

# An Independent Evaluation of the Life Changes Trust

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# Contents

<b>Executive Summary.....</b>	<b>ii</b>
<b>1. Introduction to the report .....</b>	<b>1</b>
1.1 Introduction .....	1
1.2 The scope of the Life Changes Trust .....	7
1.3 Reflections on the impact of COVID-19.....	8
1.4 The films.....	9
1.5 Reflections from the community researchers .....	10
<b>2. The (hi)story of the Trust .....</b>	<b>17</b>
2.1 Introduction .....	17
2.2 The origins of the Life Changes Trust and key events in the timeline.....	18
2.3 Reflections on the values and practices of the Life Changes Trust .....	26
2.4 Experiences of being funded by the Life Changes Trust .....	33
2.5 Conclusions and lessons drawn .....	47
<b>3. The impact and outcomes for the three beneficiary groups of the Trust.....</b>	<b>50</b>
3.1 Introduction .....	50
3.2 I live in a place that suits me and my needs.....	51
3.3. I am able to be as independent as possible.....	55
3.4 I get the help I need when I need it .....	59
3.5 I feel safe, listened to, valued and respected .....	65
3.6 I am empowered to do the things that are important to me .....	71
3.7 Kirrie Connections case study.....	78
3.8 Evidence of transformational change .....	83
3.9 Sustainability of impact .....	91
3.10 Champions Board case study .....	94
3.11 Conclusions and lessons drawn.....	100
<b>4. The place and impact of the Trust in the wider policy and practice context .....</b>	<b>105</b>
4.1 Introduction .....	105
4.2 The impact of the Life Changes Trust on local and national policy .....	105
4.3 The impact of the Life Changes Trust on practice.....	117
4.4 Evidence of sustainability within policy and practice.....	130
4.5 Conclusions and lessons drawn .....	138
<b>5. Key lessons, implications, and recommendations. ....</b>	<b>141</b>
5.1 Introduction .....	141

5.2 How the Trust works to achieve its aims .....	141
5.3 Has the Trust achieved transformational and sustainable change? .....	147
5.4 Legacy .....	150
5.5 Questions that remain .....	152
5.6 Reflections from the community researchers .....	153

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# Executive Summary

## Introduction

This evaluation is a multi-method evaluation of the work of the Life Changes Trust from its inception in 2013 through to November 2021. The project has three overarching aims:

- to tell the (hi)story of the Trust
- to demonstrate the impact and outcomes for the three beneficiary groups of the Trust
- to demonstrate the place and impact of the Trust in the wider policy and practice context

Alongside more traditional methods, including surveys and secondary analysis, the evaluation adopted life story and appreciative enquiry methods that encouraged meaningful participation and engagement with the different participants to develop a multi-perspective understanding of the work of the Life Changes Trust. It incorporated both process and summative evaluation techniques. This report provides findings from across the life of the project and draws together a number of different primary and secondary datasets.

The Life Changes Trust (also referred to as 'the Trust') is a Scottish charity, established in 2013 with a £50 million endowment from the National Lottery Community Fund. It invests in, and supports, the empowerment and inclusion of three groups of people: people living with dementia, unpaid carers of people with dementia and young people with care experience. The National Lottery's investment was time-limited, with the aim of focussing the Trust's investments on achieving a permanent and sustainable positive shift in the quality of life of the groups it aimed to benefit.

## Evaluation Project activities

The work completed by the team has involved:

- engagement with 24 members of Life Changes Trust staff and eight members of the Board through interviews, focus groups, creative workshops and written interviews
- analysis of key Trust documents
- engagement with 135 key stakeholders of the Trust by online survey and 20 by in-depth interview

- secondary analysis of 245 project and evaluation reports completed up to the end of June 2019 and 34 monitoring and external evaluation reports presenting findings on 272 projects up to September 2021
- engagement with 62 Life Changes Trust awardees representing 79 funded projects through an online survey and 39 awardees representing 27 funded projects by in-depth interview
- engagement with 147 external stakeholders who had not received funding from the Life Changes Trust through an online survey
- engagement with 68 Life Changes Trust beneficiaries through a variety of creative, qualitative evaluation methods; 8 people living with dementia, 14 unpaid carers of people with dementia and 46 young people with care experience

A team of community researchers made up of Trust beneficiaries has supported the work of the academic team. The community researchers have played a central role in the activities of the project, as reflected in their specific written contributions within this report and in the work they have done across all parts of the project.

## Findings

This report provides an overview of key findings across the evaluation project, drawing together different datasets to synthesise findings in response to each of the evaluation aims. The evaluation examines impact in relation to the two overarching aims of the Life Changes Trust.

***Transformational change:*** a radical change in attitudes, culture and systems which results in a substantial change for the better in the lives of beneficiaries.

***Sustainability:*** the benefits of a project, initiative or shift in culture and practice can be continued in the long term.

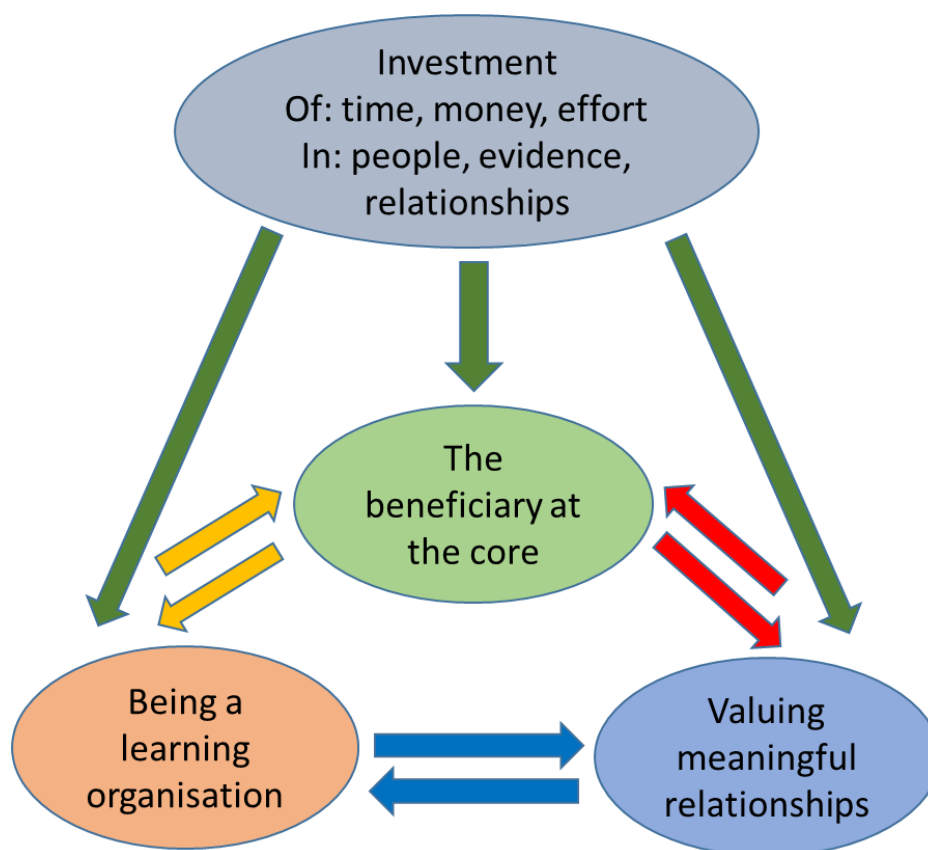
This report also explores the success in achieving the five aims that the Trust holds for its beneficiaries:

1. I live in a place that suits me and my needs
2. I am able to be as independent as possible
3. I get the help I need when I need it
4. I feel safe, listened to, valued and respected
5. I am empowered to do the things that are important to me



## ***The (hi)story of the Trust***

Examination of the origins and timeline of the Life Changes Trust alongside engagement with staff, Trustees and awardees has helped to establish a set of principles, values and practices that underpin and enable the work and impact of the Trust. These are illustrated in Figure A.



*Figure A – a visual representation of the work of the Life Changes Trust*

**Putting beneficiaries at the core** translated into the application of meaningful co-production approaches by the Trust that were shared with awardees and wider stakeholders.

The importance of and **value placed upon relationships** and collaboration was operationalised through the close and genuine working relationships between Life Changes Trust staff and their collaborators.

The Trust is intrinsically a **learning organisation** with an emphasis on collecting and responding to evidence.

The value given to the **investment approach** of the Trust is evidenced across its work and network of stakeholders and collaborators across Scotland. Being part of what was described as the 'Life Changes Trust family' was acknowledged by staff to involve hard work and the willingness to go the extra mile. This is testament to their commitment to the ideals of the Trust and the meaning, or job satisfaction, that they find in their work.

### ***The impact and outcomes for the three beneficiary groups of the Trust***

The evaluation found that the Life Changes Trust has been successful in funding projects that address its five overarching aims. Our findings illustrate the **overlap and interconnectedness of each of the five aims** from the perspective of beneficiaries and present the many positive experiences they have had of both the Trust's work and that of the projects and programmes it has funded. However, it appeared challenging for Trust-funded projects to fully counter the **wider structural constraints** affecting the beneficiary groups.

Data highlights the **diverse demographic characteristics and experiences** across and between beneficiary groups but demonstrates that **many experiences and feelings were shared by people across all three groups**. Importantly, the five aims originally identified by the Life Changes Trust resonated with and applied to members of all three beneficiary groups.

Trust-funded projects were found to **support beneficiaries to be independent**, but the meaning of this term differed between groups. All groups talked about the value of home and the need to belong, and evidence from across the datasets illustrated how Trust-funded projects provided such spaces. In order to ensure that people got 'the help they need when they needed it', **'need' had to be understood as dynamic and ever-changing**. Beneficiaries talked positively about projects and programmes that changed with them.

The approach taken by the Trust to how projects should be run placed a significant emphasis on the **involvement of beneficiaries in the planning and delivery of projects**, as well as requiring projects to operate from a relational perspective. This has clearly been successful in generating places where beneficiaries feel safe, listened to and respected. Beneficiaries offered powerful accounts of being supported by services and, perhaps most significantly, by others who were attending the service.



This push for change in attitudes, policy and practice was evident across all datasets. It was interesting that in relation to the final aim of empowerment and 'being inspired', the majority of beneficiaries related this to taking on the **responsibility for creating change** themselves.

For some beneficiaries this was experienced as energising and empowering. Others reported feelings of ambivalence; they wanted to push for change, but at the same time felt that the responsibility should rest with others.

Interestingly, COVID-19 restrictions forced a number of projects to review the delivery of services. This appears to have worked well for many of the people we spoke to. At the same time, it was the **relationships which had been established through involvement with services that were often most critical** and which some beneficiaries viewed as under threat from short-term funding.

All beneficiaries were aware of the way they were labelled by others and how these labels had impacted on their lives or the lives of those around them. For some of the younger people with care experience, there was a sense of moving beyond such labels and being seen as an adult, independent of care-experience status.

For unpaid carers and people with dementia, there was often a need to 'lean in' to the label and to try to reframe what it meant to experience dementia.

This evaluation has shown that, from the perspective of beneficiaries, the Life Changes Trust has been effective in working with both beneficiaries and providers to create services which offer helpful and relevant support to people from all three beneficiary groups.

### ***The place and impact of the Trust in the wider policy and practice context***

Across the evaluation there was significant evidence to suggest **new organisations had entered the space** of support for people living with dementia, unpaid carers and young people with care experience as a result of Trust funding creating new synergies and networks.

Findings from the evaluation demonstrate **impact on policy and practice at local and national level**, although the level of impact and degree to which impacts might be sustained in the long term was less certain and varied according to beneficiary groups. For young people with care experience, these impacts included both actual policy developments and significantly higher awareness among local policymakers.

There was evidence that Trust-funded projects directly affected current national policy for young people with care experience.

In relation to people living with dementia and unpaid carers, there was significant evidence of **policy influencing activities** that are well placed to influence national policy in the future.

At an organisational level, the impact of Trust-funded projects was clearly evidenced in policy and practice. There was evidence of **widespread and significant learning within organisations** regarding the needs, wants, experiences, and perspectives of beneficiaries, which led to significant and in some cases transformational change in the services and attitudes of organisations.

The evaluation also demonstrated the ways in which both Trust-funded projects and their **impacts have been sustained**. Many projects reported continuation of Trust-funded activities in some form; although the early closure of the Trust had led to concerns among a small number of projects who were likely to face significant funding challenges.

### *Cross-cutting themes*

Across the evaluation, four main themes emerged in relation to how the Life Changes Trust achieves its aims. These themes also reflect core elements of the impact the Trust has had for both beneficiaries and the wider policy and practice context.

- Placing the person with **lived experience** at the centre – focussing on empowerment, involvement, co-production and voice.
- Taking an **investment** approach – investing substantial time, effort and resources.
- Emphasising **relationships** – building, supporting, nurturing and valuing relationships, with beneficiaries, awardees and other stakeholders.
- **Learning** – valuing evidence and using this to support knowledge exchange and influencing work.

### *Lived experience at the core*

The importance of lived experience resonated across the evaluation. This was evidenced through: the beneficiaries' direct involvement in the work of the Trust as members of the Advisory Group or assessing funding applications; the types of projects funded by the Trust; consistent work with awardee organisations to help them adopt more participatory practices; and support for beneficiaries to drive the changes that are needed in the wider landscape of policy and practice.



Benefits to beneficiaries from this approach were clearly evidenced in the evaluation; being involved in meaningful ways with the Trust and Trust-funded projects had significant, positive impacts for people from the three groups.

For some beneficiaries this translated into concrete support through activities such as leadership training, whilst for others it was the opportunity to build slowly to ever greater active involvement. The Trust's focus on voice, empowerment and participation is strongly reflected in the types of projects funded and in the work that those projects achieved and will continue to achieve in the future.

It was clear from the evaluation that the focus on lived experience and voice needs to extend beyond the Life Changes Trust and projects directly engaged with the Trust. If stakeholders and organisations in the wider policy and practice context do not adopt these practices in a meaningful way, then progress will be limited. The work of the Trust has made significant headway into these arenas, as evidenced within this evaluation, but it is vital the legacy partners continue this work.

### *Relationships*

The word 'relationship' is peppered throughout the evaluation. In many ways, this finding fits with the growing recognition across the health and social care sector of the value and importance of relationships and relational practice.

However, what was striking in this data were the nuances surrounding the notion of relationships. There was an unusual recognition of their complexity, messiness and often challenging nature. In staff interviews, as well as the secondary data, there was an awareness that relationships had to be developed and could not be assumed as a given. There could be challenges and tensions in the process of developing relationships between funded projects and Trust staff.

Significantly, however, there appeared to be a genuine commitment to making relationships work and to creating authentic, real relationships rather than tokenistic ones. Significant resource was invested in relationship making, including in staff and project development time, in travel costs, and in creating space and places where genuine communication could take place supported by consistent staffing.

The value placed on relationships was evident in beneficiary engagement, as reported in the analysis of primary and secondary data. Many participants used family-like language to describe their relationships with the Life Changes Trust and/or the funded projects. A genuine sense of belonging and nurture shone through these responses and again highlighted that 'voice' cannot be dislocated from the person who embodies it.

Relationships were also an important part in how the Trust worked alongside awardees and in the wider policy and practice context, with lasting effects in the networks and communities that have developed with and around Trust-funded projects.

### *Learning*

The idea of the Life Changes Trust as a learning organisation emerged in the very earliest stages of the Trust's development and continues to be evident across its activities. The responses in the awardee survey, the scope and range of evidence collected within project and evaluation reports, and the manner in which evidence is headlined across its website illustrate the commitment to this aspect of the Trust's work. The Trust also demonstrates the value placed on learning from beneficiaries, seeing their lived experience as a valuable source of evidence.

As with co-production and building relationships, this approach also takes time, effort and resources. Findings across the evaluation indicate significant work for both staff and awardees attached to this process. For staff there is the risk of burnout and stress and in relation to awardees, there is the challenge of implementing a consistent approach to evaluation and learning across organisations with different evaluation cultures. Further, from our own experience in the field, there was evidence of evaluation fatigue amongst Trust-funded projects due to the number of internal and external evaluations taking place.

### *Investment*

The Trust was in a distinct and relatively unusual position in having both a significant amount of money and a limited timeframe within which to spend it. The Trust's investment approach was, however, also supported by the Trustees' active choice to be an 'intelligent funder'. This notion of investment, rather than simply of 'funding', reflects the willingness of the Life Changes Trust to commit time and resources to supporting its awardees and beneficiaries, as evidenced across the evaluation.

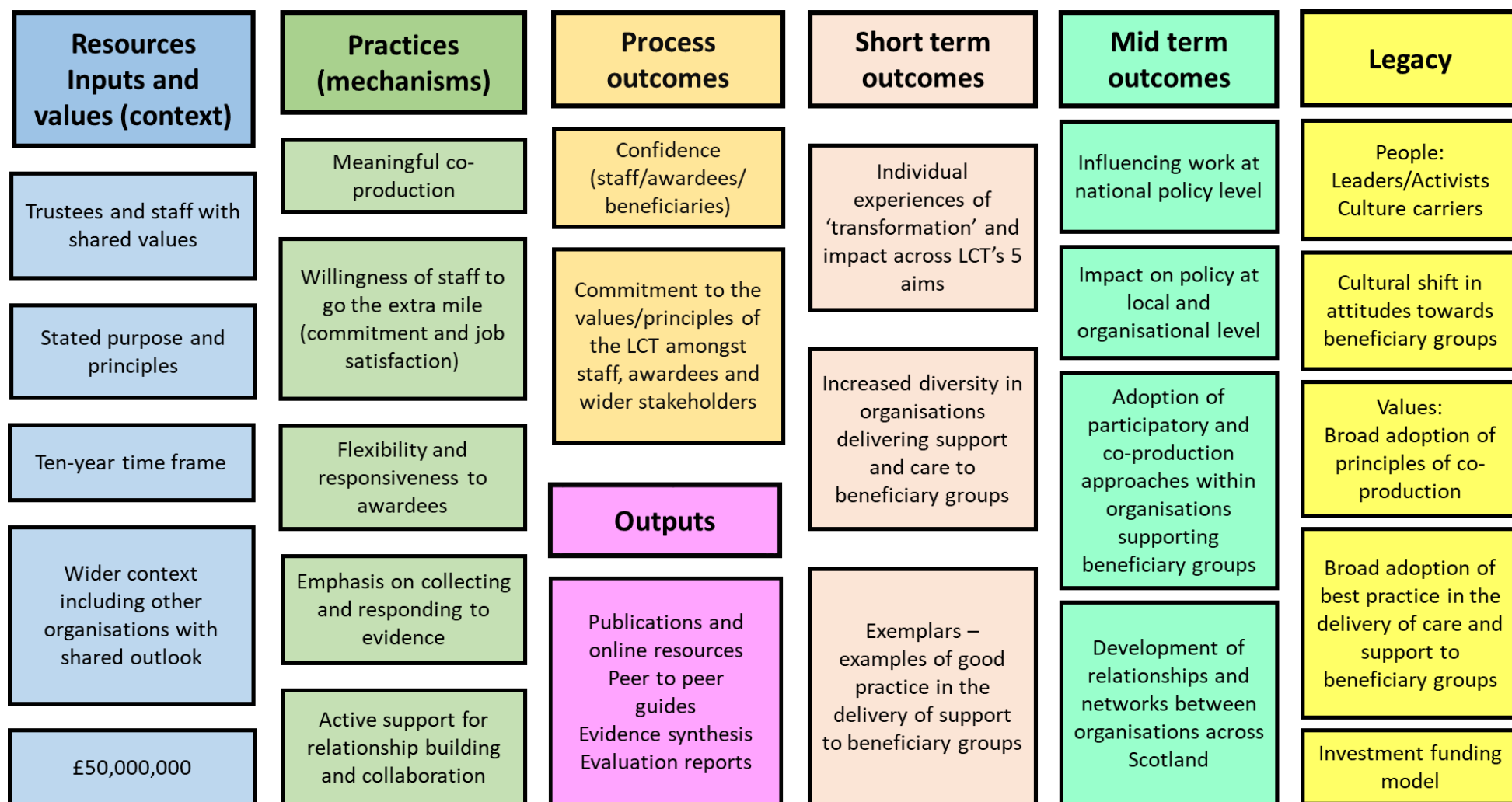
The Trust adopted this investment approach in all aspects of its work, and encouraged those it supported, funded and worked alongside to do the same. It recognised the following elements as important in effecting change: time, effort and resources are crucial; relationships must be built, as discussed; and flexibility in changing circumstances is required. There is also evidence of investment in beneficiaries, from the early part of the Trust, through the funding of the Advisory Group, to the large legacy projects focussing on leadership for beneficiaries from all three groups. It seems clear that the particular combination of £50,000,000 and the timescale of ten years supported this investment approach and underpinned the impact and legacy of the Trust.



Equally, the commitment of Trustees and staff as well as awardees, beneficiaries and other stakeholders to this approach has been crucial in shaping and ensuring that legacy.

Figure B below provides a visual representation of a simplified logic model developed across the evaluation to illustrate and explain the work of the Life Changes Trust.

This logic model links the context and practices of the Trust with the outcomes and legacy. Sections of this model are included through this report to demonstrate how it was built using the full range of data from the project.



*Figure B: Logic model summarising the work and impact of the Life Changes Trust*

## ***The Trust as an exemplar for other funders***

The Life Changes Trust has adopted a particular approach to funding underpinned by their values and principles. This is a key aspect of their legacy and one that we feel is important to emphasise within this evaluation. The four themes outlined above and the logic model provide detail on these and the table below provides a set of lessons for other funders drawn from the evaluation.

### **Keep beneficiaries at the core of everything**

Beneficiaries of funding programmes provide vital knowledge of their lived experiences, needs and aspirations as well as useful skills that should be drawn upon in the planning and operationalising of funding programmes.

### **Be flexible in approach to working with awardees**

Allow organisations flexibility in response to either changing circumstances or from learning about what works for beneficiaries, as long as the overarching aims remain in place. Flexibility is vital when facing rapid change such as experienced during the COVID-19 pandemic.

### **Invest in building strong, supportive relationships with awardees**

There is value to be gained from investing time and effort into developing open and supportive relationships with awardees to maximise impact of funding.

### **Be open to applications from a diverse range of organisations and individuals**

Having an open approach to who can apply for funding encourages community based and co-production approaches and supports innovation and sustainability.

### **Encourage, support and guide organisations with evaluation processes**

Support awardees to develop robust evaluation processes, to record impact and outcomes and to utilise this knowledge to build projects and seek further funding.

### **Avoid unnecessary bureaucracy**

Appropriate but not overly burdensome levels of reporting and administrative tasks are needed. These should be appropriate to the level and scope of funding awarded.



