed to mental distress. Supporting relevant community-based projects, likely to be vulnerable to funding cuts as the economic impact of the pandemic develops, can promote mental well-being amongst young people with care experience and play an important role in expanding their network of relationships.

⁹ CELCIS – Narrowing the educational outcomes gap <https://www.celcis.org/our-work/key-areas/education/our-education-work/>

In addition, as we have seen through the Keep Well Fund, small individual grants or personalised budgets offer young people access to coping strategies which work for them, enabling the purchase of personal equipment for connecting with others online, exercise, gaming and artistic and musical pursuits. Local Authorities and Health Boards, working with other funders and/or Third Sector partners as required, should do more to provide young people with access to small grants which they can control to support their mental well-being.

⇒ **Local Authorities should be more aware of the impact of their wider decisions on young people with care experience**

Using an Equalities Impact Assessment (EQIA) approach to decisions would support Local Authorities as Corporate Parents to better understand any potential impact on young people with care experience. For example, Local Authorities which adopt blanket bans on particular digital platforms (for example, Zoom, Teams and Skype) are making it difficult for skilled professionals to connect with young people in the right way at the right time. In this example, technology is acting as a barrier rather than an enabler of relational working, which evidence shows has played a critical role in reaching out to young people with care experience during lockdown and offering a buffer against some of its most acute effects. Using an EQIA approach can help prevent unintended consequences such as this, which can deepen inequalities.

⇒ Funders should maintain the responsive and flexible approach demonstrated during the COVID-19 crisis

We have seen during the pandemic that funders can be highly responsive. Generally, funders have specific eligibility criteria (e.g. funding directed to people with mental health issues; parents of pre-school children; care leavers) and they wish to support particular interventions. This approach can make it difficult to address the diverse and interconnected life circumstances affecting young people. Additionally, young people themselves have little opportunity to determine what can make most difference. The Trust's experience of working with other funders during this period is that there has been a much greater focus on getting funds to where they are most needed in ways that better respond to individual circumstances (such as investing in the provision of grants for individuals). Continuing this practice will support young people with care experience as it recognises their whole life circumstances and offers a more tailored response.

⇒ Co-production is fundamental to delivering effective services and supports for young people with care experience, even during times of crisis

The Trust's existing strong relationships with our Advisors (all with their own experience of the care system) made it possible for us to adapt our co-production approach during the pandemic. By working in this way and remaining committed to the principles of co-production, our Advisors supported us to create a fund that was easily accessible and highly regarded by young people and their supporters. This highlights the importance of listening to, and acting on, the voice of young people even during periods of crisis. As thoughts begin to move beyond the initial crisis to consider the medium and longer-term future where COVID-19 is still prevalent, our experience has shown that it is vital that the real-life perspective of young people with care experience is drawn out through participation and co-production, to ensure the collective response of services and supports is fully informed by their needs and aspirations.

Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

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