## *The films*

Jay Gearing of [Red7 Productions](#) has made two films to illustrate first, the work of the Life Changes Trust and second, the processes employed in the evaluation process. He has considerable experience of working alongside community groups. Both films highlight the impact of work undertaken or funded by the Life Changes Trust, and, in different ways, places the Trust's focus on participatory approaches front and centre.

### *Trust*

The first film, 'Trust' involves a participant from each of the Life Changes Trust's three 'beneficiary' groups. There are two versions of the film. The shortest version is a focused more documentary-like production. The longer version can be viewed as one, or in three separate segments. The films illustrate key findings from the evaluation. These include the effects of the Life Changes Trust's means of working with each beneficiary group, and notably their emphasis on relationship-building through creative and artistic methods, and on promoting 'voice' and participatory processes. The final segment of the longer version also emphasises how such work can continue. The participants were chosen after taking part in project interviews to illustrate different aspects of the Trust's work in different areas of Scotland.



### *Our journey*

The second film 'Our journey' reflects on the critical role that community researchers have played in the co-production of this project. They have been involved in recruitment, in the development of the research methods, and in data collection and analysis. This film explores their experience of moving from project beneficiaries to community researchers; how their understanding of research processes evolved over time and, overall, the benefits and pitfalls of this method of co-production of research. We hope that the film will be useful to other researchers who wish to adopt a similar approach and to projects aiming to self-evaluate. It also provides an illustration of practices championed by the Life Changes Trust in action.

The full films and abridged versions can be found here:

<https://www.lifechangestrust.org.uk/independent-evaluation-life-changes-trust>

## **Conclusion**

The overall picture presented in the report is positive, demonstrating an organisation whose staff, Trustees and awardees find meaning in the work they do.

The Life Changes Trust includes beneficiaries at the heart of its work, and its actions and activities have led to significant impact for the three beneficiary groups in Scotland as well as to the wider policy and practice landscape.

The impact of the Trust has been transformational in many ways and it is likely to be sustained; however, the full impact will not be properly understood for some years to come.

These different aspects of the impact of the Life Changes Trust are well known to those inside the Trust, are reflected in the work they do, and presented within their own evidence reports and online resources.

What this wider evaluation project does is provide a rigorous evidence base; drawing together diverse stories and perspectives to present an encompassing picture of the Life Changes Trust as an organisation effecting change at an individual, organisational, regional and national level across Scotland, and leaving a legacy that will continue to improve the lives of people living with dementia, unpaid carers and young people with care experience.

# 1. Introduction to the report

## 1.1 Introduction

The Life Changes Trust (also referred to as 'the Trust') is a Scottish charity, established in 2013 with a £50 million endowment from the National Lottery Community Fund. It invests in, and supports, the empowerment and inclusion of three groups of people: people living with dementia, unpaid carers of people living with dementia and young people with experience of being in 'looked after' care. The National Lottery's investment was time-limited, with the aim of focussing the Trust's investments on achieving a permanent and sustainable positive shift in the quality of life of the groups it aimed to benefit.

The Life Changes Trust has funded numerous evaluations of the individual projects it has invested in since 2013. However, there was a strong desire to better understand and evaluate the impact of the Trust as a whole. This independent evaluation was developed on this basis; to bring together findings from diverse sources in order to assess the extent to which the Trust had met its aims, and to identify what can be learned from the Life Changes Trust for future large investments and funding. As such, this evaluation draws from both process and summative evaluation techniques (Butterfloss, 2006<sup>1</sup>) as our aims are to understand the Life Changes Trust, to examine how it undertakes its work and how different activities and ways of working lead to its intended outcomes. To do so, it draws together diverse perspectives on the Trust's work to better understand its impact on the beneficiary groups, and on the policy and practice landscape, across Scotland.

This evaluation of Life Changes Trust has used core principles of life story work to determine its approach to data gathering and analysis alongside more traditional methods, including surveys and secondary analysis. Life story work is a common tool used in work with both young people in looked after care as well as with adults with dementia (Lind et al. 2021<sup>2</sup>). It is used to help create a narrative of key events, experiences and people which can be used by the young person or adult with dementia as well as those who care for them.

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<sup>1</sup> Butterfloss, F. D. (2006) Process evaluation for community participation. *Annual Review of Public Health*, 27, 323–340.

<sup>2</sup> Lind, M. Bluck, S. McAdams, D. (2021) More Vulnerable? The Life Story Approach Highlights Older People's Potential for Strength During the Pandemic, *The Journals of Gerontology: Series B*, Volume 76, Issue 2, February 2021, Pages e45–e48

Life stories aid in untangling what are often complex experiences understood and viewed by those involved in myriad ways. The aim of life story work is not to present a single 'truth' but rather to offer up a sense of the interconnection between memories, experiences, events and people. Life stories are designed to be dynamic, growing and adapting in tandem with the ongoing, lived 'story' that is unfolding day to day.

Across this evaluation, a series of evaluation methods have been used to gather diverse and in-depth perspectives about the practices and impact of the Life Changes Trust.

Table 1.1 below provides a timeline of that work with details of the participants involved and methods adopted for each stage of the project.

A mix of qualitative and quantitative methods have enabled engagement with those closest to the work of the Trust: the staff and Trustees; beneficiaries from all three groups; awardees and stakeholders who engage directly with the Life Changes Trust; as well as wider stakeholders from policy and practice. Primary data has been supplemented by secondary analysis of numerous reports from Life Changes Trust funded projects and external evaluations, as well as documents pertaining to the set-up of the Trust.

A team of community researchers, including people living with dementia, unpaid carers for someone living with dementia and young people with care experience, also formed a core part of the evaluation team for this report, working alongside researchers from the University of Stirling and Ipsos MORI Scotland across the various elements of the research.

Within this report, all these data have been synthesised to provide integrated findings in answer to the three aims of the evaluation:

- to tell the (hi)story of the Trust
- to demonstrate the impact and outcomes for the three beneficiary groups of the Trust
- to demonstrate the place and impact of the Trust in the wider policy and practice context

Reflecting these aims, this report has three main sections that present integrated findings from across these datasets collected over the course of the project. Section two provides reflection on the (hi)story of the Life Changes Trust, reflecting on how this story has shaped the principles, values and practices of the Trust that underpin all its work. It draws on primary data collection with staff and Trustees, a survey and interviews with Life Changes Trust awardees, as well as documentary analysis of key Life Changes Trust documents. Section three again draws together data from across the life of the project to demonstrate the impact and outcomes for the three beneficiary groups, including synthesis of primary data and secondary analysis of Trust reports and external evaluations.



This section highlights the Trust's achievements in relation to its five core aims for beneficiaries and reflects on the sustainability of these achievements and extent to which they represent transformational change. Section four draws together findings from a survey and interviews with wider stakeholders, a survey and in-depth interviews with awardees (organisations that had received funding directly from the Trust), findings from secondary analysis of Trust reports and external evaluations to evaluate the impact of the Trust on the wider policy and practice landscape in Scotland.

Section five provides a conclusion to the evaluation, highlighting key themes that resonate across the report and concluding with reflections on the legacy of the Life Changes Trust and recommendations and lessons to take forward. In Section five, the community researchers also provide their own reflections on the current state of play in Scottish policy and practice, providing the perspectives of those who have worked alongside the Life Changes Trust and who will take forward crucial aspects of the legacy in their own work as activists and campaigners.

Within this report we have adopted the language used by the Life Changes Trust to describe different groups but recognise that this language may not be widely used or acceptable. Organisations and individuals who have received funding from the Life Changes Trust are known as awardees, the term 'wider stakeholder' refers to organisations and individuals who are part of the wider policy and practice landscape in Scotland in relation to one or more of the beneficiary groups, and 'beneficiaries' are people living with dementia, unpaid carers and young people with care experience who have been supported by or were involved with a project funded by the Life Changes Trust.

It is this last term that is most problematic as it is not recognised by those people it is used to label. The people we spoke to did not identify with or use this term and during discussions with Life Changes Trust staff there was a growing recognition that it is one which is not widely used or accepted.

Photographs are included with permission from the subject or creator of the image or from royalty free websites. Images of paintings included in Sections two and five were created by staff members of the Trust during a creative workshop in September 2021.

*Table 1.1 – Timeline of work completed*

<b>Date</b>	<b>Activity</b>	<b>Participants involved</b>	<b>Methods</b>
Oct 2019	Recruitment of community researchers commenced	Community researchers from three beneficiary groups	
Oct 19 – Jun 20	First period of secondary analysis of project reports	41 end of project reports	Qualitative, thematic, secondary analysis
Nov 19 – Jan 20	Online survey with stakeholders identified by Life Changes Trust as collaborators	135 stakeholders from across Scotland	Online survey
Feb 20	In-depth interviews with key stakeholders of the Life Changes Trust	20 stakeholders from 18 organisations	Telephone interviews
Mar - June 20	Engagement with Life Changes Trust staff	20 members of Life Changes Trust staff	Online focus groups Qualitative survey by email
May – Jul 20	Engagement with Life Changes Trust Trustees	8 Trustees	Online interviews
<b>June 20</b>	<b>Interim report 1 submitted</b>		
Jul 20 – Feb 21	Second period of secondary analysis of project reports	245 reports, 149 from Dementia Programme, 96 from Young People with Care Experience Programme	Qualitative, thematic, secondary analysis
Aug 20 – Feb 21	Engagement with Life Changes Trust beneficiaries	7 people living with dementia 10 unpaid carers 10 young people with care experience	Online and written interviews Online focus groups Reflective diaries
Oct 20 – Feb 21	Documentary analysis of key Trust documents	Series of reports from 2008 – 2021 with relevance to Life Changes Trust set-up	Documentary analysis
Nov 20 – Feb 21	Awardee survey	62 awardees of Life Changes Trust funding	Online survey
Dec 20	Life Changes Trust staff interviews	7 members of Life Changes Trust staff	Online interviews

<b>Date</b>	<b>Activity</b>	<b>Participants involved</b>	<b>Methods</b>
Jan – Jul 21	Wider stakeholders	147 wider stakeholders, who had not received any direct funding from the Life Changes Trust	Online survey
<b>Mar 2021</b>	<b>Interim report 2 submitted</b>		
May – Sept 21	Third period of secondary analysis	34 reports, reporting on 272 projects	Qualitative, thematic, secondary analysis
May – Sept 21	Beneficiary engagement	Total: 8 people with dementia, 14 unpaid carers and 46 young people with care experience	Online, in-person and written interviews In-person focus groups Reflective diaries
Jul – Sept 21	Awardee interviews	39 people representing 27 awardees of Life Changes Trust funding (also includes data from 5 earlier interviews)	Online individual and group interviews conducted with community researchers
Sept 21	Life Changes Trust staff and Trustees	15 members of Life Changes Trust staff and 4 Trustees	In person creative workshops and written interviews

Within the report, identifiers are used to protect the identity of the evaluation participants and these are set out in Table 1.2, below.

*Table 1.2 Identifiers used to distinguish evaluation participants*

<b>Participants</b>	<b>Notes</b>	<b>Examples</b>
Life Changes Trust staff and Trustees	Indicated with an S and a number, the two groups are not distinguished due to small number of Trustees	S1 – S35
People from the three beneficiary groups	Indicated with a pseudonym to distinguish individuals, a note of beneficiary group and gender. Age is included for people living with dementia and unpaid carers as there were more significant age ranges amongst these groups.	Dave, person living with dementia M56 – this is a male of 56 years who is a person living with dementia  Janet, unpaid carer, F45 – this is a female of 45 who is an unpaid carer  Jack, young person, M – this is a male young person with care experience
Excerpts from reports	Title of report and role of person providing the quote where known	Dementia Friendly Communities Evaluation Report, Project leader
Awardees of the Life Changes Trust	Indicated as Awardee with: D to indicate Dementia Programme, C for Unpaid Carers, YP for Young People with Care Experience Programme, and a number to distinguish individuals.	Awardee D2, Awardee YP13, Awardee C4
National stakeholders	Indicated with 'National Stakeholder' and a number to distinguish individuals	National Stakeholder 14



## 1.2 The scope of the Life Changes Trust



Before we begin to report on our findings, we feel it is helpful to include this short piece setting out the scope of the Life Changes Trust as context for the report that follows. Projects funded by the Life Changes Trust reflect the diverse experiences of beneficiaries according to geography, age, ethnicity and social or cultural backgrounds. The range and scope of funded projects were notable in their ambition and the diversity of sectors they engaged with.

*Figure 1.1 The scope of the Life Changes Trust*

The Trust boasts a vast capacity for outreach. Projects benefitted children with care experience from preschool years ('Little Champs') to their late twenties and supported people living with dementia at all stages of their lives, including people living with early-onset dementia. Activities and groups took place across Scotland, covering urban and rural regions and more isolated areas, such as the Western Isles, Orkney and the Shetland Islands. The Trust funded a significant number of projects that had a special focus on intersectionality and provided tailored support to beneficiaries with experience of the justice system, with disabilities, belonging to the LGBTQ+ community, or belonging to minority ethnic communities, including asylum-seekers.

The Life Changes Trust is administered by a Board of nine Trustees and a 'protector' who provides a link between the Trust and the National Lottery Community Fund. The endowment funding is allocated across two programmes, one providing funding for projects to support people living with dementia and unpaid carers of people with dementia and the second to support young people with care experience.

The work of the Trust is undertaken by a staff group of around 25 staff and they are supported by advisors from each of the three beneficiary groups. People from the beneficiary groups play an active role in nearly all activities of the Trust including funding decisions.

## 1.3 Reflections on the impact of COVID-19

As we conclude the evaluation process and look back over the challenges faced in the past eighteen months, we are pleased to have completed this work given the very difficult circumstances. COVID-19 brought many changes and challenges to us as a team. However, in relation to the evaluation, the most negative impact of COVID-19 and the resultant restrictions has been on our engagement with beneficiaries and our ability to experience Life Changes Trust-funded projects in person.

The COVID-19 pandemic hit at a point in the evaluation where we were poised to go out into the field, to meet people and spend time understanding their experiences, especially those of the beneficiaries. The restrictions related to the pandemic meant we had to revise these plans and move our work online.

We took a flexible and responsive approach that enabled us to continue with our planned activities. Indeed, being able to respond quickly to people and bring people together from different places using online videoconferencing enhanced some aspects of our data collection. However, we were only able to engage with beneficiaries who were happy and confident to speak with us online using videoconference software or by telephone. Our recruitment processes were also almost entirely digital, again restricting who we reached. We were not able to spend as much time as we planned to get to know people and share information about the evaluation project. As such, we recruited fewer participants than hoped, especially among people living with dementia and unpaid carers.

Once restrictions started to lift, we found a notable difference across the groups. Young people with care experience were quicker to take up opportunities to get back to 'normal' and we engaged with a significant number of them face-to-face in the last months of the project. For people living with dementia and unpaid carers, things were more difficult, and the process of reopening created more barriers to engagement as services were focussed on working safely. As a result, we did not engage with any people from these two beneficiary groups on a face-to-face basis. Nonetheless, we have benefitted enormously from our enthusiastic and engaged community researchers who were able to share their lived experiences and feed into the evaluation findings and conclusions.

## 1.4 The films

Jay Gearing of [Red7 Productions](#) has made two films to illustrate first, the work of the Life Changes Trust and second, the processes employed in the evaluation process. He has considerable experience of working alongside community groups. Both films highlight the impact of work undertaken or funded by the Life Changes Trust, and, in different ways, places the Trust's focus on participatory approaches front and centre.

The first film, 'Trust' involves a participant from each of the Life Changes Trust's three 'beneficiary' groups. There are two versions of the film. The shortest version is a focused more documentary-like production. The longer version can be viewed as one, or in three separate segments. The films illustrate key findings from the evaluation. These include the effects of the Life Changes Trust's means of working with each beneficiary group, and notably their emphasis on relationship-building through creative and artistic methods, and on promoting 'voice' and participatory processes. The final segment of the longer version also emphasises how such work can continue. The participants were chosen after taking part in project interviews to illustrate different aspects of the Trust's work in different areas of Scotland.

Jay spent time with each participant online prior to meeting them in person and chatted with them at length prior to filming. Further filming of each participant's environs, of their artwork where relevant, and of material reflecting visual imagery inspired by their words have been combined into the resulting films, especially the second, longer version. The films are not documentaries as such but aim to convey the feelings and experiences associated with the Life Changes Trust's work in a more affective and less individualised way.



*Figure 1.2 A still from chapter one of the film*

The second film 'Our journey' reflects on the critical role that community researchers have played in the co-production of this project. They have been involved in recruitment, in the development of the research methods, and in data collection and analysis. This film explores their experience of moving from project beneficiaries to community researchers; how their understanding of research processes evolved over time and, overall, the benefits and pitfalls of this method of co-production of research. We hope that the film will be useful to other researchers who wish to adopt a similar approach and to projects aiming to self-evaluate. It also provides an illustration of practices championed by the Life Changes Trust in action.

This second film was shot at Verdant Works in Dundee and involved elements of group filming and 'talking head' approaches associated with more conventional filmmaking. One community researcher, who was unable to travel to Dundee, recorded her own comments. The approach taken in the film was developed through meetings between the research team, community researchers and the filmmaker.

The full films and abridged versions can be found here:

<https://www.lifechangestrust.org.uk/independent-evaluation-life-changes-trust>

## 1.5 Reflections from the community researchers

Co-research is said to be an approach that empowers individuals and communities, incorporating their diverse voices throughout the research process (Daly and Westwood 2018<sup>3</sup>), and reflects a growing trend towards asset-based approaches within health and social care. Co-research aims to create mutually respectful research teams that blend experiences and perspectives into the research process. Moreover, a co-research approach has been shown to increase community resilience when those involved are equipped with new skills and confidence (Hashagan 2011<sup>4</sup>).

The plan for the evaluation was to work alongside community researchers with care experience or living with dementia or providing support or care for someone with dementia, at all stages of the evaluation process. The initial invitation sent out to enable people to come forward to be community researchers suggested why the team were looking for community researchers:

**You bring your experience and expertise which will help shape our evaluation.**

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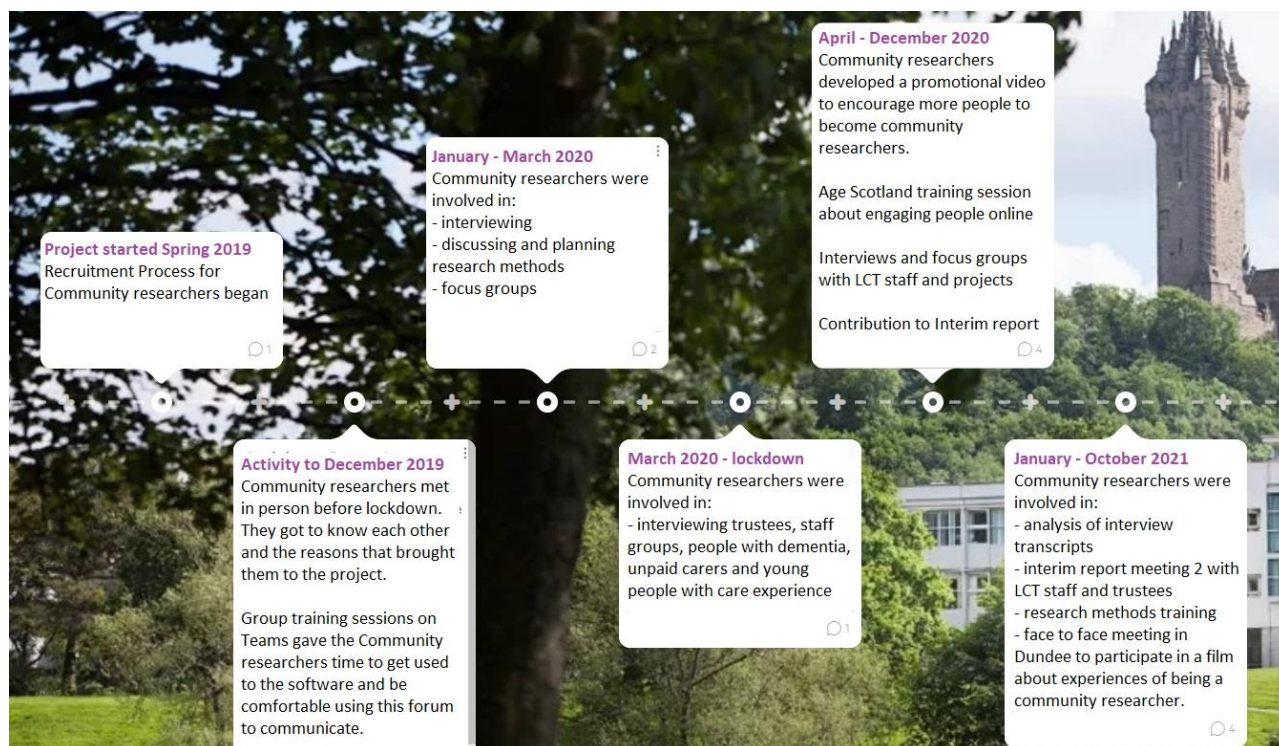
<sup>3</sup> Daly, M., & Westwood, S. (2018). Asset-based approaches, older people and social care: An analysis and critique. *Ageing and Society*, 38(6), 1087-1099. doi:10.1017/S0144686X17000071

<sup>4</sup> Hagashan, S., Kennedy, J., Paterson, A. & Sharp, C. (2011) *Doing with, not to: Community resilience and co-production*, Scottish Community Development Centre



Furthermore, brief details of what was entailed in the community researcher role were listed in the recruitment advert.

The advert also stated some of the possible activities including: workshops to jointly develop research methods; research skills training; working together using these research methods to generate and analyse data to find out about the impact of the Life Changes Trust projects; and working as a team to produce evaluation reports.



*Figure 1.3 Timeline with examples of the work of the community researchers*

**The following piece is written by the community researcher team. The team includes three unpaid carers of people living with dementia, two people living with dementia and one young person with care experience. The team has had several other members over the life of the project who have contributed to the work in different ways.**

The Community Researcher role was a new concept for us all. We were recruited through the Life Changes Trust's networks. Not one of us had previous experience of the Community Researcher role, although many of us contributed to research in many different ways, mainly by volunteering to research that involved us personally or to service evaluations. As individuals with lived expert experience, a range of skills, competencies, and as beneficiaries of the Life Changes Trust, we felt well qualified to undertake the Community Researcher role, while also acknowledging that training and support were essential.



*I joined the evaluation team as a Community Researcher back in January 2020. Having only been involved with Scientific & Educational research, the Community Researcher role was totally alien to me. (MC)*

*I joined the team a couple of months after it had been set up, so I felt I bit lost at first. With the support of the University staff, and the other Community Researchers, I soon felt comfortable and began to really enjoy our sessions. (AT)*

*I came to the research late on but am very glad that I did. I don't think that I would have started without COVID forcing organisations to use Zoom etc, as I find it hard to travel, and felt at that time my input would be not valuable enough for the larger expenses required, e.g. overnight stays. Having been involved I believe that I now have both the learning and confidence. (MR)*

Like every new role we come into, we needed a deeper understanding of what the role was about, this included knowing how we would fit in with the academic team who were involved from the outset, and who had planned the research and written the proposal that included Community Researchers. What we all had in common was enthusiasm, interest, and our lived experience.

*The debates about involving 'People Living with Dementia' in qualitative research are extensive, yet the range of methods used is limited. Researchers tend to rely on interview and/or observation methods to collect data, even though these tools might preclude participation. The setting up of the Community Research Team by University of Stirling to work with the Academic Staff for the evaluation report has provided an excellent platform as a multi-method evaluation of the work of the Life Changes Trust. (MC)*

*Initially I struggled a bit to understand all that was going on with the project. As the role progressed, however, it all began to make much more sense, and I think that the tangents we all sometimes went on were an important part of this process and resulted in outcomes which may not have been expected or achieved had we (University staff and Community Researchers) not been so comfortable with each other. (AT)*

*I was quite nervous before my first Beneficiary Interview but having the session with University staff beforehand really helped me to relax more during the interviews. (AT)*

Training in interviewing techniques, in other methods, in reading reports, in analysis as well as developing templates for reporting back were developed in partnership with us and provided by our team colleagues from Stirling University. This helped us build our confidence and brought our team together on a level footing.

We felt empowered and very much part of a team. Training from Age Scotland in interviewing techniques with individuals and focus groups was also provided. After the initial induction, training was provided at different stages, at a point when we had a bit more experience. This reinforced our understanding of the role and research methods.

### **As Community Researcher I was involved in:**



designing the questions and choosing research methods.



collecting information from LCT Trustees, staff and beneficiary groups through interviews and reading through transcripts with academic staff.



review and analysis of Life Changes Trust reports including external evaluation reports and Trust outputs.



training in Qualitative and Quantitative sessions, helping my understanding of the role as I learned about research evaluation methods.



contributing to the final report, starting with our first face to face meeting in 18 months.

*Figure 1.4 Activities undertaken by community researchers*

*Reviewing the Interview Transcripts. I found the Life Changes Trust Themes quite hard to fit into the Transcripts and there was often a lot of overlap between the Themes. It'll be interesting to see how this all fits together in the final report. (AT)*

*I have learnt the different types of analysis and the importance of each, also the importance of research that might not seem relevant at the time. My interviewing technique requires further improvement as I only did one, although I found it interesting and was able to use my lived experience to dig a little deeper. (MR)*

Being involved in the research gave us insight into the much wider aspects of the Life Changes Trust. What stood out for us was the extent and reach of the Trust and links with partner organisations. As a group of beneficiaries from all three strands of the work of the Trust (people living with dementia, unpaid carers and young people with care experience), we only knew about our own specific area. Over the duration of the research, young people with care experience were not as available to join our team, therefore our contributions within this report are weighted more towards the dementia strand.

*As someone Living with Dementia, my role as Community Researcher has allowed me to connect with various Dementia groups which are doing extremely valuable work in Scotland - About Dementia, Deepness, Alzheimer Scotland, STAND (Fife), Kirrie Connections. Meeting up with many wonderful people. Recently, I have been recruited by NHS Scotland - Neuroprogressive and Dementia Network as a Partner in Research - which has similar role as Community Researcher. (MC)*

*Although I haven't been able to take part in many sessions about Young People with Care Experience (only read a couple of transcripts of interviews), I've learned a little more about this element of the Life Changes Trust work. Before this, I was only really interested/involved in the Dementia and Unpaid Carer aspects of the Life Changes Trust. I'm sure the Community Researchers from the Young People with Care Experience project feel the same about living with dementia. It has been interesting to see that the themes of respect, support and empowerment have been clear in all the Life Changes Trust projects I have researched. These are the same values I experienced with the Life Changes Trust since I became involved with them – firstly being in the Steering Group for the first 'By Carers for Carers' Dementia Conference in Glasgow, and since then taking part in conferences, carer groups etc. I really hope that these skills will help all the Life Changes Trust funded projects continue once the Life Changes Trust ends. (AT)*

The COVID-19 pandemic struck early in the research, resulting in us all having to find new ways of working and connecting with the communities and beneficiaries we were trying to recruit for the research. A new experience for us all, challenging us and learning along the way. We embraced technology with Teams and Zoom and once we became familiar with it, found it was an effective way of connecting. We feel confident our lived experience and knowledge of our specialist area influenced the research interviews and connections to our communities.

*Before COVID, the thought of doing video calls would have been a real deterrent for me, but this technology has been crucial during lockdowns. It has been key to the Team, as we have been able to get together from all over Scotland without the need to travel. I even took part in the Beneficiaries Video in August 2020 which really was out of my comfort zone. This helped us all I think, demonstrated by how comfortable we all were when we finally met up in person in Dundee and took part in the filming about being a Community Researcher. (AT)*

*My lived experience came in useful from my very first meeting as, having been a cynical Fraud Officer, I look for discrepancies. Everyone involved in the meeting had nothing but positive views of the report (Independent Evaluation Interim Report March 2021); I pointed out that 15% of a survey was a large enough number to be worried as to why they were dissatisfied. From my childhood, living with a father who was very business oriented, I know that for organisations to learn and grow one needs to understand the bad more than the good, so one can learn from one's mistakes. (MR)*

Our experience of Community Research was unique due to COVID-19. Recruitment, training, interviewing, focus groups, meetings, peer support, analysing, writing reports in addition to learning the use of presentation tools, was all "online". This was a very different way of working for the Community Researchers who generally expected to establish partnerships and actively participate with members and organisations in communities. We missed opportunities for meeting people in person, which may have helped with recruitment of participants to the evaluation. What our experience demonstrates, is that if you know your subject and communities well, Community Research can work remotely.

*Being an active Community Researcher is much more fulfilling than being passively researched, which is the norm. It allowed me to use my experience to both dig below what was being said and to alter the direction of the research if I could back up what I believed was erroneous. It also gave me an enormous personal boost, as my family believes academia is important and I had spectacularly failed in this throughout my life until this project. I am very glad to have been part of this journey and feel that it has given my life a sense of purpose as well as stimulating me beyond my comfort zone. The Life Changes Trust has been of enormous value to Scotland and its people. (MR)*

*I have really enjoyed being a Community Researcher on this project, have developed new skills. Community involvement in research is crucial, as those with lived experience can connect with others who have gone through, or are going through, similar situations, in a way that others cannot. Everyone's experience of dementia or being an unpaid carer of someone with dementia is different, but if you have personal experience, it can result in important aspects, info, etc. that would not have occurred or happened without the Community Researcher input. (AT)*

COVID-19 will have had some impact on the research evaluation, as we were all locked down and restricted for the timescale of the research.

Being Community Researchers helped us as a peer group while services and volunteering roles were suspended. The research kept us busy, planning, reading and connecting "online" with the communities and subjects we were familiar with, in addition to our regular two-weekly meetings.

We have all learned and developed new skills and have a better understanding of community research, building our confidence and resilience, to take part in future community research. Our academic colleagues from Stirling University, with whom we developed relationships as peer researchers, were supportive in every capacity to help us develop our role. We were treated as partners throughout the whole process.



## 2. The (hi)story of the Trust

### 2.1 Introduction

This section of the report provides insight into the Life Changes Trust as an organisation, exploring the origins of the Trust and how these early events have shaped its work going forward. The principles and values of the Trust are explored, as are the activities and ways of working that have enabled it to work towards its defined aims of sustainability and transformational change. The Trust's work is underpinned by two key concepts that it defines as:

**'Sustainability'**: the benefits of a project, initiative or shift in culture and practice can be continued in the long term.

**'Transformational change'**: a radical change in attitudes, culture and systems which results in a substantial change for the better in the lives of our beneficiaries.

The principles of process evaluation and logic modelling ask us to carefully consider the specific context of a process or intervention. Therefore, to understand how and why the Life Changes Trust has achieved the impact and legacy discussed throughout this report, we need to understand that context and how it has shaped and influenced its work as well as illuminating the mechanisms, or ways of working, that support this.

In this section, we present distilled information from analysis of data from staff, Trustees and awardees and of key Trust documents to capture the core of the Trust's principles, values, and practices. The first part of this section provides an overview of the origins of the Trust, and key events in its timeline identified by staff and Trustees as illustrative of the Trust's values and aims. These key events and decisions demonstrate how the Trust's core principles and practices developed, as well as illuminating key elements of the organisational and strategic contexts that have shaped the Trust's impacts. The second focuses on these core values, drawing out four key values that underpin the work of the Trust. In the final section, we introduce the perspective of awardees, testing out the fit between staff and Trustees' perceptions of the Life Changes Trust with those they work with. The section concludes with the first part of a logic model that builds across this report. In this section, identifiers such as **S34** indicate a member of staff or Trustee of the Life Changes Trust.

## 2.2 The origins of the Life Changes Trust and key events in the timeline

### **2005: Big Lottery Fund publishes ‘Learning Lessons from Past Evaluations’**

The first step in a series of decisions leading to the establishment of the Life Changes Trust can be found in documents produced in 2005 in which the Big Lottery Fund (BIG)<sup>5</sup> reflected on lessons learned from their work to date and developed key tenets of its future approach to funding, including the idea of investing in a strategic way.

### **June 2009: Big Lottery Fund publishes ‘Big thinking: Our Strategic Framework to 2015’**

Many of the core ideas embedded in the funding approach proposed by BIG were formalised within its Community Fund Strategic Framework to 2015 (BIG 2009). This set out the importance of directly engaging with beneficiaries and included a pledge to provide funding that is:

*...supported and inspired by the communities we are looking to help...setting priorities, making decisions and delivering funding as close to the beneficiary as possible. (page 11)*

Identifiable outcomes were emphasised by BIG as central to the proposed funding process as well as its acknowledgment of the importance of sharing lessons learned with other funders. It set out the key attributes of what it referred to as an ‘intelligent funder’ as including a focus on: outcomes; innovation and sustainability; flexibility and responsiveness; and collaboration.

This document also detailed the emergence of the decision to focus funding opportunities on periods of change in people’s lives. In 2010, the idea for a series of endowment trusts around this notion was formalised, leading to the establishment of the Life Changes Trust, envisioned as a ten-year investment.

Four organisations working in relevant policy and practice fields in Scotland made a successful bid to BIG to establish the Life Changes Trust. These founding partners were initially intended to manage the Trust’s investment and staffing.

A Trustee involved in the early days of the Trust reflected on their understanding of the reasons that it was established as a time-limited endowment trust:

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<sup>5</sup> On 29 January 2019 the Big Lottery Fund became known as The National Lottery Community Fund.

*...there would be a Big Lottery project for one year/two years/three years, sometimes five years and it'd come to the end and then suddenly these projects would turn to their local authority and expect the thing to go on. And what hadn't happened was there hadn't been a change, it was just like an add on, so this is about changing, it's not about adding on, it's about altering and changing and redesigning how things are done. (S24)*

### **19 February 2013: Deed of Trust signed**

The Deed of Trust is a key document that sets out the guiding principles for the working of the Trust and its aims and objectives. The overall aim of the Trust is described in this document.

*To have substantial and lasting impact, and achieve long-term transformational change for two groups of young and older people in greatest need. It will have the overall purpose of helping improve individual lives. (Deed of Trust, Schedule 8)*

The commitment of current staff and Trustees to these guiding principles is strongly evident in the data collected within this evaluation, reflecting the importance of this founding statement of intent.

*The Trust is there primarily for its beneficiaries...even if all we did was benefit the individuals that are our beneficiaries; we would have fulfilled the purpose of our Trust. (S10)*

While some current members of staff questioned where it was helpful to bring these beneficiary groups (young people with care experience and people with dementia and unpaid carers of people with dementia) together, one member of the Board could see the synergies between them from the start.

*Pretty early on we realised we were grappling with the same issues but differences in approach. So, it's very much about relationships and love and care, you know, the things that matter to people are the same but the way in which you support that and encourage that and put structures in place are potentially quite different. (S25)*

The Deed of Trust set out how the Life Changes Trust should operate, introducing some of the ways of working that have endured through the life of the organisation.

- *The Trust will need to evolve over time so that it remains fresh and innovative and relevant to Scottish society.*
  - *Appropriate and relevant support and guidance should be available to potential applicants in completing an application for a Life Changes Trust Award.*
  - *Recipients of Life Changes Trust Awards should benefit from ongoing advice and support over the life of their project to help them achieve their goals.*
  - *The Life Changes Trust should track and evaluate the impact of its investment over the lifetime of the trust to help understand the difference that funded activities have made in both the short and the longer-term. This should be robust, empirical and detailed.*
- Deed of Trust, Schedule 8

One of the key strengths of the Life Changes Trust lies in its ability to have both operationalised and maintained these principles over the lifetime of the organisation. Its work has demonstrated that such a funding approach can be sustained within an increasingly challenging context and, in so doing, it provides vital learning for other funders.

### **March 2013: First meeting of the Life Changes Trust Board of Trustees**

The first Board meeting took place in March 2013. In this initial phase of the Board's work the focus was on establishing the programme of work and the staffing and management structure. Almost immediately there was agreement to increase the number of Trustees to enable the inclusion of young people with care experience on the Board to complement the involvement of people with dementia and unpaid carers. The scale of the work undertaken to develop the Board, staffing and management structures in this first year was significant:

*Right at the start there was no committee, there was no programme, there was nothing, there was no organisation, yeah there was nothing at all. (S25)*

During June 2013 the Trustees moved to accept, in principle, the proposal put forward by the four founding organisations, but also to review it further.

*You had a Board of Trustees who came together and quite quickly basically said to themselves 'are we happy that this is the way it's going to be run, are we happy with what's being proposed?' (S28)*

### **Sept 2013 – Trustees decide they want to do something different**

Documents from this period reflect tensions between the new CEO and Board members, and the founding partners. By September 2013, a decision was taken by Trustees to run the Trust as an independent organisation with an independent Board and their own staff rather than staff drawn from the founding partners, as had initially been planned.

Reflections from the Trustees who were involved at that point suggest that part of the decision to move away from the proposal outlined by the founders related to a wish to use the funds in a way that they felt would be more effective in reaching beneficiaries:

*...supporting those organisations and their own costs would be such a cost that there wouldn't be the volume of money that we wanted to see actually reach a range of groups in the community. (S25)*

There was also a desire among the Trustees and the CEO to do something radically different and a feeling that by funding large established organisations it would be more difficult for the Trust to take a substantially different path, if that was what the Trustees felt was needed. The Trustees and first members of staff also saw benefits and opportunities from being a new, independent organisation and felt that as a result the Life Changes Trust was not burdened with expectations based on its history.

*Here was effectively a new kid on the block and with the opportunity to do things differently and was not affected by any other way. (S28)*

However, unsurprisingly, those who had been involved as founding partners of the Trust felt quite differently about the way forward. Interviews conducted for this evaluation indicate that, although all those involved had moved on with their own work (and for some this involved joint working with the Trust) there was a lasting impression that the work of the founding partners had not been appropriately valued or recognised. This challenging early period of the Trust's development was seen as having contributed to some ongoing tensions with other organisations particularly in the Dementia sector in Scotland, with implications for the nature and level of joint working across the sector.

This experience of change continued over the first year to eighteen months of the Trust's development with a series of resignations and new appointments to the Board of Trustees. Trustees who have remained on the Board are able to shed some light on this period in relation to the commitment in time and energy required of Trustees, which they believed had made it difficult for people in full time work and for beneficiaries to remain involved.

*There's a sadness for me because also at the beginning we had representatives on the Board who were care experienced, two people...but they found it difficult as well because of the kind of posts that they were in. (S24)*

### **2014: Individual Awards Pilot**

Individual awards have been an important part of the Life Changes Trust's approach to funding across both the Young People with Care Experience and Dementia Programmes and are an embodiment of its desire to trust beneficiaries as experts in their own lives.

*Our early decision to launch an individual grant scheme I think was a critical decision point which communicated that we wanted to fund our beneficiaries directly, that we trusted our beneficiaries to know what would make a positive difference to their lives and to communicate that they were worth us spending money on. (S25)*

### **2015: Life Changes Trust First Business Strategy**

The Trust's first Business Strategy was an opportunity to collate and publicly set out the Trust's strategic plan and funding priorities for their two programmes. This included defined core values of being: people centred; authoritative and influential; independent; open and collaborative; honest and responsible; and pioneering.

### **2016: Young People's Advisory Group forms**

The Advisory Group, made up of young people with care experience, put beneficiaries directly at the heart of the work and demonstrated an early commitment to genuine co-production.

*Some of the most important times for me have been in panel/selection meetings with young people as advisors and contributors. The quality of their contributions has been very satisfying. More importantly is the sense of young people developing and holding a wider agenda for change in the future. (S26)*

### **November 2016: Launch of Aspirational Awards**

The Aspirational Awards were of significance as they emerged from the Young People's Advisory Group's own reflections and involved funding decisions being made explicitly by the Group.

### **2018: Rights and Equalities and Rights Made Real in Care Homes funding**

These funding streams in particular signalled the promotion of a human rights-based approach from the Life Changes Trust.

### **2018: Storytelling approach taken within regional events – Dementia Programme**

The Life Changes Trust took a novel approach to consultation and introduced a narrative or storytelling approach to support regional events in the Dementia Programme. This again highlighted the commitment to capturing and amplifying the voices of beneficiaries and their lived experience to set the agenda as well as bringing in creative methods to this process.



*We approached the Glasgow Village Storytelling Centre...as a new way to engage and involve people with dementia and unpaid carers and telling and expressing their experiences, but in a way that was more engaging and less about directing people around particular themes or questions, but very much giving them an open and safe way to express how things were for them. (S04)*

### **2019: Change of CEO and merger of Glasgow and Edinburgh offices**

These changes were cited by staff as being influential on how the team had come together, with the two work programmes becoming more closely aligned and building relationships across the Life Changes Trust.

### **2019: Refresh Strategy**

An updated business strategy was produced in 2019 and outlined plans for the remainder of the lifespan of the Life Changes Trust. Of note were changes in the language to be used in reference to the beneficiary groups, as a result of consultation with these groups: 'care experienced young people' were now to be known as 'young people with care experience' and 'people affected by dementia' were separated into two distinct groups, 'people living with dementia' and 'unpaid carers of people with dementia'.

### **2019: Legacy funding for the Dementia Programme**



*Figure 2.1 Felicia the Flamingo image, Festival of Voices*

As the latter stages of the Trust were reached, legacy funding was awarded to About Dementia and the Bringing Out Leaders in Dementia programme (BOLD) to lead on policy and practice and to consolidate leadership in the sector, signalling the Trust's commitment to longer-term legacy from its work.

### **2019: Festival of Voices**

The Festival of Voices was cited by many staff members and a Trustee as having been a particularly memorable occasion, symbolic of humour, fun and a buzz of excitement. Having these 'high' moments as part of a collective memory can also function to sustain a team in more stressful times and to enhance motivation towards the common goal.

*I think for me the standout...was the Festival of Voices... We had Felicia the Flamingo which (young person with care experience) would bring to meetings at the time and it...added that fun element to it and...reminded us all that even though things were a bit stressful, that that was the main thing, it was that young people were to come along to that day and share their experiences but have fun... I think it was really...seeing all the projects coming together, all the LCT staff coming together to make the event as successful and go as smooth as possible, just...spoke to the relationships that LCT have built, I don't think it could've been as successful or well received without having those core relationships at the heart of it. (S01)*

### **2020: COVID-19 lockdown**

The COVID-19 pandemic had a significant impact on everyone involved with the Trust and their funded projects, through the stress and anxiety for individuals alongside significant restrictions in everyday life and the loss of important services and support.

### **2020: Keep Well Fund and Caring for the Carer Fund**

These funding programmes were put in place in direct response to the COVID-19 pandemic and demonstrate the Life Changes Trust's flexibility and ability to respond quickly to beneficiaries' immediate issues in both the Young People with Care Experience and Dementia Programmes. The entire staff team pulled together in order to make this possible and this further highlighted their effectiveness as a team.

### **2020: Decision to end a year early**

While this came as a surprise to many, a key motivation was to be able to commit more funding to beneficiaries, reflecting staff and Trustees' commitment to keeping beneficiaries at the heart of all the Trust does.

*I think an organisation that shuts a year early so that people – beneficiaries – can benefit, it's not a bad...you know? It's huge. It says what the Life Changes Trust is about. (S32)*

### **2021: National Leadership Network**

Investment was made through funding for internal posts to work on the National Leadership Network, which is the central element of the Young People with Care Experience Programme's legacy plans. The Network will be run by a collaboration of organisations, including a host organisation, following the Trust's closure. The creation of dedicated roles to support this handover shows a commitment to building on existing learning and developing the National Network in a strategic way.

### **2021: Voice and Vision events for young people and 100/6000 dementia conference**

These events, held in the final full year of the Trust, reflect the progress it has made in supporting beneficiaries to take on leadership roles and to speak out. In the final months, as the Trust winds down, it is envisioned that these leaders will become a key part of the Life Changes Trust's legacy.

This brief overview of the origins of the Trust and reflections on key dates and events in its lifespan helps to demonstrate the emergence of the key principles and values that underpin the work discussed further here.

## 2.3 Reflections on the values and practices of the Life Changes Trust



*There's something about feeling a sense of calling to what you do... this is not just about money, it's not about that, it's about something bigger than that. (S10)*

*(The image is about) love, relationships, trust, co-production, diversity, inclusion, ambitious, creative, heart, people, colour, life. (S35)*

It was evident from interviews conducted for this evaluation that the work that the staff and Trustees of the Life Changes Trust undertake holds meaning for them; it is important to them and aligns with a set of values and principles that is shared between them. Furthermore, as discussed through the wider report, many of these values were also shared by awardees and beneficiaries of the Trust. These values and principles have been crucial in shaping the practices and everyday work of the Life Changes Trust staff and Trustees, and the mechanisms by which they aim to achieve the outcomes and legacy discussed in this report. This sub-section presents data from staff and Trustees, including images chosen and/or created by the staff to help express and explain their understanding of the work of the Trust.

**The '50 houses' image**, opposite, was a picture that had been displayed in the Life Changes Trust office, drawn by one of the young people who was a member of the Young People's Advisory Group. The design represented the 50 different places that he had stayed in his life and was chosen by staff as reflective of their understanding of the work of the Trust.



Staff members commented on the evocative and powerful nature of the image and related this to a deepened understanding of their beneficiaries, made more powerful as the artist was personally known to them. Its physical location in the office was observed to act as a visual reminder to staff of 'why we do the job that we do' and to provide a natural opportunity for staff to share their approach to working with beneficiaries with those who visited. This modelled the Life Changes Trust approach to others and tapped into a wider discourse around how this work and the relationships created between staff and beneficiaries should be experienced.

Across the data provided by staff and Trustees it has been possible to draw out a set of values and principles that underpin their work and that are modelled through the practices of the Trust. These findings are summarised here using a series of images and quotes that represent the values of the Life Changes Trust and a discussion of the practices through which the staff and Trustees of the Life Changes Trust operationalise these values. The modelling of these values is a crucial principle of the way the Trust works.

*We can't be influential around our themes of rights and relationships, the importance of collaboration, the value of agenda free conversations if we don't practice in this way ourselves. (S16)*

*We have been in a position to both directly give money to our beneficiaries and give them control over decision-making about funding for others. These actions have communicated strongly to them but also to other funders, policy makers and practitioners; that people with dementia, their carers and young people with care experience matter, they know what is important to them and should be trusted to have some power and control over decisions that affect them. (S25)*

## The centrality of beneficiaries in everything the Life Changes Trust does – voice, empowerment, co-production

*Beneficiaries are the expert, they inform every aspect of our work ... It (the image) represents people's voices being at the centre of everything and the Trust being the amplifier. (S05)*



It is clear that staff and Trustees share a strong belief that beneficiaries should be central in how the Life Changes Trust works, supporting strategic decisions, managing funding programmes and guiding and influencing all the work of the Trust. Throughout the work of the Trust, it was evident that beneficiaries were treated as the experts and that their voices were prioritised. This aspect of the Life Changes Trust's work was repeatedly highlighted by staff and Trustees:

*...we have, as a Trust, put a real focus on young people with care experience, people living with dementia and unpaid carers, you know, having a voice and being in the room when important decisions (are made). (S16)*

*...driving it from community level, listening to the voices of people who were actually experiencing all the frustrations, all the good parts and all the frustrations that went along with it, and actually created networks for those people to feel that they had a voice, were being listened to and were driving forward the change themselves. (S29)*

Staff noted the importance of language in reflecting this aspect of their work.



*I think the whole area of language is an area that the Trust has been quite active in from the beginning, in terms of really trying to respect the way that people want to be referred to. I remember early on in the dementia programme a lot of stuff about, you know, people picking up on this language around suffering and sufferers and stuff, and just finding that really disempowering and the Trust playing a strong role in highlighting and elevating that. (S16)*

Of equal importance to Life Changes Trust staff was that the power dynamics involved should not entail the casting of themselves as expert over the experience of beneficiaries, but that they should be seen as equals.

*Progress is always fragile in a lot of the territory that we're in, is about power, who has it and who doesn't? And people don't give up power easily, we know that, so it's not been a linear journey for us, not at all. And I wouldn't imagine at all that it will be in the future either. But I do have this sense that we've passed a little bit of a tipping point...the idea of just going back to business as we used to do it, some people in a room just making up policy on the hoof, I don't see that coming back in a wholesale kind of way again. (S16)*

*I think we have had a privileged opportunity to model trust and transfer some power, and I am confident that this will now help others to take leaps of trust too. (S25)*

## **The importance of and value placed upon relationships and community**



*Relationships are key in all of the work that we do, all of the work right across the programmes, but without that, then the game's a bogie really. (S26)*

*This is the not-so-secret ingredient that makes the Trust what it is. Recognition of both the importance of relationships and the time it takes to build them is key. (S17).*

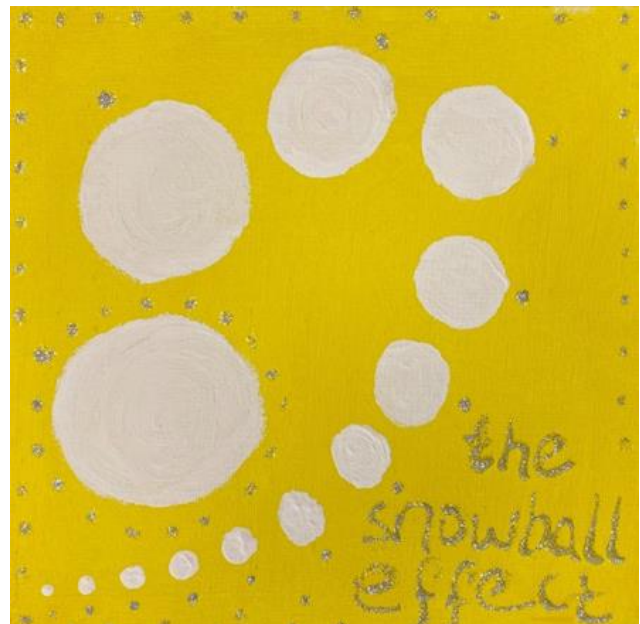
*Figure 2.2 Image represents relationships, connections, and love*

Relationships were very highly valued by Life Changes Trust staff, including relationships between staff, between staff and Trustees, and relationships with awardees and beneficiaries of funded projects. Staff and Trustees believed that this value, in turn, impacted on the quality of the work carried out by rooting it in philosophies of respect and of strengthening others. With the focus here on working practices, it was the particular ways that the Life Changes Trust brought people together and encouraged collaboration that stood out.

*Not just individual to individual relationships but the supporting, nurturing and creation of community. (S25)*

The Life Changes Trust staff and Trustees described taking positive steps to build relationships and networks to support its aims, such as the early gatherings of Trust-funded Dementia Friendly Communities and more recent regional events. The Trust has also adopted ways of working that support collaboration in meaningful and creative ways, such as the storytelling approaches used at regional events. The staff and Trustees believe that these mechanisms have led to greater diversity in the range and types of organisations involved in supporting the different beneficiary groups across Scotland and more collaboration between these organisations, as well as benefiting work with other funding organisations to influence how funding is provided. Later in the report, awardees and stakeholder views on these activities are discussed. The image below represents the growth of the Life Changes Trust's networks through the notion of snowballing:

*...we are inviting a whole new group of players to the scene who are all now very much invested in dementia and providing the right support for people, but are also invested in that learning and embedding that learning... I think it's been the shift for me of the narrative. I think what the dementia landscape was before the Trust was very much dominated by only one or two organisations driving the change. Very much from a top-down approach... What I think the Trust has done is mixed that up, given lots of opportunity to lots of organisations who would never have had a look in in the past and not just those traditional dementia organisations, but organisations like Paths for All. (S04)*



## Taking an investment approach



The documents that set out the early vision for the Trust established some of the key principles that underpin the Life Changes Trust's way of working. One of these principles was to be a responsive funder, an intelligent funder, or an investor, and involved allocation of time, effort, and resources with a strategic and open-minded focus. The operationalising of these concepts is evidenced in the way staff described working with awardees. They provided examples of support and collaboration with awardees that was flexible and responsive in a way that enabled projects to develop within their local needs and circumstances. This approach is further discussed in later sections which engage with the views and experiences of Life Changes Trust awardees.

*...with the grant holders...through the application process and kind of talking with them and establishing with them what they need to do for whatever sum of money we're giving them and you being there because all that investment is genuinely worthwhile. (S11)*

*...and also being a funder that seeks to share its experience with other funding organisations, and further develop different approaches e.g. participatory funding, peer-to-peer funding. (S26)*

As well as the specific investment approach taken to funding, staff and Trustees invested time and significant effort into their work. Both staff and Trustees spoke of their commitment to the Life Changes Trust, their belief in the values and aims of the Trust and their willingness to go the extra mile.

The influence of time on the work of the Life Changes Trust is a theme that recurs throughout this report from across different groups of interviewees and different sources of data. The ten-year timeline set at the start of the Trust provided a specific focus and impetus for staff and Trustees to progress their objectives without becoming complacent. At the same time, staff and Trustees described how they felt the significant pot of funding provided enabled them to dedicate time to meeting the aims of the Trust rather than focussing on fundraising.

*I do wonder if that fact that we had a pot of money (so didn't need to fund raise) and the fact that we had a limited amount of time to achieve change (so didn't attract people who wanted a 'job for life' or require us to find future money or purpose) were key in helping us do this. (S25)*

Time was also identified as an important component for supporting co-production. It takes time to build relationships with beneficiaries and to ensure their meaningful involvement and the Life Changes Trust funding enabled that.

*And it's time, isn't it? It's making the time and the space, because if you don't have that then it's panic and it's, 'oh, we need to get to a certain point at a certain time'. And if you make space for it to happen and you don't put those pressures on people or on yourself. (S35)*

*(It's) about leaving time to build relationships, leaving time and space to allow that to happen and recognising that everyone is different and everyone has had their own journey, and just making sure that you can find ways to respect that and find ways to bring out the strengths that everyone has to contribute. (S17)*

There was an additional benefit identified in being able to provide longer-term funding compared with some other funders.

*I think we've really made the case that funding people for three to five years has a huge impact in what they can do because the money, the time and effort it takes to chase money year on year and to not be able to give. (S11)*

## Being a learning organisation that is responsive to evidence

The origins of the Life Changes Trust, described above, demonstrate the importance placed on learning and evidence by the Big Lottery Fund and then by the Life Changes Trust itself. Staff and Trustees described how this focus encouraged the Life Changes Trust to develop processes to support collection of evidence, to recognise evidence in all its forms and to be able to respond to this evidence to drive wider change.

*It's about recognising our own limitations and the limitations of our own knowledge and kind of being curious and wanting to know more. (S04)*

*Recognising that we are not the experts and working in collaboration has been important to ensuring we gain a rich evidence base and share this learning as widely as possible. (S01)*

Staff at the Life Changes Trust explained that the culture of the organisation was to avoid the notion of failure; rather the Life Changes Trust philosophy that they followed was to use everything as a learning point. Moreover, staff's accounts of how this was implemented suggested that, within the Trust, they felt they had successfully avoided this leading to a fear of making mistakes.

*And we don't get it right all the time and it's okay not to get it right. But we learn from that and we adapt and we move forward. (S04)*

Here we have highlighted four key values that underpin the Trust's work and noted some of the practices that have developed to enable it to uphold and operationalise these values. These values and practices echo throughout the report and are drawn out in more detail again in the final section. The next part adds the perspective of awardees to build a fuller understanding of the work of the Life Changes Trust.

## 2.4 Experiences of being funded by the Life Changes Trust

This sub-section focuses on the experience that awardees had of being funded by the Life Changes Trust, and whether and how that differed from their experiences with other funders. The perceived strengths and weaknesses of the Life Changes Trust's funding approach (from the perspective of their awardees) are discussed.

To do this, it draws on the data collected from awardees through an online survey with 62 people and interviews with 39 people from 27 awardee organisations. In this sub-section identifiers are, for example, Awardee D11, Awardee C7 and Awardee YP4 – codes indicate a Life Changes Trust awardee with letter to signify which beneficiary group the project supports.

Overall, the majority of awardees who responded to the survey were very positive about the experience of receiving funding from the Life Changes Trust – most said it had been either a very (50) or fairly (9) positive experience. Three respondents out of 62 said it had been either a fairly negative, or neither a negative nor positive experience.

Most respondents (53 out of 62) had experience of receiving project funding from other funders, apart from the Life Changes Trust. A majority of this group felt the Trust had been either much more supportive (30) or a little more supportive (10) compared with other funders. Ten felt they had been about the same, two said they had found the Life Changes Trust to be less supportive, and one that experiences of funding varied too much to say.

Respondents' comments about the Life Changes Trust's flexibility in allowing them to adapt plans in response to circumstance or learning, and the positive benefits of building links between the projects the Trust funds echoed the views of staff and Trustees, discussed above, on the features that distinguish the Life Changes Trust's overall approach. Recurrent themes from the open text responses of those respondents who viewed the experience positively are demonstrated in the figure below.





The themes raised in open text responses to the survey were all discussed in more detail by awardees who took part in qualitative interviews for this evaluation. In addition, the impact of Trust funding in enabling projects to evidence the value of services, often with the aim of securing funding from other services in the longer-term, was further substantiated through the qualitative data. Both positive and negative aspects of each theme are discussed below.

## Flexibility and willingness of the Life Changes Trust to take and enable (controlled) risks

Awardees reported that the Life Changes Trust allowed them to try things out and to adapt projects or how money was spent in response to changing circumstances and to emerging learning about what did or did not work in the delivery of project aims. Awardees described being on a 'learning journey' with the Trust, with some surprise expressed at the willingness of the Trust to take risks.

This was perceived to be a strength in terms of effecting change, for example in having moved towards bringing young people with care experience together at a time when staff believed that this was seen as risky and thus giving space to evidence the benefits of doing so, such as enhancing their collective voice.

*I think that was an enormous thing to achieve, to reconfigure a landscape that said 'don't be bringing people together' and to say actually we're going to invest money in that, we're going to do that. (Awardee YP7)*

Another awardee talked positively about being allowed to develop how best to deliver their project as they went, and to try things they had not done before.

*I think LCT took a risk with us with that - probably a well mitigated risk, because we had a good relationship...but (project) was a bit less clear. We knew what we wanted to do, we just didn't know how we were going to do it. So we probably wouldn't have managed to get funding for (project) without the LCT. (Awardee YP2)*

Awardees described the Life Changes Trust's written briefs for specific projects as being detailed enough to convey a vision but still allowing flexibility for creativity. They also noted the strong support from the Life Changes Trust for building in stakeholder and beneficiary engagement to shape awardees' approaches to individual projects, rather than insisting that they start with a fixed idea of what needed to be done and how. Flexibility was particularly appreciated during the COVID-19 pandemic. Awardees gave examples of how they were able to pivot their approach with support from the Trust (see case study below).

There was also a perception that there was no pressure on awardees for instant answers when COVID-19 hit; they reported that they were able to pause and reflect on how to move forward in light of radically changed circumstances. The scope to be flexible and creative, supported by the Life Changes Trust, was felt to be more important over the last 18 months than ever.

*Actually, thinking about the Life Changes Trust, there was no pressure from them (when COVID hit), that was a really positive thing, they weren't saying, 'you need to get something new up and running instantly'. They were saying, 'you tell us what you think is needed when you think it is needed'. So, we paused. Then as we began, as everybody began to calm down a bit and we all began to look at where we were at. (Awardee D3)*

The flexibility in the Trust's approach included flexibility about how budgets were used. One awardee reported that they were able to move some unused transport budget to extend the length of their project, while another was able to divert money to buy equipment for young people with care experience during lockdown. However, this experience of budget flexibility was not universally shared. One awardee spoke about feeling slightly penalised for success; they had not needed to use their marketing budget and had to return this, when they would have preferred to use it to extend the project. One other awardee felt they have been placed under some pressure to spend money quickly rather than being allowed to extend their project.

### Case study – the flexibility to pivot in response to COVID

The Bringing Out Leaders in Dementia (BOLD) programme is one of the Life Changes Trust's main 'legacy' investments. The five-year project has funding from the Trust to run until 2024 and is being delivered in partnership by Edinburgh University and Queen Margaret University. The programme brings together diverse people living with dementia, including those with a diagnosis, unpaid carers, and those working with people who have dementia. It works with them as 'partners' through an initial seven-week programme and beyond to bring out their leadership potential to make a difference and help those living with dementia flourish.

When COVID-19 first hit, BOLD had delivered their programme to one cohort of BOLD partners and were part-way through the initial seven-week programme with a second cohort. The programme was being delivered face-to-face, so COVID "*brought everything to a grinding halt*". The team running BOLD spent a couple of months "*just really trying to figure out what to do*", and decided to redesign the programme as a predominantly online programme:

*We started to look quite creatively at what could we do with BOLD that actually would not be taking a face-to-face programme online, but actually reconceptualising BOLD as an online with support programme.*

This redesign had led to unexpected benefits – including reducing the burdens of finding suitable venues, and opening up the programme to people from different areas, rather than having to take a staged, area-by-area approach. The redesigned programme had been run with two cohorts, with a third about to start, at the time fieldwork for this evaluation took place (August 2021). The supportive and flexible approach of the Life Changes Trust was seen as extremely helpful during this period of unexpected challenge and transition:

*They have been amazing and I couldn't praise them more...They have just really allowed us to find our own way, as long as we keep them in the loop and we always check in with them...But honestly, they have been absolutely amazing in terms of being supportive and not getting in our way, but also offering help if we need it, connecting it with their networks, which has been great. But, yes, absolute joy and without a massive bureaucracy.*

### Quality of relationships with Trust and Trust staff

The quality of relationships between awardees and the Life Changes Trust, including specific relationships with Trust staff were highly valued by awardees. Awardees appreciated the Trust's openness to meeting potential awardees and several described the Trust arranging early meetings with them when they were exploring whether funding would be a good fit – it was commented that not all funders will do this. The Trust was described as '*incredibly approachable*' and as a '*critical friend*.'

*I thought they were brilliant as a funder because they gave us the free rein, but they were also helpful. You know, there was always somebody that you could turn to for advice if we needed it. But the fact that we could do this on our own, I just thought it was incredible the way they worked with us. (Awardee C4)*

*But I think the thing that was, for me, that felt especially beneficial was there was never a sense that the Life Changes Trust was this kind of cold, clinical funder in its approach. It was people who were interested and who had a point of view and a perspective. But also, generally speaking in my experience, they were always really good listeners as well. And I think that made a real difference. (Awardee YP7)*

An awardee who worked with minority ethnic communities reflected on the importance of funders such as the Life Changes Trust working together with them to build upon existing pathways and relationships, rather than starting from scratch.

*I think it's really, really important, I think authorities and funders and organisations need to understand, it's really important when an organisation is working with these service users you build a trust, you have this support mechanism, you know... we've already broken the barriers you know, trust is a very big thing. So I think it's expectations. It makes our job a lot harder, because sometimes we can't meet these expectations, because we obviously need funders to help us, yeh. So I think it has to be a balance. If organisations and funders want to help, want to reach out to the hard to reach, they need to go through organisations that they are already working with. (Awardee D16)*

While they valued the funding they had received from the Life Changes Trust, they also felt that the Trust could have done more to sustain the relationship in order to support them to access repeat funding, as for small organisations with limited staffing resource it is difficult to find out about and have the time to respond to funding rounds. There was a sense that the Trust and awardees were working together towards the same aims and learning together as they went. These relationships were supported by shared values and awardees described that 'it has felt like a partnership' with the Trust. These shared values parallel those set out in the earlier part of this section.

*I feel that the values of the Life Changes Trust chime really well with our own, which is what encouraged us to put in an application. (Awardee D8)*

*Life Changes Trust; like kind of working with an organisation that just shares your values and shares that vision for young people...it's been fabulous. (Awardee YP9)*

While there were many positive examples of how the relationship between the Trust and awardees was seen as having helped to deliver on the Trust's vision, a couple of more critical points were also raised. For one awardee, there was a feeling that the relationship between them and the Trust had changed over time, related at least in part to a change in staffing structure at Life Changes Trust. They felt this change had resulted in a move from being a partnership, to feeling they were being managed as a 'project' in a more transactional and rigid manner.

In addition, the early closure of the Life Changes Trust did not receive a universally positive reaction from awardees. One awardee noted that this had been communicated to them with little information that they felt could help them make sense of the decision and another felt that the Life Changes Trust was quite 'defensive' about the early closure and that it led to a shift in energy at the Trust towards 'self-reflection'.

*I don't know, it just felt like everything was about capturing legacy. And actually, a lot of the projects were still very much, you know, and we were only just working through what we were doing, and we were like, 'are you done already with us?' I just felt like they were done with us. And I mean, I don't think they were, but it did feel like it.*  
(Awardee D12)

## The role of the Trust in linking organisations

The work undertaken by the Trust to connect organisations and build networks across Scotland was valued by awardees. This was a particularly strong theme in interviews with awardees in the Dementia Programme. Dementia Programme awardees talked about networking opportunities provided by the Life Changes Trust's 'gatherings' and 'hubs', and several awardees spoke of the impact of the legacy projects, About Dementia and BOLD, providing a more robust route to link projects. These networks were viewed as having provided opportunities for knowledge exchange and development and to consolidate and improve the potential of awardees to influence policy.

The mix of participating organisations in terms of size and setting was seen as a strength of these networks.

*The networking was unparalleled, you know, I think the way they worked, there were some other projects working like that, that Creative Scotland was running around the time, but I've never seen a Trust pull people together so much, which was one of the really strong things.* (Awardee D12)

However, while the Trust's work to link projects was seen as positive, there was a perception that, in the dementia sphere specifically, it could have gone further and started earlier.



For example, it was suggested that the Trust could have required, rather than simply encouraged, Trust-funded organisations to work with each other wherever opportunities arose, as there was a perception that there were still barriers to greater cooperation across the sector (such as perceived competition for resources) that needed to be overcome. However, one awardee, who reported that they were obligated to attend quarterly meetings as a compulsory condition of their grant, conversely felt that more could have been gained from encouraging a voluntary buy-in to the process.

There was also a view that the Trust might have done more earlier on to extend the reach of its networks into the statutory sector, particularly in relation to its Dementia Programme. Finally, there was a perception among some national stakeholders, interviewed in the first part of this evaluation, and from a small number of awardees interviewed later in the evaluation that the Trust's networks were not as inclusive as they might have been, particularly in the dementia sphere. It was suggested that while the Trust had built a strong network of organisations who enjoyed close, supportive relationships with Trust staff, organisations who did not feel part of this had felt excluded. In terms of networks of awardees, a minority view was that the Life Changes Trust appeared to have 'favourite' projects and that these tended to get additional encouragement, for example, to apply for further funding, while relationships with those who did not feel they were among these could be more difficult at times.

At a national level, one view was that these perceived limitations to the reach of the Trust's network had, to a degree, led to different networks of organisations working on dementia in Scotland in 'parallel lines', and that more might have been achieved if there had been greater collaboration. However, there was also a belief among both awardees and national interviewees that the Trust had made efforts to reach out to other organisations, particularly in recent years.

An individual awardee also questioned whether the 'reach' of the Life Changes Trust's networks was always as wide as it could be. They raised the point that while they had been able to go along to meetings and 'felt able to say yes' to things, others will be missed from these opportunities by not being in the right place at the right time. Further, what they perceived as the Trust's reliance on digital media may have excluded some people affected by dementia from becoming aware of these opportunities.

## Scale of funding

There was wide agreement among awardees that the Trust has invested “properly” in projects in terms of funding. Funding has supported longer term, complex projects that required significant investment and which awardees believed would not have been possible without the Trust. Furthermore, it was observed that the long-term funding allocated allowed awardees the time and space to reflect on what they were doing and how it was making a difference, in contrast to ‘*always looking over your shoulder*’ with shorter-term funding. The Life Changes Trust were also seen as having enabled projects to consolidate work that may have previously been undertaken in smaller chunks. The Trust’s funding of core staff costs was appreciated, as was the ability to provide quality equipment and materials to beneficiaries.

*I think the difference that the funding made to projects like that is we didn't have to cut corners in the quality of the stuff we were sending out...we invested quite a lot of money in that, but I think there is good, you know, what am I trying to say, yes, we invested a lot of money in it, but actually that bore more fruit than it would have.*  
(Awardee YP2)

However, a slightly contrasting view from another awardee was that it could be possible for smaller amounts of funding over a longer period to lead to increased sustainability by allowing organisations to grow organically and learn as they go without becoming dependent on a larger, but time bounded, income stream.

*I think in some respects, if we'd had smaller amounts of money over a longer period of time, we might have learned, you know, better as we went. I think having a large pot of money over a short piece of time, has probably set us off running, but now we've kind of hit a plateau, and we're kind of saying, you know, it's very difficult to sustain it at that same level. Because we can't get that same level of funding from anywhere, you know, which other organisations will be in the same position for.* (Awardee C2)

## Support from the Life Changes Trust to collect and share evidence about projects

Most awardees reported positively on the Life Changes Trust’s focus on collecting evidence both through self-evaluation and through the wider, external evaluations commissioned by the Trust. However, there were some notable differences in attitudes to the nature of the Trust’s evidence requirements across the awardees interviewed for this evaluation.

Awardees reported using the evidence gathered as part of their internal monitoring and reporting to the Life Changes Trust to support funding applications to continue their work. While some felt that the reporting requirements from the Trust were demanding, they appreciated that this had helped them to be more robust in recording evidence about their project.

*And then the monitoring on a quarterly basis I think is a very good discipline actually to see are you actually achieving what you said you would achieve, and if not, why not. And I felt during that big project that there were opportunities to say, 'actually, this bit's been tricky, we didn't get as many responses as we hoped', and to feel that those things didn't come as a shock at the end, that you'd flagged them up as you went along. So no, I think it's an efficient way of doing it. (Awardee D8)*

However, others expressed somewhat less positive views on the Life Changes Trust's reporting and monitoring requirements. On the one hand, it was suggested that the Trust's financial and reporting requirements were inflexible and that the Trust's desire for consistency of reporting meant that this didn't fit as well as it might with concepts of experiential and action learning. On the other hand, it was also suggested that the reporting requirements were too loose. While flexibility around reporting was felt to be good for awardees in some respects, there was a belief that the Life Changes Trust could have been more demanding of evidence as to how money was spent, or in tying reporting more closely to assessing whether the original outcomes, as set out in the application, had been achieved.

*It might have been better if we had been more tied to reporting against that (the outcomes set out in their application). Our budget heading for reports were spent on equipment and fees and that was it. (Awardee YP3)*

The Life Changes Trust has also invested significant resources in external evaluation of key funding programmes. Among awardees whose project had been externally evaluated, one view was that independent evaluation was a key strength of the Trust's approach to funding. For example, an awardee described how having externally produced evidence had allowed them both to lever in alternative funding to continue and extend some of the work originally funded through the Life Changes Trust, and to evidence to other services where their gaps in support for people with dementia were and to have conversations about how to fill these.

*I mean, to me, it is the best experience I have had with funding because that has allowed me to have the evidence to get it funded, and to do joined up working with housing, health and social care. (Awardee D6)*

In contrast, other awardees reported finding the external evaluation process more challenging than useful. It was suggested that the external evaluators were not always felt to be looking at the right things, and awardees found it frustrating having to funnel concerns about this through the Trust.

Finally, there were comments from awardees about whether the Trust had done enough to collect together and share all the learning from projects, including sharing all the evaluation findings externally<sup>6</sup>. It was also noted that evaluations did not tend to extend beyond the end of Trust funding, and that they therefore missed some important longer-term impacts of funding. Awardees were keen to share longer-term evidence from their work and to include the experiences and stories from beneficiaries in this.

These different views may reflect diversity in terms of organisations and projects funded by the Life Changes Trust and their own beliefs and preferences for evaluation. However, they underline the need for reporting activities to be considered carefully and for potentially diverse awardee expectations and understanding of 'evidence' to be managed. They also highlight the importance of, and opportunities for, the Trust's investment in Age Scotland continuing their legacy of learning to continue to engage with awardees in generating and sharing evidence of impact.

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<sup>6</sup> Awardee interviews took place before the announcement that Age Scotland would take on responsibility for hosting the Trust's evidence and learning for the Dementia Programme and prior to final decisions being made about the host of the Learning Channel for the evidence and learning from the Young People with Care Experience Programme.

## Collection of images, phrases and memories that encapsulate the Life Changes Trust for awardees

*It's a bit like when your parents send you off to summer camp, and they know what they want you to get out of the experience, and they know what they want to get out of the experience for you, like they want you to come out of it having achieved a whole bunch of things, but they will never know what the experience actually was like on the ground, and you will come back different from where you started.*



*Figure 2.3 Summer camp*



*Figure 2.4 Smiley face in water*

*I mean the image for me is less visual and more of a feeling, which is it is that first time in my entire professional life where the thought of a meeting with my funders makes me feel happy and excited. ...they are as individuals incredibly friendly and approachable, but as an organisation they are there to be positive, and that encourages openness and honesty about the things that are not maybe working so well.*

*My phrase is one that is quite familiar at the moment: Wash Hands. LCT have given us a substantive amount of funding – but, for me, it feels like they have washed their hands.*



*Figure 2.5 Hand washing*



*Figure 2.6 Relay race*

*I would say a relay race - we are all moving in the same direction, but sometimes the baton change doesn't go so well, sometimes it does and we can gain back some ground.*





*It is an event that made me feel utterly joyful, and it was the launch event of the singing network. ...it was so powerful, and to me that's what it is all about. It's joy, it's music, it's joy, it's new things, it is old things, it's all ages coming together. So, it is a memory rather than a sound...it definitely encapsulates what the Life Changes Trust has made happen.*

*Figure 2.7 Singing Group*

*The first thing that came into my head when you said that was a love heart...it's not been without its challenges right, but...we have got a really strong relationship. Our organisations, we have similar values, the people in the teams have similar values, they have challenged us in good ways and vice a versa. ...We will miss the Life Changes Trust as an organisation, but the relationship we have with the people we will miss as well.*



*Figure 2.8 Heart hands*



*Figure 2.9 Plant in Hands*

*Just the whole kind of growing a plant, sort of like it (LCT) provides a bit of the...it's providing the nutrients, but it hasn't specified which crop to grow.*

*I am going with a unicorn because I think they are optimistic animals somehow, I don't know why. You know that whenever you see a picture of a unicorn it seems to have its head held high and it is marching forward, it is not dragging its face along the ground and feeling glum and miserable.*



*Figure 2.10 Unicorn*



## A note on the secondary analysis of project reports

While this section does not present findings from the secondary analysis of reports, the process of reading and analysing the reports illuminated aspects of the awardees experiences which are worth noting here. The reports demonstrate the significant amount of evaluation and reporting activities that projects were expected to deliver, including three-monthly reports and engagement with external evaluation teams. However, the secondary analysis further evidences that the Life Changes Trust also modelled authentic, long-term, and flexible forms of engagement that continued after the end of projects in several cases. Awardee organisations generally felt well supported by the Life Changes Trust, for example, by feeling able to take different ideas or initiatives to the Trust, based on the Trust being an open and supportive funder.

## 2.5 Conclusions and lessons drawn

The principles, values, and practices of the Life Changes Trust, as informed by its origins and implemented by staff and Trustees, have in turn influenced the experiences described by awardees. Figure 2.11 below sets out the key attributes of the context that Trustees and staff felt have shaped the work of the Life Changes Trust (blue boxes) and the practices and ways of working (green boxes) that they felt have been central in achieving its aims and objectives.

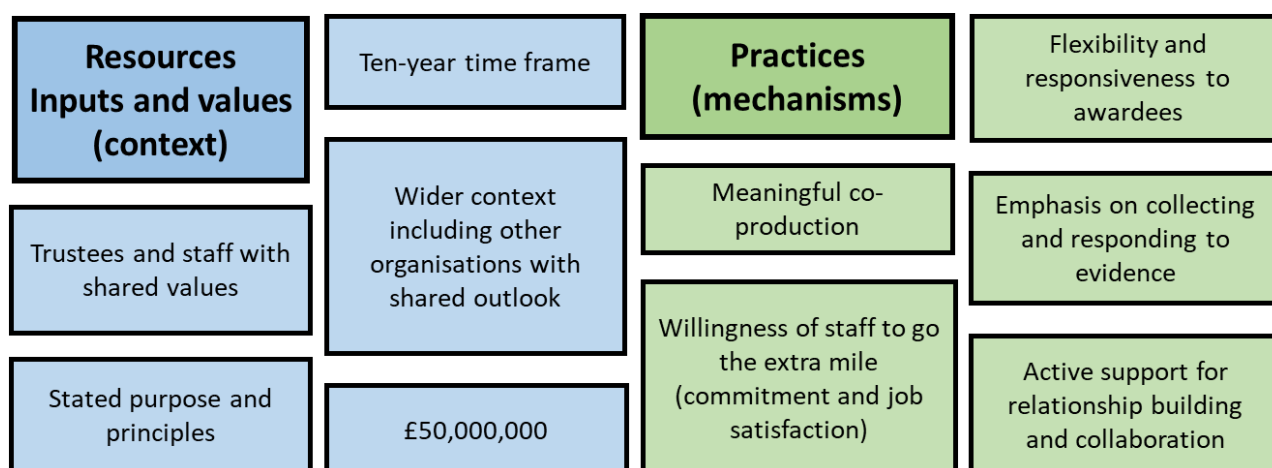


Figure 2.11 – Logic model stage one

As discussed, the **value base** of the Life Changes Trust has been built upon its history and guiding principles and was felt to have great meaning for the Trust staff and Trustees. The **stated purpose** of the Life Changes Trust was articulated into a common goal by leadership and used to provide a vision to guide them.

Having a **ten-year time frame** to work with was often referred to by staff as a motivational factor in driving forward and maintaining a focus on being able to extend the impact of the Trust beyond its lifespan. Being able to work with **other organisations with a shared outlook** was particularly important when it came to awardees, as the Life Changes Trust incorporated a value-based approach to selecting them. And, of course, the strategic investment of **£50,000,000** was a crucial opportunity to try things on a bigger scale than would otherwise have been possible.

The value of putting beneficiaries at the centre of everything the Life Changes Trust does translated into the application of **meaningful co-production** approaches that could in turn be learnt about and adopted by awardees to change practice in this regard and make projects/services more attuned and responsive to the needs of beneficiaries.

The importance of and value placed upon **relationship building and collaboration** was operationalised through the close and genuine working relationships between Life Changes Trust staff and awardees. This enabled responsiveness in the networks and connections described by awardees, although limits were also noted to these networks in the Dementia Programme in relation to their (perceived) exclusivity and reliance on use of digital media.

The value given to the **investment** approach of the Life Changes Trust is evidenced in the length of funding given, the opportunities for training and development for awardees, and the flexibility and responsiveness of the Trust to awardee ideas and experiences. The latter in particular was cited by awardees as being something they really appreciated during the COVID-19 pandemic.

The Life Changes Trust is intrinsically a **learning organisation** with an emphasis on collecting and responding to evidence. This has helped awardees to develop knowledge and skills in evaluation and in using evidence to support sustainability, as well as to benefit from knowledge exchange between awardees of the Trust where possible. At the same time, the findings demonstrate the challenges around arriving at a shared understanding between a funder and organisations with diverse evaluation cultures around the nature and level of evidence needed to support robust evaluation and learning. The opportunities for the Trust's legacy investment at Age Scotland to build on and extend the evidence base from the Life Changes Trust's investments are also highlighted.

Being part of what was described as the 'Life Changes Trust family' was acknowledged by staff to involve hard work; the **willingness of staff to go the extra mile** is testament to their **commitment** to the ideals of the Trust and the meaning, or **job satisfaction**, that they find in their work. Whether this was by travelling out to see projects or by enthusiastically taking part in festivals or conferences, staff have been the human face of the Life Changes Trust for awardees and the conduit of their partnership.

In addition to these values and practices, the Life Changes Trust also had substantial resources in terms of both **funding** and **time**, and these were also key elements underpinning their impact.

Overall, the views expressed by Life Changes Trust awardees and other stakeholders who participated in the evaluation are positive. The Year 1 stakeholder survey, Year 2 awardee survey and individual interviews with awardees and stakeholders showed that a majority felt the Trust was having a positive impact across a wide range of areas.

*I really don't have anything negative to say, genuinely, from my perspective, there's not been any negative experience, (the Life Changes Trust) have been very supportive, and very encouraging, actually, of getting our work out into the world. (Awardee D10)*

Awardees suggested a number of perceived strengths of the Life Changes Trust's approach as a funder that should be shared as lessons for other funders.

Being flexible in their approach, allowing organisations to change what they were doing in response to either changing circumstances or learning about what works for beneficiaries, as long as the overarching aims/principles remain the same.

The value of investing in building strong, supportive relationships with awardees - something many awardees felt had been done uniquely well by the Trust, compared with their other experiences of funding.

Being open to applications from both individuals and a very diverse range of organisations in terms of scope and size – this was seen as influential in sparking innovation and being receptive to community expertise.

Avoiding unnecessary bureaucracy – while, as noted above, there were different views on the level and nature of reporting required by the Life Changes Trust, there was general agreement that the Trust's approach of avoiding bureaucracy where possible was welcome.

To encourage, support and guide organisations with evaluation processes, whether internal or external, and ensure clear communication is provided about impact and involvement in external evaluations.

### 3. The impact and outcomes for the three beneficiary groups of the Trust

*The Life Changes Trust aims...to help drive transformational improvement in the lives of young people with care experience and individuals living with dementia and those who care for them. Their voices, needs and well-being are at the heart of all of our work. ('About Us' Life Changes Trust)*

#### 3.1 Introduction

This section presents an analysis of data collected directly and indirectly from beneficiaries in relation to the impact of the Trust's projects. Of necessity, such evidence focuses on individual experiences and on particular projects and programmes. However, the section will explore the broader influence of Trust activities, before considering the extent to which the impacts discussed may be considered transformational and sustainable.

'Impact' is complex to measure, not least because the beneficiary groups are each made up of individuals with diverse experiences, views and beliefs. Furthermore, as highlighted in Section one, the Trust has funded a wide range of projects and resources over its lifetime. Efforts were made therefore to involve as many individuals, groups, funded projects and funding programmes as possible in this phase of the evaluation, utilising a range of methods to encourage participation.

These methods included two phases of secondary analysis of the Life Changes Trust reports covering the Trust's activities up to and including September 2021, as well as individual and group interviews with 68 people. Secondary analysis data included internal and external evaluation reports, final and interim project reports, other project outputs, web pages, videos and application forms. Data collection with individuals included traditional interviewing and focus group methods, as well as 'walk and talk' meetings, research diaries and visual methods, including arts-based activities and involvement in a short film.

It should be noted that only a few reports provided quantitative measures of satisfaction or change. As such, this section primarily relies on qualitative evidence across both primary and secondary datasets.

The first part of the section analyses the success of the Trust in meeting its five core aims for beneficiaries:

- *I live in a place that suits me and my needs*
- *I am able to be as independent as possible*
- *I get the help I need when I need it*
- *I feel safe, listened to, valued and respected*
- *I am empowered to do the things that are important to me*

The role and capacity of the Trust's funded projects with regards to achieving transformational change, and the sustainability of such activities and learning beyond the lifetime of funding is considered throughout but in more detail in the second part of the section. Transformation and sustainability at practice and policy levels are considered in Section four.

## 3.2 I live in a place that suits me and my needs

In many ways, this statement encapsulates both the fundamental needs of beneficiaries, as well as the complexity of the challenge for Trust-funded projects, given that the Trust does not actually provide accommodation. Furthermore, what beneficiaries required from a 'place that suits [them]' could shift and change over the time they were involved with Trust-funded projects. However, the needs and aspirations associated with a sense of 'home' or belonging to a broader community were regarded by most as essential to this aim being met.

Beneficiaries' sense of 'home' in terms of belonging to a broader community was augmented by the Trust-funded support networks, and projects that offered spaces where new friends could be made and needs could be noticed and met. Indeed, some services were described as 'lifelines' after previous routines and sources of identity had been undermined, for example, by dementia. The role of the Life Changes Trust's projects in developing a sense of home or belonging will be further discussed in the following sub-sections.

When considering the places where beneficiaries actually lived, the experience of the beneficiary groups varied.

Most unpaid carers and people living with dementia interviewed felt that they lived in quite comfortable surroundings, although some described concerns relating to them or their loved one moving to residential care, as discussed in sub-section 3.4.

By contrast, some of the young people with care experience had previously experienced homelessness and spoke of living in places that they disliked and of frequent moves. Making such places homelier had become even more difficult during COVID-19 restrictions, since many had lost jobs.

Moving into supported accommodation or independent living was described as critically important to feeling a member of broader society, but also difficult. Lee related strongly ambivalent feelings: *'I was excited and nervous because it was like my first property by myself'* (Lee, young person, M). His nervousness related to having to be an 'adult', paying bills and rent on time, cooking and cleaning.

The support provided – for example by the Life Changes Trust's Home and Belonging programme – in helping young people to make these transitions and learning *'how to actually make a house a home'* as Jenna (young person, F) put it, was regarded as crucial in interviews with young people and housing providers. She appreciated the co-produced 'housing booklet' she had received in her supported accommodation, as well as cookery advice. Lee was proud of his flat and gave the interviewer a tour. The conversation highlighted his control over the sensory environment of this place and how he had learned to make it more homely.

*I: Candles and quietness, uh-huh. Why are candles and quietness important to you?*

*R: Just candles smell nice. Quietness, I don't like big noisy stuff...* (Lee, young person, M)

There was further evidence in the secondary analysis of how the Home and Belonging hubs had identified young people's home-related needs and aspirations. Outcomes for young people involved in these services were positive, although, as mentioned earlier, 'evidence' of change relied on personal accounts rather than being measured or reported in the available evaluation data.

The 2020 Progress Report for the Home and Belonging programme indicates that external evaluators saw a number of examples of better home environments and of people being more connected in their communities. The projects had supported better health and wellbeing, relationships and opportunities to learn and develop skills, and participants had kept their tenancies for longer than previously.



*(It was) amazing and wholesome. It has made me realise that home is not just the place, but the people. (Young person, Home and Belonging Progress Report, p. 5)*

While most such evidence related to young people with care experience, the importance of providing support to create or maintain a sense of home was also evident in the analysis of evaluation reports of the Trust-funded projects supporting people living with dementia and unpaid carers. Secondary analysis of such reports submitted from 2019 highlighted that five programmes, encompassing a range of 20 projects, had prioritised helping beneficiaries to live in their independent homes for longer.

The Dementia Dog project may be viewed in this light. To some extent, this was also an aim of the individual grants, like the Caring for the Carer fund and the Individual Awards scheme for people living with dementia. These schemes funded adaptations to home environments, including care homes, to make them feel more 'homely', comfortable, and for some beneficiaries, quieter and more joyful places to live in. Indeed, these themes of 'peace' and 'quiet' recurred in many evaluation reports.

Data suggested that there were some difficulties where, as part of these processes, families and carers became more involved in care choices, however for many, family ties were also enhanced as a result.

For beneficiaries in all groups therefore, such initiatives could be transformational, and have produced understandings of needs and aspirations that may influence practice more broadly. At the same time, it is important to recognise the challenges posed by wider societal factors.

For members of all three beneficiary groups, despite their involvement in the Trust-funded projects, home could feel precarious and significantly influenced by how the beneficiary groups were perceived by wider society. Young people reported stigma as a key barrier to feeling 'at home'. Such stigma was evident in their accounts of public attitudes in general, and of some professionals' negative reactions to housing young people whether in residential care or as care leavers.

*The council tried to build another children's home a few years ago in (location removed), and that got denied because of all the complaints from neighbours. (Skye, young person, F)*

*Moving into a property, like they kind of get problems and then hate from like public because obviously you've been in care and stuff. (Lee, young person M)*

Young people with care experience housed by a local authority suggested that this stigma was not linked only to their care histories, but also to their age, and was shared by other local authority workers.

*Our housing officers aren't great with young people because like me and my next-door neighbour are...both in our 20s and she's more harsher on us than the older tenants within the block... That's clearly ageist. (Gemma young person, F)*

A group of young people who participated in a focus group at a housing project felt criminalised, even de-humanised by the stigma they experienced.

*Yeah, they think you're in care because you've done something wrong. They (parents) don't love you because of you. You done something. (Brodie, young person, M)*

*Yeah, you'll be hard pressed to find a young person who has been in or around a court. (Blair, young person, F)*

*Yes you have a social worker, but don't judge somebody. We're still humans at the end of the day. We're still people. (Naomi young person, F)*

Such accounts reinforced the importance of work to counter stigma as emphasised across the Life Changes Trust's projects. While beneficiaries were generally positive that this work had made a difference, doubts remained, pointing to the need for further work.

*I: Do you reckon (those attitudes are) changing?*

*I think people like to say it's changing, and people like to 'oh well we've done this' but like people's actions unless there is a consequence for them they won't change. (Blair, young person, F)*

Structural concerns were also evident in the accounts of beneficiaries living with dementia and carers. Several highlighted the fear associated with losing their homes due to the rules around paying for social care. Richard recounted how such anxieties had had a long-lasting effect, and how the related sense of persecution his partner had experienced had complicated family decision-making around setting up a power of attorney.

*And that was another thing to add into the mix for her when it came time to make these decisions when there was all of this angst over the house... 'But that's our home! Don't they care that that's our home?' And that really hit her really, really, really, really hard. 'It's my home. Why do they want to take my home away from me? It's my house. You know, it's my home. (Richard, person living with dementia, 57M)*

These accounts highlight the tension felt by individual beneficiaries between the fulfilment of this aim of 'living in a place that suits [them] and [their] needs' and broader structural realities. It seemed that for many, Trust-funded projects offered a bridge, a type of support that stood outside more established systems and providers.

The Trust has recognised these broader structural realities and has invested where possible in work that has explicitly aimed to tackle them. For example, the Each and Every Child Initiative has evolved from research funded by the Trust and carried out by the FrameWorks Institute, exploring public attitudes on the care of children and young people, and care experience itself.

Each and Every Child is now one of the Trust's legacy activities for young people with care experience, with the Trust acting within a wider collaboration of funders to support its work. The initiative will use an evidence-based toolkit to work with young people with care experience and organisations supporting them across Scotland and will seek to challenge stereotypes and change narratives around young people with care experience and care more widely.

### 3.3. I am able to be as independent as possible

Across the various datasets, it was clear that 'independence' was understood and experienced by beneficiaries in differing ways. For some, the notion of independence was closely linked to having and maintaining a sense of home, as suggested in the previous sub-section. However, analysis suggested other important understandings of this term which are discussed in greater depth here.

Independence was seen by many beneficiaries as being able to take part in a life outside of home. For people living with dementia, many of the Life Changes Trust-funded projects provided opportunities to get out and about and participate in social activities. From interview data, these beneficiaries felt supported not only by the activity itself, but by the reassuring knowledge that they would be provided with a non-judgemental safety net if unable to manage whilst participating in the activity.

From secondary analysis, it was clear that people living with dementia were also provided with opportunities to develop new skills, and, in some cases, to recover some abilities that they had thought lost.

*Mr (person living with dementia) became more confident in getting outside the house and engaging with other people as a result of attending the Dementia Friendly Group. (Case study, REACH Project, Evaluation of Dementia Projects for Minority Ethnic Communities Final Report, p. 44)*

Similarly, the Dementia Dog project was also viewed as having supported and extended beneficiaries' autonomy, since the dogs allowed people living with dementia to overcome insecurities and fears, to regain the confidence to leave the psychological and physical safety of home to discover and explore new opportunities.

Physical wellbeing was also linked to independence. Physical activities were funded as part of wider initiatives such as the Sporting Memories Network or Paths for All, or as elements of other services. For example, a number of peer support projects involved physical or outdoor activities that allowed beneficiaries, particularly people living with dementia, a chance to rediscover the pleasure of 'feeling able' and of engaging in fun and meaningful activities.

Moreover, for all beneficiaries, physical activity groups proved to be powerful social connectors. New friendships were made through these groups and, as a result, new support networks were established based on a shared enjoyment of the activity, not simply the beneficiary 'label'. In addition, the Life Changes Trust funding supported individual physical activity at home across all beneficiary groups. This took on an added importance during the COVID-19 restrictions during which a meaningful number of individual grants were used to purchase fitness equipment (165 requests for the Keep Well Fund for young people and 59 requests for the Caring for the Carer Fund.)

Independence within relationships was also supported by the Life Changes Trust funding. Unpaid carers greatly appreciated those Trust-funded projects which offered activities to their partner or relative in a safe and welcoming environment. This allowed them to take time for their own work or leisure, without guilt or anxiety, knowing that their partners or relatives were engaging in activities that they enjoyed. Many reported that the Trust's recognition of unpaid carers as individuals, and as a beneficiary group in their own right, was often missing from their experience of working with other dementia care organisations.

As one of the respondents who organised the Carers' Conference emphasised, this recognition and support allowed them to recover their own identities, which, to a significant extent, they felt had been lost to their caring duties.

*I like to do things with my husband, yes. But I also like to do things on my own. But that doesn't matter, if he's got dementia and I'm the carer, that's the way we are. So why should I be lumped in? I'm not a second-class citizen. I'm a person in my own right. So no, my husband's got dementia and I'm his wife, his carer second. But I'm not 'the carer'. You know what I mean. (Joan, unpaid carer, 60F)*

Carers also expressed their appreciation for the way such projects had adapted to COVID-19 restrictions, by providing innovative online experiences and opportunities, such as, Kirrie Connections' online support or singing groups.

*It allows an hour's time that I can go and do something by myself and have no concern about (name removed)'s welfare, because I know she's in front of a camera, she can be seen by someone, if she does go down she's got her mobile beside her or the people that she's conversing with and singing with have my number and I also carry my mobile beside me so they can contact me and I can just come upstairs. Because (name removed) likes to be independent, as independent as she can be, so I leave her to her singing because that's personal to her; that's her time away from me – because we're with each other twenty-four seven and that's a difficult thing to do. (William, unpaid carer, 60M)*

Independence within care relationships was also supported by the Trust's Individual Awards. People living with dementia and unpaid carers used this money for a variety of experiences and resources, including respite trips, allowing them a couple of days away from caring responsibilities.

In relation to young people with care experience, independence was often conceived of, in policy terms, as improving their experience of transitioning out of being in care and into adult life by providing them with targeted resources, skills and opportunities.

The Trust-funded peer mentoring projects helped young people with care experience to gain further independence through accessing higher education, getting job opportunities, moving to an independent home and, in more general terms, developing the sense that they could start to shape their own futures. Many of the young people who took part in interviews mentioned that they had been invited to take part in initiatives, often through being hired in professional roles related to their care experienced status.

*I basically said I don't want to go to college or uni or that, because I wasn't really sure what I wanted to do. So I just wanted to work, and I think they mentioned the developmental assistant role and asked if I would be interested in it. And I went to the first interview that we had and got the job, and have worked here on and off. (Ava, young person, F)*

*I have not got the best education and this doesn't...you don't need any qualifications, you don't need any...it is just they are willing to take you to help, so... (Morgan, young person, F)*

*I was complaining about how bored I was because I wasn't at college or university yet. And she went, well we're looking for people and I think you'd be really good, so come along. (Bradley, young person, M)*

The development of a sense that a good future was attainable was further facilitated by the provision of individual grants and Aspirational Awards. These schemes, also administered by members of the Life Changes Trust's young people's Advisory Group, gave beneficiaries the option to manage relatively small budgets, awarded on the basis that the money provided would support their future aspirations.

During interviews and focus groups, young people discussed the ways that funding, for example, driving lessons and bursary costs had made such a difference for them. Jenna, for example, had received funds for driving lessons and for an iPad through an individual award.

*So, they had grants for people for up to 250 pounds that people could apply for (...) I just put in an application to raise funds towards an iPad because I only had my laptop and I was trying to maintain a relationship with my friends and family at the same time. So, I managed to get 150 pounds from the Life Changes Trust (...) which I thought was really amazing. (Jenna, young person, F)*

All such opportunities were greatly appreciated in themselves. However, it is interesting that for many of the young people, the opportunities and services provided were valued as supporting the development of interdependence rather than independence.

They provided them with opportunities to make new friends and develop trusting relationships, something that is often more difficult for young people with care experience. The safe spaces described more fully in sub-section 3.5 can be seen in a similar light.



*...it's been good to make new friends and, kind of, take me out my comfort zone a bit... I've realised that not all people are bad people, because quite often like normally I'm scared to make new friends because I'm scared that they're going to judge me for being care experienced or whatever. But like I know within (group) that we've all got similar experiences and we're, basically, there to make a difference. (Gemma, young person, F)*

Young people also reported the positive effects of sharing their stories and successes with others, a finding explored further in sub-section 3.6. The following excerpt is from a Champions Board.

*Two that are due to be parents, we've got some that are now in college, some that are now working. And before they all just didn't know what they were going to do; and through the support of the Champions Board and the opportunities that we were able to help give them, they're all in positive places right now. (Skye, young person, F)*

Overall, the Life Changes Trust's approach to supporting the independence of young people with care experience was appreciated as both ambitious and realistic.

*I feel like they want to have high expectations of young people, but they are aware of the difficulties people can face. (Emily, young person, F)*

## 3.4 I get the help I need when I need it

Providing direct help and support to people from each of the beneficiary groups was at the core of most Trust-funded projects and included both practical and emotional support. Such supports were referred to by beneficiaries on many occasions across all datasets. At the same time, the difficulties in maintaining this support in the long term and the enormity of the task in relation to providing and embedding flexible and responsive help within the current structural climate was also evident.

The Trust's funding made a significant contribution to the practical help available during lockdown through the provision of parcels with essential items, for example, the Outside the Box's Food Buddies project, or kits to support wellbeing and exercise at home, provided by Sporting Memories.

*I find this equipment really beneficial. I am ever so grateful. It's good from a wellbeing point of view and we're all mentally engrossed in the meetings. It's excellent.* (Person living with dementia, An Active Future with Dementia: How Sport & Physical Activity Can Connect Us. Summary and Evaluation by Sporting Memories Foundation Scotland. Linked video evidence)

The importance of practical help was not restricted to the periods of COVID-19 lockdowns and was highlighted across the beneficiary interviews, although some were unclear as to the Life Changes Trust's role in funding the services they mentioned. The support most frequently identified included financial, housing and educational support, help with social networking and with accessing benefits, job or volunteering opportunities.

Providing small grants directly from the Trust to beneficiaries, or under the management of a localised organisation, such as Care and Repair for the Dementia Enablement Project, was a relatively inexpensive way of addressing people's needs. Even such small-scale interventions could have significant effects and were highly valued by beneficiaries.

*The clock and the whiteboard are the best thing since sliced bread.* (Person living with dementia, Evaluation of the Pilot Dementia Enablement Project, p. 24)

Another important source of practical help was the signposting role played by many Trust-funded projects. They helped to make people aware of their rights and/or assisted them in their many battles with institutional obstacles. For people living with dementia and unpaid carers, navigating the different supports provided was often experienced as a highly complex matter.

*And nobody will tell you what your rights are. (...) You've got to find out and fight for them as a carer.* (May, unpaid carer, F)

*NHS Inform...Age Scotland do loads of stuff, Alzheimer's do loads of stuff. Dementia Awareness do loads of stuff but there's no coordinated signposting at local level to direct anyone to it... It's just that it's a jumble right now, because, nobody knows their rights.* (Joan, unpaid carer, 60F)

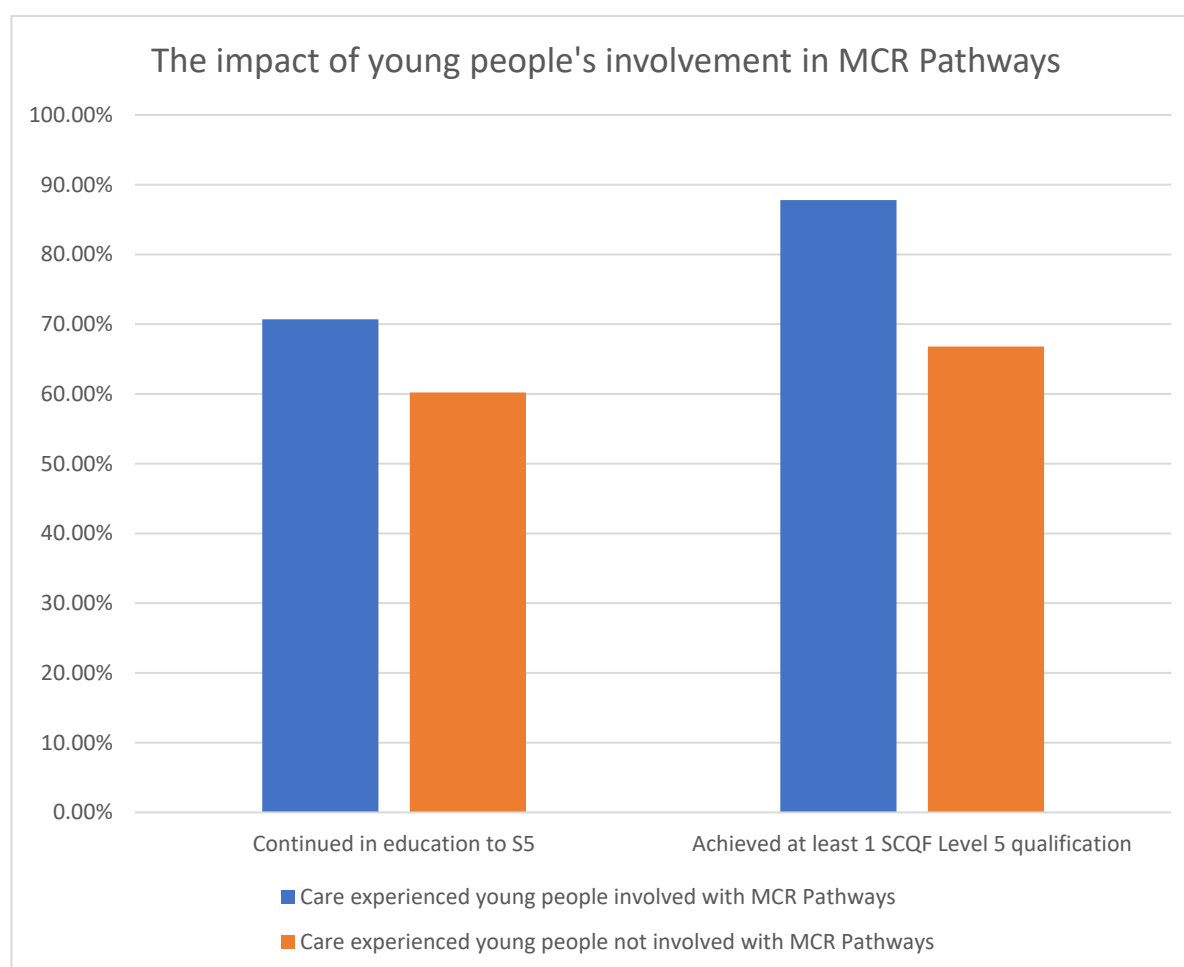
Many beneficiaries were confused as to their rights but the difference that Trust-funded projects, where available, had made in this regard was reported as significant.

*The Life Changes Trust are funding...I can't remember what they're called, but Care and Repair here in (location removed), they got funding for dementia support. And they are telling people what their rights are. They are costing the local authority probably nearly... I think it's almost three quarters of a million (pounds), because that wouldn't have been spent if that person hadn't told them of their rights, what they were entitled to. (Joan, unpaid carer, 60F)*

Similarly, for Lucy, advice from a Trust-supported agency on the complexities of negotiating funding social care had proved crucial at a critical time.

*If it hadn't been for that contact with...I probably would have been forced to sell the house. (Lucy, unpaid carer, 64F)*

There is also evidence from both secondary analysis and beneficiary interviews that the provision of practical help served as a gateway to gaining the beneficiaries' trust, which in turn facilitated access to emotional and social supports. Project workers, and their thoughtful and genuine approach, were seen by many beneficiaries as key to accessing information and navigating the wider care, health, education and benefit systems.



For many, the opportunity to access support on a one-on-one basis also meant that they felt less ashamed about seeking help. Interview data and secondary data highlighted that key to the effectiveness of support was the presence of authentic relationships between beneficiaries and project staff.

In relation to young people with care experience, one example was projects associated with enhanced educational attainment. For example, secondary analysis highlighted that as a likely result of involvement with the MCR Pathways mentoring project in Glasgow, 70.7% of mentored pupils - many of whom were care experienced - continued their education into S5, which was 10.5% higher relative to other young people in care, or previously in care. Moreover, 87.8% of mentored pupils achieved at least one SCQF Level 5 qualification, 21% higher than their peers. These findings provide evidence of the efficacy of providing one-to-one support to young people with care experience to enhance their educational attainment, and of the importance of the relationship-based, holistic nature of this support.

*The sort of support I received from my mentor during that time (during a family bereavement) was invaluable. I've often said I probably wouldn't be here if it wasn't for that support. (Young person, MCR Pathways Report, p. 42)*

This relationship-based support was greatly appreciated. As stated in the evaluation of the Rights and Equalities Initiatives and Empowerment grants, supportive relationships were deemed the reason why people came back to the projects. The importance of this sense of connection extended to those who were involved in the work of the Trust more directly. As an example, members of the Life Changes Trust Advisory Group described their loyalty to the Trust thanks to this deep sense of belonging.

*...I would never walk away from the group, I love it honestly, I don't think I could see myself not being involved, it's like my one connection sometimes to the outside world. (Life Changes Trust Advisor, Evaluation of the Life Changes Trust Advisory Group, Interim Summary Report – February 2021, p. 8)*

Emotional help and support were also provided to people living with dementia and unpaid carers by both project staff and peer networks. Its impact is particularly evident in the Peer Support evaluation of projects providing peer-based activities for people to meet and get support from others in similar situations. In the secondary analysis of evaluation reports, for example, the Peer Support, Get Outdoors and Befriending projects, both people living with dementia and unpaid carers consistently reported reductions in loneliness, social isolation and stress.

Unpaid carers also outlined improvements in their quality of life and wellbeing, through increased participation in social and physical activities. Such peer support was valued by all beneficiaries as it provided the opportunity to let go and share worries, joy and grief. It was especially appreciated by those who had previously lacked support networks, or whose friendship networks had declined.

The value attributed to peer support can also be seen in findings related to feeling safe, valued and listened to, discussed in sub-section 3.5.

*They just totally understand (...) they so understand. And what I've often said is you don't need people to give you solutions necessarily to what your current problem is, you just need someone to hear you sometimes, really hear you, and really listen. And I just feel that in that little group, that little Zoom thing, and I know I can pick up the phone to them anytime as well, I just feel I've got the support I need because it can be tough, and especially during the pandemic. (Hannah, unpaid carer, 59F)*

*It's been amazing. (...) being able to tell their stories and being able to find that that is a safe space for them, that they can come to talk to us at any point. (Finlay, young person, M)*

The availability of such supports both to the newly diagnosed and to younger people with dementia were also noted.

*It was quite difficult to find somewhere. Not being funny, most of the dementia clubs and most of the projects that will go for people with dementia were aimed at old age pensioners. It wasn't aimed at a young person. So it was difficult. You would go along and you would be youngest in the group by about 30 years. There was nobody there that we could relate to. The Heart for Art project takes in all ages. (Douglas, unpaid carer, M)*

COVID-19 learning reports, the Life Changes Trust Flash Reports and evaluation reports published after 2020 suggest that during the first COVID-19 lockdown all ongoing programmes had found a way to continue their activities virtually. There is evidence that technological connectedness reduced loneliness and revived latent ties, while project staff provided meaningful emotional support to beneficiaries by this means.

*If I hadn't had the Champions Board I don't think I would have got through it (the lockdown). (The staff) are so amazing and I don't know how I could ever thank them for their support over the last year. (Young person, Champions Board Partnership Scorecard Results 2020, p.30)*

However, the transition to online delivery was not always a smooth process, and some beneficiaries reported losing their support networks as a result of the lack of face-to-face opportunities; the move to online provision had quickly severed these important sources of help and support. Projects such as Playlist for Life reported losing engagement with participants who were not comfortable with the online delivery. On the other hand, they later increased their engagement levels by reaching people living in remote areas. The Champions Board Scorecard Evaluation also reported mixed reviews on the ability of the Boards to keep up their activities in lockdown, with some Boards reportedly 'going a bit quiet' at a particularly vulnerable time for young people. The need for consistency of support was evident in the interviews.

*So I think it's really amazing to get to the point where I've built up relationships where I can literally (...) just send them a text message and I'm like well, please, I've got this thing. It's got nothing to do with anything we've ever spoken about. But please help me. (Jenna, young person, F)*

Reviews on the consistency of support were, overall, positive across the evaluation data. Much of the help was facilitated by the relationship-based, personalised practice adopted by Trust-funded project workers and by the Life Changes Trust's staff themselves, as outlined in Section two. It was repeatedly noted that, across the board, most staff were ready to 'go the extra mile' for beneficiaries.

This consistent support, which appeared to be a mainstay of the Life Changes Trust and its funded projects, see for example Dementia-Friendly Communities, helped to build trust and overcome the boundaries of conventional practitioner-service user relationships. However, this emphasis on relationship-based practice was perceived by some beneficiaries as creating a burden on staff. Relationships could also vary in quality and consistency where there were frequent changes in staff.

Analysis across the datasets revealed some problems relating to accessing the help provided or supported by the Life Changes Trust. Language and cultural barriers were the most common obstacles identified by beneficiaries accessing Trust-funded groups and services, although there was clear evidence that some interventions were explicitly tailored to the needs of minority communities and provided culturally sensitive activities.

Success in attracting diverse groups varied: for example, the projects for people living with dementia in Minority Ethnic Communities were more or less successful on a case-to-case basis and the reasons for this were less clear.



These challenges are not unique to the Life Changes Trust. Indeed, it is important to remember that factors such as gender, age, ethnicity or presence of other disabilities can negatively affect people's access to services and resources, and the way they are treated by institutions and wider society. Interestingly, a lack of transport was also identified by beneficiaries as a key barrier to participation. This appeared to be a less complex issue to address but one which endured, although some projects sought to address it.

During interviews and focus groups, many beneficiaries shared their concerns about the continuity and sustainability of support, particularly towards the end of the Life Changes Trust's funding. They viewed the likely impact of funding withdrawal as considerable, disrupting the close-knit relationships between beneficiaries, between beneficiaries and staff and the wider support networks which had grown out of Trust-funded projects. Few felt that Trust-funded projects were secure in the future.

As previously discussed, it was clear too that, although the work of the Life Changes Trust had been able to mitigate some gaps in formal services, its projects could not erase the challenges posed by a gap in government support. A lack of signposting remained a major issue for many. Unpaid carers felt that, despite the Trust's efforts, their needs remained largely unaddressed at a broader policy level, while a young person argued that some categories of beneficiaries were still slipping through the cracks and their needs were largely hidden to the institutions.

*None of us should have to be in hundreds of pounds in debt on Council Tax or having to pay £300 a week towards a homeless hostel (...). Like I shouldn't have to, at 16, work full time. (...) But I'm left on my own with no support. I don't get trauma counselling. I don't get anything like that, because I'm not classed as care experienced. And it shouldn't be like that, like, the system needs to change. And (name removed) who is part of the, she's like the Who Cares? Scotland worker in Champs, she's quite big about it (...) we need to find these hidden care experienced and actually get them support and stuff, advocacy and things like that. (Poppy, young person, F)*

### 3.5 I feel safe, listened to, valued and respected

The importance to beneficiaries of feeling safe, listened to, valued and respected, was clearly established in the evaluation data. In many ways, this aim was seen to be at the core of how Trust-funded projects operated, in that by feeling safe and valued, beneficiaries also felt part of an 'extended family', experienced a sense of belonging and felt able to take on new skills and challenges. Such points have already been made implicitly in sub-sections 3.2 and 3.4, illustrating again the ways in which the Life Changes Trust's aims overlapped.

Involvement with Trust-funded projects, therefore, provided beneficiaries with what they perceived and experienced as safe and supported spaces. People living with dementia and unpaid carers felt welcomed into spaces where they felt that the staff and peers 'genuinely cared' for them, and where they found chances for 'escapism, mutual learning and support' – and in the case of unpaid carers, also respite.

This was particularly evident in the evaluation reports for the Dementia Friendly Communities, Get Outdoors, and Rights Made Real in Care Homes programmes.

*I didn't like it here at first. I was wary of the staff. I didn't know them. I didn't really trust them. I've managed to make friends. People can be funny at times. After being here, I notice that the staff seem to be genuinely interested in me. They ask me the funny questions and get a bit of a laugh. I feel protected here. I look forward to the lovely meals and sitting here in the lounge watching the world go by, you can just sit here in peace and quiet. (Person living with dementia, Recognising, respecting and responding: promoting human rights for residents of care homes in Scotland, p. 35)*

Similar experiences were voiced by beneficiaries engaging with other Trust-funded projects. Through them, they also had the chance to share guidance and tips gathered from their day-to-day lived experiences and to access helpful information, for example, thanks to monthly carers' information sessions. Beneficiaries so valued the support offered by volunteers and peers, and the sense of being safe and of being listened to, that, for some, it literally was seen as the difference between life or death.

*The drop-in café has been a lifeline, because if I hadn't gone to them, I wouldn't be here now. (Unpaid carer, Dementia Friendly Communities Final Report, p. 20)*

Similar outcomes were identified in the analysis of young people's project evaluations. In the evaluation of the Rights and Equalities initiatives and Empowerment grants, staff from most projects involved reflected on the 'togetherness' between young people and adults working within them, reinforcing the importance of creating 'safe spaces' to make connections and share experiences and understandings. A similar finding is shared by a young person with care experience from the Relationship-Based Practice report.

*And that's it, we can all learn from each other as well, and learn skills and tips from each other...it sets a nice safe space for us to go, and escape from your home life for a while, and then just have a wee bit of freedom. (Young person, Young People with Care Experience Programme: Relationship-Based Practice and Policy Interim Report, p. 11)*

Furthermore, for many of those interviewed, these spaces did not detract from the other supportive circles they had. Rather, they complemented and augmented them.

*I've terrific family, I've got two sisters who, you know, and lots of friends but...I think because we all understand one another and what we're going through, we're all at different stages, but we have the same, you know, sort of centre sort of thing, and yes we can, at this carers' meeting you can say, we have a lot of laughs and you say exactly what you think and you can cry, you know, just whatever, and nobody judges you, everybody has an upset sometimes so it's really, really important. (Joyce, unpaid carer, 72F)*

Beneficiaries identified critical elements of the practices of the Life Changes Trust itself and of funded projects, including peer-to-peer support projects that contributed to feelings of safety and of being valued, respected and treated with dignity. Referring to their experiences in the project as compared with other settings, one young person explained:

*It's a place where you can go and express yourself and your own art and you can be yourself. If you go to some other places, you have to go and not be your complete self. When I go there I feel my complete self. (Young person, Young People with Care Experience Programme: Relationship-Based Practice and Policy Interim Report, p. 15)*

The emphasis placed by some projects on never being pressured to mask their mood was highlighted by many. There was no evidence to suggest that any projects did not allow this, however some projects seemed to put a specific emphasis on the chance for beneficiaries to 'be themselves' regardless of how they were feeling.

*Talking to people who understand how you feel - if you are not in a very good mood that day they accept whatever mood you are in...(because) they are all going through the same sort of thing. You are not embarrassed, as I say, if it is just a carers' group to just have a good cry; you are not embarrassed by doing all these sorts of things. (Unpaid carer, Life Changes Trust Peer Support Projects Evaluation Report, p. 31)*

Speaking freely created a sense of camaraderie amongst members. In turn, this appeared to start conversations on new topics, such as the innovative concept of 'living bereavement' for unpaid carers, discussed across the TIDE network. Although the approach of many of the Trust-funded projects was oriented towards enhancing individual abilities and strengths, the importance of being able to share vulnerabilities in a supportive, group environment was clear.

Similarly, for Shaun, the Trust-funded group he attended provided a place of support for people with care experience, without the group feeling defined by that experience, or particular forms of that experience, in the way it operated. Instead, he could 'just be'.

*That was part of the group that I really enjoyed... We were always very clear that it's a care experienced group...but not...in the sense that we all have to come here and talk about (it). ...I was quite glad that I didn't have to admit that I was never in a care home...and some people had been deep in the care system and some people, probably more like me, had been shallowly in it... You picked that up from the conversation, but we never spoke about it explicitly... There's something about that that's really at the heart of our group. (Shaun, young person, M)*

For others, having a space in which to talk about their experiences was essential. Tyler emphasised the importance of knowing that, when he did speak about his care experience with group members, he could do so without a pitying response.

*When I tell my story about how I grew up...they can understand rather than just sympathise. They can empathise as well because they had similar experiences... It's not someone who's going: 'Urgh I'm sorry that happened to you'. ...I would never want someone to feel sorry for me or have that kind of feeling because it makes me feel less, it makes me feel inferior. (Tyler, young person, M)*

The significance of being treated as 'normal', complex human beings, and not defined by a 'label', was raised by beneficiaries across all three groups. This appeared to be a critically important feature of Trust-funded projects and their practice in creating safe spaces; looking beyond their beneficiary categories to recognise individuality and complexity.

This approach contrasted with some previous experiences; for example, a member of the Trust-funded theatre group described how an intended compliment, expressing surprise at his acting ability ('despite' being care experienced), had felt like a '*punch in the gut*'. Similarly, Brodie emphasised that in other contexts, his emotions would always be interpreted through the prism of care.

*Everything went down to being care experienced, you're feeling down today, 'oh no wonder, you're care experienced.' 'Oh, you're feeling sad, it's because you're care experienced'. It's not! It's human emotion! (Brodie, young person, M)*

Across each of the evaluation reports included in the secondary analysis sample, it appeared that staff working within the Trust-funded projects were regarded as working hard both to provide tailored support and to promote community living and positive, non-stigmatising relationships. Once again, the trusting relationships with and between staff and members developed across all projects evaluated were seen as essential to their success and to their sustainability over time.

*I've worked in a few other organisations in the sector and the Life Changes Trust definitely stands out as being unique, partly maybe because it's a little bit smaller, there's much closer personal relationships with the staff from the top to the bottom of the organisation. Co-production has been such a key part of it. We feel we are part of the Trust, we don't just work for the Trust or volunteer with the Trust we are part of the Trust, as opposed to working for them or with them. (Life Changes Trust Advisor, Evaluation of the Life Changes Trust Advisory Group, Interim Summary Report – February 2021, p. 9)*

The role of trusted workers in creating these supportive environments was much appreciated and emphasised by young people with care experience in interviews and focus groups. Members of a Champions Board and the theatre group focus groups highlighted the role played by support workers.

*...she's always there behind the scenes, you know, if someone's late, someone misses a meeting, or someone's just quiet...she'll always message you and be like, are you OK? ...just having that wee someone checking in on you, it makes you feel so, I don't know. (Harry, young person, M)*

The time that the theatre group had been afforded to engage in a series of team-building exercises including skills-based masterclasses was also highlighted as exceptional.

*What we did do was the team-building...and it felt fantastic. Because...it came to the show, and it did feel like a family, it did feel like, everyone involved, I could trust... So, I think it was really important, that slower process, instead of just like, deep-end, go and you don't know each other but try... That really was such an important factor, you know, that we had the time, and space, and funding for it to be able to be such a long process. (Shaun, young person, M)*

Participants were well aware that such funding, space and time are not the norm. One related her experience of another much less well funded theatre company project that felt much less supportive.

*We were only meeting once a week, it was for a much shorter time, there was only, like, one guy, sort of mediating it, and it was a much bigger group. And it was sort of discussed, like, how important was what the Life Changes Trust project had, because that's what made it able to, like, flourish into what it did. (Rachael, young person, F)*

The use of creative methods may be viewed similarly, enabling processes of active and informed listening, including in relation to end-of-life arrangements. Creative methods were employed by a variety of Trust-funded projects for all three beneficiary groups.

The Empowerment Grants and Rights and Equalities Initiatives for younger people used a range of creative methods including music and arts, film-making and drama projects to engage young people with care experience to build their confidence and create a sense of community. The Champions Board projects used a variety of creative methods to support young people with care experience to build relationships with their Corporate Parents, to ensure that shared goals could be identified, and that young people with care experience had a voice in decisions that affect their lives.

*In East Dunbartonshire, the Champions Board set up a choir for young people and Corporate Parents. The idea was to create an activity which everyone could take part in and enjoy, to provide informal ways of starting to be involved in the Board. It also meant that young people and Corporate Parents were learning together, creating a level playing field and opportunities for building relationships and sharing experiences. (Evaluation of the Champions Board Approach Final Report, p. 24).*

For people living with dementia, the Rights Made Real in Care Homes programme and the Storytelling Sessions used methods involving music and storytelling to engage people living with dementia on several topics, such as supporting rights-based approaches for care home residents and engaging people living with dementia in decision-making processes in Health and Social Care Partnerships. Other examples included the wide variety of activities across the Dementia Friendly Communities networks and the Dementia Inclusive Singing Network and related singing activities. The experience of such activities had clear benefits for attendees.

*I just feel that there's just a great need. And I think it's not just for the actual people with dementia, but for their carers. If it's family or friends or whatever, it's sometimes nice to have an activity you can do together, as well. (Project worker: Dementia Inclusive Singing Network Evaluation report, p. 7)*

Such methods also had the goal of ensuring beneficiaries' participation went beyond tokenistic approaches to engagement. Nonetheless, some evaluation reports included in the secondary analysis evidenced the need for increased use of more creative and participatory methods to ensure the authentic and wide-ranging participation of beneficiaries. For example, the Home and Belonging report shows that:

*There has been a range of good work to engage young people in decision-making however, we felt this could become more structured. It would be useful to provide support and guidance on participation and engagement in decision-making to all projects. This should focus on using creative and engaging methods and could learn from some of the projects that have delivered this successfully in Year One. (Evaluation of the Home and Belonging Initiative, Year One Progress Report, p.9)*



The development of such structured practices may be key to the sustainability of this learning in the future.

Considering intersectional needs and recognising beneficiaries' multiple social identities and pre-existing disadvantages is another important element of feeling safe, listened to, and respected. As previously mentioned, some Trust-funded projects had a specific commitment and remit to listen to and meet the needs of minority community members, LGBTQ people, disabled and neuro-divergent people.

The Aberlour Rights and Equalities project is a meaningful example of intersectional, innovative practice. For example, a young person with a learning disability living in residential care shared his views, and those of his non-verbal housemates, with MSPs, and was empowered by learning about his rights, to discuss and take greater ownership of his future care planning with his social worker. Other relevant projects included the Dementia Projects for Minority Ethnic Communities, the Rights and Equalities initiatives and the Proud to Care project.

Reviewing the evaluation reports as a whole, there is evidence to suggest that all projects intended to meet the intersectional needs of their beneficiaries and provide them with comprehensive and nuanced support. This view was primarily expressed by project staff, but in the evaluation reports for the Dementia Friendly Communities and the projects supporting Minority Ethnic Communities there is also direct and reported evidence that participants appreciated this approach.

## 3.6 I am empowered to do the things that are important to me

Across the data, it was clear that Trust-funded projects enabled beneficiary groups to feel empowered and inspired to make change in their own lives and in the lives of others. For the majority of beneficiaries interviewed, this centred on a drive to improve the experiences of people from their beneficiary group to ensure that 'things were different' for them.

This push for change was also evident in the secondary analysis, where it appeared at both individual and collective levels, in projects such as TIDE, Who Cares? (Scotland), About Dementia, BOLD and the Champions Boards, as well as in the reports from the Storytelling Sessions. Overall, this aim has formed a critical element of the Life Changes Trust's work, providing examples of practice and experiences that are likely to inform future leaders in these areas.

As discussed in sub-section 3.2, many beneficiaries emphasised their desire to challenge the stigma associated with both being in the care system and with having a diagnosis of dementia. They regarded the Life Changes Trust as playing a central role in this regard. The Trust's practices with awardees and their overall approach to funding were regarded as offering a challenge to traditional power dynamics and contrasted with beneficiaries' experiences with other funders, whose practices had made them feel '*pretty childish*' (Richard, person living with dementia 57M).

*We are very independent and we want to run things whilst others are quite happy to be run and get funds that make them do things, we want the funds and we want to decide what to do with the funds. We want to be independent.* (Oliver, person living with dementia 62M)

Evidence collected from the secondary analysis demonstrated that beneficiaries were involved in decision-making across a wide range of Trust-funded project activities – from everyday activities to life-changing decisions (such as anticipatory care and care planning) and policy-making at a national level. There was evidence that the participatory approaches adopted had felt genuine to participants, rather than carefully managed or tokenistic. Flexibility, open communication and the chance to change their minds were granted to beneficiaries in ways that were appreciated as unusual or ground-breaking. Beneficiaries did not feel obliged to embody the message of a specific agenda or a stereotype, but they felt they could express their own views and choices, even if these contradicted current dominant narratives or beliefs.

Whilst such approaches are not exclusive to the Trust, for many beneficiaries this had been their first experience of such participation. As a member of the Life Changes Trust Advisory Group put it, they didn't need to embody a pitiful character in order to be heard.

*I've never been asked my experience. I've never had to sell my soul.* (Life Changes Trust Advisor, Evaluation of the Life Changes Trust Advisory Group, Interim Summary Report – February 2021, p. 9)

Another meaningful example is the TIDE network, a platform that, in the words of its member carers, is ready to share uncomfortable opinions based on real-life experience.

*I don't mean to decry any other organisations...[but] they are very keen to use proper wording like they don't want people to say people with dementia are 'suffering'. They want to say that people 'live well'. Well, from my side of it, some days they do suffer, and some days they don't live well... And on the days that they don't live well, as a carer, I think I'm failing in some way.* (Unpaid carer, TIDE - Together In Dementia Everyday in Scotland: Mixed Methods Evaluation, Interim report, p. 37)

This high degree of autonomy was true both for funded projects, but also for beneficiaries, who experienced a high degree of autonomy, choice, control and freedom in making decisions about how to use funding. Beneficiaries emphasised that they were not seen as mere recipients of the Trust's funds and services, but were often given 'free rein' to run their own, self-governed activities and that this was positive in terms of the 'outputs' produced.

*There was no limitation, we can do what we wanted, really, within that budget...we weren't thinking of the Life Changes Trust, will they be happy with this or not? They left us alone. (May, unpaid carer, 66F)*

*We had the autonomy...we were able to do what we wanted. And I think that was why it was such a successful event, because it was really for carers by carers and we led the whole thing. (Frances, unpaid carer, 73F)*

The Individual Grants and Aspirational Awards schemes are examples of Trust-funded projects which gave recipients of grants full autonomy to spend funds on whatever they felt would be of personal benefit to them. Experiences of being trusted, including with a budget, were important to many of the beneficiaries involved, and particularly to young people involved in the Advisory Group and the Champions Boards. Notably, members of the Advisory Group were supported to come up with, develop and implement their ideas, and the Individual and Aspirational Awards programmes were co-designed in this way. The interviews suggested a sense of happy disbelief that this had been the case.

*(The Trust were) ...just open to supporting what we wanted to do. And again, there's that level of trust because this was a Board who are running a charity putting all this financial trust...like, autonomous trust into a group of young people, you know. (Bradley, young person, M)*

One of the further benefits of the degree of autonomy and empowerment offered to projects was in the diverse range of activities that projects were able to provide to beneficiaries. Alongside more typical projects, such as peer support groups, projects were able to seek funding for a wide array of activities, including some activities that may not have previously been tried with the beneficiary groups. Some of the activities on offer to beneficiaries included physical activities such as dementia-friendly walking, walking football or golf, as well as sporting reminiscence activities arranged around these sports. A number of Trust-funded projects fostered inclusive access to cultural activities such as theatre or ballet. The Creative and Active lives project for young people with care experience used theatre activities to give beneficiaries the opportunity to, for example, build confidence and opportunities to realise career aspirations.

*[The project] got me back into doing theatre...gave me a link into actually coming onboard, being a paid employee and doing community work, which is what I've always wanted to do but never really had the opportunity to do before the group was funded. So it's been a really life-changing experience for me. (Young Person, Citizen's Theatre: Young People with Care Experience Programme: Relationship-Based Practice and Policy, p. 14)*

A number of individuals across the beneficiary groups and across projects became closely involved with the work of the Life Changes Trust itself, for example by speaking at a wide range of Trust events or sessions, giving lectures, educating the local community, schools, police etc., and taking part in meetings with organisations linked to policy and practice.

*I would be invited along to, say like, we did the primary schools, a couple of primary schools just before lockdown. (Richard, person living with dementia, 57M)*

*We have a big huge meeting with all, like, the police, the council, the education side of things. Like the people from those sectors come to Champs and actually talk to us and we give them what we want and they go and try to get it done. (Carly, young person, F)*

Giving beneficiaries a platform to be involved in important decisions, for example, over a substantial grant allocation or application process, resulted in increased leadership skills, which could potentially propel further initiatives and changes. This is a key legacy aim for the Life Changes Trust, but was also recognised by participating beneficiaries as having built up their confidence and sense of future possibilities.

*I definitely would say that being a leader, being allowed to be in charge of stuff like this and being involved in it and the way that I was involved in it has made me much more confident in myself. (Ava, young person, F)*

*I want to be a role model. I don't want to be a millionaire; I don't want to be anything like that. I just want to be a good example... I've got a bit of a sketchy past, so even people with bad backgrounds and criminal backgrounds I just want to be like, look it doesn't matter. You can still be what everyone says you can't be. (Bradley, young person, M)*

*Raise awareness with others of the fact that they don't have to take at face value something that they're told. That they do actually have rights and that they can actually use those rights and that in legislation, that actually lays down that they should be informed and the level of information and the frequency at which they should get information. (Lucy, unpaid carer, 64F)*

Many projects provided examples of young people, unpaid carers and people living with dementia 'climbing the ladder' through experiences of speaking at national or local levels. The confidence developed could also help them with developing skills to move forward in gaining employment and education, as discussed in terms of independence in sub-section 3.3.

*I think it was really a powerful moment for me to think that, do you know, I can literally just step into a room and say okay, we want this and you've got it kind of thing. That was really a big, big step for me and to realise that actually. (Jenna, young person, F)*

The data collected also provided interesting insights into the complexities of engaging in such activism over time, as well as some doubts as to the effectiveness of approaches taken. Such learning is also important in terms of the legacy of the Trust in developing sustainable change. For example, one young person interviewed was concerned that her care experience had come to define her to too great a degree.

*If we're talking about breaking the stigma, and normalising care experience, why do I need to proclaim that? Why do I need to be like, hi I'm Kaelyn and I'm care experienced. If we're normalising it, you wouldn't be like, hi I'm (name) and I'm not care experienced, or hi I'm YP02 and I grew up with a mum and dad. So, if we're trying to normalise it, why does it have to be a thing? (Kaelyn, young person, F)*

Others were concerned that there was not a clear enough strategy driving the projects they were being asked to engage in, or that their voice could be used in ways they did not agree with. It was also clear that sustained activism had a cost. Such work put a lot of responsibility onto individuals living in often difficult situations. Susan found that the scale of change required could be difficult to manage, and at times the sense of responsibility to create such change could feel overwhelming.

*I think all of us thought we really wanted to not be quite so widespread, we'd rather keep it to a general local thing that we could be able to cope with actually because that's one of the other things, you know, when you are a carer you don't have much time to do anything else. (Susan, unpaid carer, 82F)*

Similarly, there was a recognition amongst some of the funded projects, that co-production in its fullest sense was not always the most appropriate vehicle for bringing about change. It was acknowledged that children and young people should not be burdened with 'fixing' how things work. Furthermore, the limits posed by the structural context were also evidenced in the data. For example, there was frustration at the slow pace of change in some contexts, perhaps particularly within Local Authorities and NHS services, as well as mainstream policymaking.

*I would say I've tried for years to influence local strategies and it never happened. It was just a tick box exercise. ...So, I've given up, to be honest, because I've got better things to use my time with, you know. Like this sort of stuff we're doing. Because...it's just almost impossible to influence local strategy. Sad, but I did try. (Joan, unpaid carer, 60F)*

A young person involved in a Champions Board was acutely aware that the people in the room, who attended the meetings, were not necessarily the people that needed to be there if real change was to occur. In her view, there were many social workers and others in positions of authority who avoided any engagement with the group, resisting all efforts at co-produced change.

*...it's the people who are not attending, they're not the ones who are improving, whereas everyone else, they know what it is that needs to be changed. (Alex, young person, F)*

For some, being involved in smaller, local Trust projects had left beneficiaries with a sense of frustration that, from their perspective, the efforts of individuals or local groups were not joined up or coordinated in a way which would result in system level change.

*I just felt there was all these little pieces of work getting done and then it was never going anywhere because it was all so sporadic. (Skye, young person, F)*

Some young people had even come to dismiss the possibility of wider societal change. In their view, they needed to work on their own ability to carry on in spite of these attitudes. They therefore insisted on the importance of self-acceptance rather than more general societal acceptance.

*I don't think anyone feels respected in society, you know... I think once you're accepting in yourself, and who you are as a person, then that's all that matters... I don't really care about...society's view on me. I care about how I view myself, and my friends, and my family, and the people that I hold dearest to me... So whatever pressure society wants to throw at me, or whatever labels...I really don't care, because I know who I am, and I know, ultimately, I'm a good person, and I try my best. (Josh, young person, M)*



For Harry, this stance also reflected his position as:

*an openly gay person, who talks about being care experienced...not letting anyone be prejudiced towards me. (Harry, young person, M)*

Overall, therefore, there was a strong recognition of the difficulties associated with 'driving' change. However, not all the beneficiaries interviewed were as pessimistic as this group.

*...change is beginning to drip-feed into the wider public. It's only made a tiny, tiny difference so far, but I think that that will pick up very quickly. (Kaelyn, young person, F)*

It is clear that an important legacy of the Life Changes Trust will be to take these nuanced messages and experiences on board. Before discussing these issues of transformation and sustainability at greater length, a case study illustrating the impact of the Life Changes Trust's working practices across the five aims is presented.

### 3.7 Kirrie Connections case study



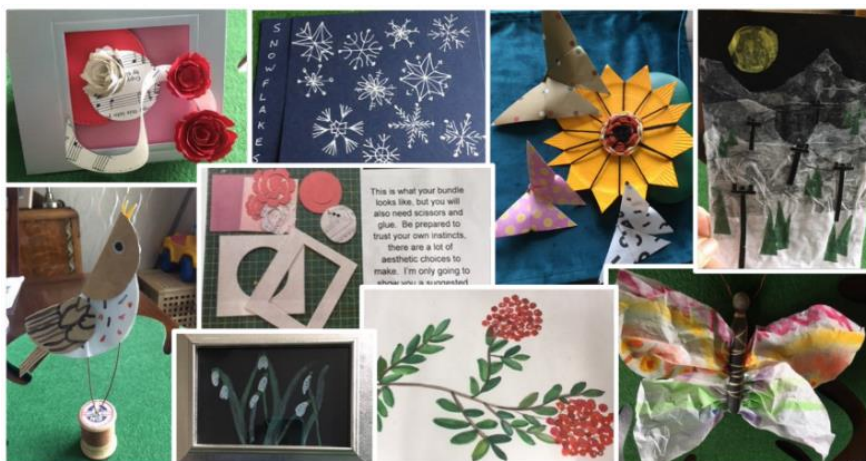
Kirrie Connections is Scotland's first 'Meeting Centre' and the base for Dementia Friendly Projects in Kirriemuir. Activities include Kirrie's Singin', a dementia inclusive choir; Orlang, an artistic project centred on months and seasons; Health Walks with Paths for All; and a Community Garden.

As part of the Life Changes Trust evaluation, several Kirrie Connections members participated in interviews, as well as producing reflective diaries across a six-month period. Joyce supports her husband David who is living with mixed dementia.

They live close to family and friends and have experienced the transition from in-person to online services during the COVID-19 pandemic.



Father and daughter, Ken and Laura, also completed a reflective diary where they shared the activities that Ken has been participating in, including pony therapy, stone painting, pet of the week, and bird watching; as well as documenting the COVID-19 pandemic and the changes in communication options that were offered.



Susan supports her husband, Ron. During the COVID-19 lockdown, they received regular support visits from Kirrie Connections, including hand delivery of newspapers for Ron to read.

Nicola moved back to her parents' place in order to provide support for her mother, Catriona. They are relatively new to Kirrie Connections but their experience shows how having a 'foot in the door' of services can lead to snowballing of support opportunities.

Finally, Elaine is supported to engage in activities at Kirrie Connections by her husband William. Their interview emphasised the range of activities that Elaine enjoys and how the organisation helps William to feel safe and independent.

### ***I live in a place that suits my needs***

Across the interviews and diaries, there was a clear sense that the presence of Kirrie Connections helped people to feel part of their local community and in a place that supports their needs. Susan describes walking into Kirrie Connections unsure of what to expect, but finding that her needs were discussed and support was offered, beginning with a six-week carers' course.

*You feel, definitely feel supported. They care about all the people, you know, and they appear to enjoy contact with them, with all of us actually and that comes across, the fact you're part of a caring community. (Susan)*

Diarists also shared examples of how Kirrie Connections engage with the wider community, particularly in regard to intergenerational support. For example, with the pony therapy:

*It was absolutely amazing...there were people just coming in from the street. (Laura)*

*I think the sessions that we do with the school kids, you know, the nursery kids, bringing them into the hub...'cause you love that, don't you? (Ken)*

During the final reflective diary interview, Ken highlighted a letter that one of the school children had written to him about what she had been doing since they last visited Kirrie Connections.

### ***I am able to be as independent as possible***

The community support has also enabled both people living with dementia and carers to be as independent as possible, notably allowing them to feel able to do activities independently. William shared how Elaine feeling comfortable at the group allowed him to be more independent:

*When Elaine was doing her time at the hub I was out volunteering and supporting other people. Elaine was safe, I was safe to go and do what I wanted to do... It does give us separation; it does give us time for each other by ourselves. It allows me to do things that I want to do... (William)*

Some activities may be harder to do separately, however, as Nicola explains:

*I push her in her wheelchair on the walk. She (Catriona) doesn't actually walk but... Some people leave their relatives there as a, sort of day care type thing. But I think that's...in the earlier stages, whereas with my mother, I would always be at the centre with her. So hopefully I shall be useful while I'm there. (Nicola)*



As a result of the COVID-19 pandemic, the group implemented a new system for video calls that allowed Ken to be involved in meetings without Laura needing to be present to set up and accept the calls. As well as allowing continuation of group support, this development has had a transformative and sustainable impact on Laura's daily life by having the option of online face-to-face contact while being based 30 miles or so away.

*I can also dial in during the day, you know, to speak to Dad face-to-face, which is a good thing. So they've gone beyond, you know, everything to keep in touch. (Laura)*

Laura repeatedly referred to Kirrie Connections as a 'lifeline', with a feeling of belonging in an extended family of support: 'It's been a lifeline for us really, you know, especially through the pandemic'.



### ***I get the help I need when I need it***

During the pandemic, many services and support networks were removed or changed substantially. Joyce emphasised how Kirrie Connections were a consistent, supportive presence who could be contacted whenever was needed.

*I mean they're amazing... They support us and are understanding...they were genuinely interested...I don't feel in the least bit apprehensive about contacting them about anything. (Joyce)*

Similarly, William discussed how other support services are too financially focussed and not person-centred in their ethos.

*There was no other group that offered the services that Kirrie does. (William)*



Susan described how something as 'silly' as a newspaper was identified as help that her husband needed after the local newsagent had limited deliveries during lockdown.

*A stupid silly thing at that stage, the one thing that Ron (husband living with dementia) would read would be a newspaper...so all three of them (Kirrie Connections staff), my husband had a newspaper every single day at lockdown, you know, and they had a newsletter that came out every single week. (Susan)*

### ***I feel safe, listened to, valued and respected***

As with other carers, Joyce often expressed that taking time for herself felt selfish. However, the support from Kirrie Connections had enabled unpaid carers such as Joyce to feel able to take time for her own needs without being guilt-ridden.

*They've introduced so many different things, and when you hear other people you don't feel the guilt. Other people feel the guilt as well, so together you work through it. (Joyce)*

Elaine and William shared a similar feeling about the group and also emphasised how Elaine feels able to share her experiences with others.

*It's an absolutely wonderful situation and a place to go to feel safe and to feel happy. The singing is on a Friday and it's just amazing. It makes me feel so, so happy and it's like, wow, the world opens up for me and I can do what I want to do and be able to have fun and am able to have friends who are all in the same boat- It's amazing.*  
(Elaine)

### ***I am empowered to do things that are important to me***

The peer-to-peer support and encouragement provided by the carers' group allowed Joyce to feel empowered and able to be as independent as possible. The group received funding for a short break, and despite thinking it would never be possible, Joyce was able to go. The experience was transformational and felt sustainable to her.

*I would do it again now. It was just because I was given that opportunity and I think will I? And it was great.* (Joyce)



The group also offers a supportive space that encourages a feeling of inclusion and supports attendees to re-engage with activities they would have done in the past. For instance, Ken helped to put up shelves, as well as teaching people to fly kites, and shared his experience of working on sites that the group have visited.

*They do try to modify things so that everybody can take part, and I think it's a really good thing.* (Laura)

### ***Reflections on Kirrie Connections***

Kirrie Connections has provided a safe, enjoyable physical and virtual space. The group was described as a lifeline both because of the type of support they offer as well as the signposting that they provide. Throughout the diary entries, participants emphasised the importance of its staff and their contributions. There was a strong feeling of being part of an extended family, where help was available not simply because it was 'someone's job to do it' but that staff went above and beyond expectations to ensure that needs were noticed, heard and met. Importantly, Kirrie Connections continued during a time of isolation and limited services, allowing continuity and access to as much support as possible.

## 3.8 Evidence of transformational change

The previous sub-sections and case study have evidenced how the beneficiary groups' experiences align with the five core aims of the Life Changes Trust. Building on discussions started there, the remaining two sub-sections and second case study will explore beneficiaries' views on the role and capacity of Trust-funded projects in achieving transformational change, and the sustainability of activities and learning beyond the lifetime of funding.

The *Life Changes Trust Progress report* (April 2015 -September 2016) highlights how the Trust's vision for transformational change is guided by the five beneficiary priorities, which are based on the issues raised by people from the three beneficiary groups. The strategy also outlines that transformation may manifest itself at individual, group, community and societal levels.

The subsequent Refreshed Business Strategy 2019-2023 further defines transformation as '*a radical change in attitudes, culture and systems, which result in a substantial change for the better lives of beneficiaries*' (Refreshed Business Strategy 2019-2023, p. 33). This definition could be seen as somewhat ambiguous, as the benchmark for 'achieving' transformation remains vague. As Ava put it, it is '*a vague word*' (Ava, young person, F). Such ambiguity affords the projects a flexibility to prioritise the needs of their beneficiaries. However, it also raises the question of who is responsible for, and qualified to judge, the extent to which 'transformation' is accomplished.

Nonetheless, it is worth noting that beneficiaries valued the focus on transformation and considered transformation to be required within their respective sectors, as was discussed in previous sub-sections in relation to stigma. The 2019-2023 strategy further emphasises that transformation is predominantly underpinned by 'hard work' at both policy and project levels, as well as 'occasional eureka moments'. It foregrounds the role of multi-agency work, collaboration and strong partnership in this work.

When asked directly about 'transformation', participants drew attention to the subjective nature of transformation, and highlighted how it could be both a personal as well as an emotional process. They also pointed out that transformation could be '*slow*' (Laura, unpaid carer, 51F) and unpredictable. Other interviewees equated transformation with societal change, a change in attitudes and practice, emphasizing the importance of starting conversations, '*challenging ideas*' (Shaun, young person, M), and changing of '*old minds*' (Emily, young person, F).



This section highlights the importance of the Trust's focus on transformation and how transformation is related to socio-material changes for both individuals and projects.

The following sub-section relates transformation to relationships and the new skills people acquired, as well as the choices that empowered them throughout their involvement with Trust-funded projects.

Thereafter, it considers transformation in terms of the changes in wider societal narratives relating to being 'care experienced' and dementia and co-production. Co-production and participation have become increasingly dominant in practice and organisational discourses in Scotland since 2013 and the Life Changes Trust has played a key role in this.

*(The Life Changes Trust's work) is a really good example of what effective co-productive participation work looks like...that's put on a pedestal a little bit, and rightly so...of how to do it well. So I think it does provide that role model effect.*  
(Kaelyn, young person, F)

## Personal transformation

Participation in Life Changes Trust's projects played a significant role in the accounts of beneficiaries' personal transformation and sense of empowerment. Across all three beneficiary groups, people described how their involvement with different Trust projects had influenced how they related to their sense of self, to their care experience or to their dementia status.

Poppy, for example, had learned of her care experience through workers at a Trust-funded project.

*And that was a huge breakthrough for me. I didn't know that I was care experienced before I met a (worker). (...) It was weird. I didn't really think it settled in for the first few weeks until I actually looked at everything and well this actually is part of my identity. When go onto a Champs, like when I go onto Champs, you're around people that have got the same things as you.* (Poppy, young person, F)

Meanwhile, Finlay had learned to reframe past experiences and encounters.

*It's just feeling more comfortable with like actually this happened, this happened I dealt with it. There has always been challenges, I still face challenges just now as...I'm only 21, but I still face challenges today, if you know what I mean, so yeah, it can be a kryptonite, but it can also...if you make it your superpower, then it'll make it all better for you. It won't so much make it better for you, it'll make it sort of easier for you to accept, if that makes sense. So yeah. (Finlay, young person, M)*

*It has given me quite a lot of optimism about the future. Excitement, it has given... I am excited to see the people who work with so much passion, that is what I like. I like seeing adults who care. (Morgan, young person, F)*

Similarly, some people with dementia who took part in interviews discussed how their involvement with a Trust-funded project had shaped their relationship with their diagnosis.

*The support I get from the group, if we didn't have that, you'd probably struggle to live, to be honest, like. I think, yeah, I mean, as I say, when I was first diagnosed, there was absolutely nothing. And I couldn't see any future, I just thought, there's nothing. I mean, I've lost my job, I can't drive anymore, you know, what can I do, there's absolutely nothing. But I think, through STAND. (...) One of the things that you lose when you've been diagnosed with dementia, you do lose a sense of purpose, you know, why am I here, what's the point. But being involved with the STAND group and with DEEP, and Life Changes Trust has been amazing, it's given me a new lease of life, so to speak. (Richard, person living with dementia, 57M)*

*... 'cause I'm not going to be sitting greeting all day. I'm going to...got to get on with it and have a fight. If you...you've got to have hope, haven't you? (Maggie, person living with dementia, 54F)*

Beneficiaries from all three groups reported personal transformations, including in relation to how they relate to their sense of self and their perspective on the future, therefore. These transformations were often reported in very positive terms, including *Richard's 'new lease of life'* and Morgan and Maggie's hope for the future. At the same time, as these excerpts also illustrate, these transformational experiences were often bittersweet and non-linear, and took time.

It was also clear how such individual processes of transformation were linked to group processes. While some beneficiaries emphasized the acceptance of the group as instrumental to their personal transformation, others highlighted how peers normalized their experiences and aspects of their identity.

*The label kinda loses its meaning cause we're all the same here. (Blair, young person, F)*

The centrality of relationships was also highlighted by Lucy, who stated that without their worker, they:

*...would have been completely lost... (Lucy, unpaid carer, 64F)*

While some credited the consistency of various Trust-funded groups that enabled them to create and maintain a 'routine', others attributed their '*new lease of life*' (Richard, person living with dementia, 57M, and Eilidh, young person, F) to the opportunities they encountered within the Life Changes Trust project, including many holding strong emotional significance. This is evident in the Playlists for Life report.

*Our members are thrilled with their playlists. This not only benefits the person living with dementia but also their caregiver as the music takes them back to happy memories whilst enhancing quality of life and wellbeing. One of our members borrowed the playlist from her husband and played it whilst ironing... The playlist made whilst someone is alive can be a treasured memory for family to cherish, of their musical story when they die. (Partner organisation representative, Playlist for Life - Community Help Point Network and Music Labs: Evaluation Report, p. 23)*

The extract above exemplifies the transformative effect of the joy and nostalgia associated with such activities. Sharing the music significantly improved carers' wellbeing, generating excitement and '*buzz*' (Douglas, unpaid carer, 58M).

Beneficiaries' sense of transformation was also enhanced by the different skills they had acquired. For instance, Frances and Joan discussed 'public speaking' skills that they developed through involvement with the Life Changes Trust projects (Conference for Carers run by Carers, focus group). The sense of accomplishment afforded by such skills and new understandings is demonstrated by Emily.

*My skills on that have become so much better. I didn't really know what trauma-informed was before (...) I've always been one of those open-minded people but it's made me so much more open-minded. I think (name removed) helped with that as well, she was a big impact in my life I would say. (Emily, young person, F)*

Recognising that they could contribute to the lives of others proved powerful in terms of transforming beneficiaries' sense of self. This is illustrated in the exchange between Frances and May.

Frances: *We all had a different story to tell and...but each one...it was quite difficult to get, you know, they were hearing these things but they were actually thinking, gosh, that's me. I think that was the biggest impact, wasn't it? I think we thought that...*

May: *Yes, because a lady came up to me afterwards and she said, you know, after listening to you talking, she said, I need to go home and have a word, not with my partner but with my father.* (Conference for Carers run by Carers, focus group)

Young people and their mentors also considered that the MCR Pathways project had given them the opportunity to improve educational and career prospects, as well as their confidence.

*I want to stay on to school so I can get all my main Highers for the rest o' my subjects, so I can go on to uni.* (Young person, MCR Pathways Social Bridging Finance Initiative for Educational Outcomes End of Project Report, p. 42)

*Yes, she was going to leave in fourth year and she stayed on to sixth year.*

(Mentor, MCR Pathways Social Bridging Finance Initiative for Educational Outcomes End of Project Report, p. 42)

Such mentoring projects reported greater confidence among both mentors and mentees. MCR Pathways supported skills development for both mentors and mentees; enhancing the overall skill and knowledge of a workforce as well as the beneficiaries. A similar impact was also found in projects such as Side by Side, Rights and Equalities, Community and Dementia, the peer support projects and peer-to-peer resources, where beneficiaries and staff described the huge increase in their knowledge as a result of their engagement in projects.

*And I want to show that, you know, people with dementia can actually do actual research and don't need the researcher, sorry that's you out of a job!* (Oliver, person living with dementia, 62M)

## Material transformation

Personal transformation was also related to socio-material changes. For many beneficiaries, these material changes resulted from an individual award. Indeed, secondary data analysis equally highlighted that all beneficiary groups valued the immediate and lasting benefits that the individual awards provided. Whether people used the money to purchase material items, such as technology, equipment, or respite services, there was evidence that the benefits were experienced for lengthy periods beyond the award itself.

As previously mentioned, in many cases, fitness or activity-based equipment reduced feelings of isolation and loneliness during the pandemic, providing routine, a healthy lifestyle, and an overall improvement in quality of life. Evaluation reports equally discussed how the funding used by beneficiaries for services such as housework and gardening enabled people to connect with, and feel more included within, their local community, and to become aware of other community-based services which may have been able to provide longer-term support.

*Those two things (a tablet and a trip) were the best things happened to me, I can say, for a long, long time. The (trip) is not something I'm going to forget. It's not a wee fly-past thing, it's a lasting thing for me. (Person living with dementia, Individual Awards Scheme Final Report, p. 6)*

*It's made a big difference to us because now we're spending more time together, we can go out now. (...) We wouldn't be able to do that if I had to do the cleaning or the gardening. (Unpaid carer, Individual Awards Scheme Final Report, p. 8)*

*There are no bursaries out there that would have enabled me to do this elsewhere and there's no kind of ability or the funding to come through University or anything like that so, yeah, I wouldn't have been able to do the course...there's no doubt about that. (Young person, My Choice, My Future Individual Grant Awards, Personal Stories Evaluation, p. 17)*

There was evidence that beneficiaries experienced the receipt of this individual funding as empowering. The design of the individual awards scheme in a way which enabled beneficiaries to exercise choices over how money was spent was seen as critical here, since they were able to make their own respective decisions about which services or items best met their needs (as discussed previously in sub-section 3.4).

Certainly, being offered an award was seen as life changing for a number of beneficiaries of the My Choice, My Future Award. Interestingly, it seemed for many beneficiaries that it was the act of being awarded, being recognised and thought about, as much as the money itself, which had had an impact. Similarly, where individual awards were sought to aid skills development, it appeared that this provided a sense of external validation and recognition of the applicant's potential to succeed.

*It gave me a wee bit of a glimmer of hope that actually there was potential for me to get out of the job that I was in, because I felt stuck... But in terms of that psychological benefit, I think initially from when I was awarded or got the acknowledgement of being successful, it made a real benefit on my mood. (Young person, My Choice, My Future Individual Grant Awards, Personal Stories Evaluation, p. 11)*

As mentioned earlier, it is also important to acknowledge the complexity of capturing the 'transformational' in temporal terms. For some beneficiaries, transformational change was seen as an ongoing, long-term impact, stretching beyond the life of the funded project into the future.

*I think sometimes the ripple effect ends up being more important than the project, because it's all the spinoff benefits that you never anticipated. So the project is this, but the impact of the project is that.* (Lucy, unpaid carer, 64F)

Furthermore, secondary analysis highlighted how changes across individual, community and societal levels are often interconnected. Thus, small-scale or personal changes, as considered in this sub-section, may be dependent on structural and cultural shifts. The Rights Made Real in Care Homes programme evaluation report, for example, reported on how small changes in a care home, such as the opening of window coverings in the common areas, required a cultural shift within the organisation, away from more risk-averse practice. The opening of the blinds had immediate effects on residents' wellbeing, allowing them to enjoy the beauty of the outdoor space.

*About two weeks ago, she came up to me and said, "do you know, the blinds were opened and I got to see the sunset. It was beautiful and I wished you were there, and I could have taken a picture for you".* (Care home business support manager, Recognising, respecting and responding: promoting human rights for residents of care homes in Scotland, p. 34)

## Changing the narrative

Beneficiaries regarded awareness-raising and 'changing the narrative' as central to broader processes of transformation. All beneficiary groups described playing an active role in 'developing resources', 'educating others' and 'confronting expectations'. Exemplars of educational resources developed by beneficiaries are the Peer-to-Peer Resources for people living with dementia and unpaid carers. Here, 37 written and visual resources were created by beneficiaries with the aim of sharing the lived experience of people affected by dementia and educating their peers on topics like sensory challenges, travel safety, work and dementia, activism, and many more.

However, beneficiaries' perceptions of whether such a change of narrative was achieved by the Life Changes Trust's projects varied. While stigma and discrimination were viewed as remaining generally prevalent in what were seen as the general narratives around being care experienced or having a diagnosis of dementia, some beneficiaries reported incremental changes, and the lessening of taboos.



*Yes, I think, (local area) is by far more a dementia friendly place than what it was probably a couple of years ago, yeah. And people have heard of (Life Changes Trust Project), people have heard of dementia, people aren't scared to talk about dementia anymore, like, whereas before, it was a no-no. (Richard, person living with dementia, 57M)*

Others similarly highlighted the greater visibility of people with dementia and young people with care experience and how their involvement helped to challenge stereotypes.

*He's not dribbling, he's not lying to the side, you know... [it makes] a personal impact on people's perception of dementia. (Eliza, unpaid carer, 60sF)*

*This project had a lot of media attention and I feel like it has changed people's views on what it looks like to be in care. Being in care we have always been stereotyped as the bad kids, as the underachievers that would never amount to anything. This project has put the spotlight on these issues and showcased a group of young talented individuals who all have the shared experience of being in care. We have taught society that we will not be defined by our circumstance. We have the right to succeed just like any other person. (...) at least we have sparked the conversation. (Robyn, young person, F)*

Progress was seen as slow and as requiring continuous work to combat the persistent stigma, also reported in sub-section 3.2.

*I think things are better and I think things are getting better. There's still very much a separation between... I think the gap between, like, general public and care experienced is getting less, but that's still there. Otherwise, we wouldn't need these discussions. (Bradley young person, M)*

*So I think that, although technically, attitudes might not have changed just yet, the steps have definitely been taken to get to that point, like the groundwork. (...) Very slowly, very, very slowly. And I think, I've noticed that there's a difference in the priority given to changing people's opinions. (...) I think that that impact, and that change is beginning to drip-feed into the wider public. (Laura, unpaid carer, 51F)*

Overall, throughout this section, personal and material transformation are evidenced as something that has been encouraged and facilitated by the Life Changes Trust. Support to learn new skills, imagine different futures, and work towards a cultural shift in attitudes was clearly important to all involved.

Beneficiaries tended to focus more on the changes they have experienced in themselves and amongst their peers. They acknowledged that while the notion of transformation in relation to wider perceptions of and responses to the beneficiary groups at a cultural and policy level is important, some identified the pace of such meaningful change as slow.

Literature which explores notions of participation and empowerment, equally recognises transformation to be elusive, and as associated with a wide range of differing expectations, ideologies and projects (Hickey and Martin, 2002<sup>7</sup>). Ahmed (2004<sup>8</sup>), who explores the politics of the word transformation in her seminal work 'the politics of emotion', describes it as dynamic and a process that requires people to emotionally invest in the social norms which they ultimately aim to change. Similar to the beneficiaries interviewed here, she maintains that while the transformation of society can often 'feel impossible' (2004: 62), the hope of it can often have far-reaching effects, as it can provide a catalyst for solidarity and action.

### 3.9 Sustainability of impact

*I think initially for me, as the week has went on, I think we met just about every month and it began to dawn on me that we would all have to stand up and do presentations, like speeches ourselves, because the personal stories were probably more colourful than the factual stuff we were presenting. I think at that point TIDE offered to give us presentation skills training, which was really useful, for me, certainly, because I had done technical stuff before but not emotional... I wasn't sure if I'd be able to stand up and speak. And I don't think I would have without that training. I had two days' training, the first day was presentation skills and then the second day we did dry runs. So, we all stood up and did our bit and got feedback. It was pretty powerful. (Joan, unpaid carer, 60F)*

In the previous sub-section, beneficiaries reported that their involvement with the Life Changes Trust had had a significant impact on them as individuals and regarded the change in them as long lasting. However, for many, individual change was not enough, and they felt a sense of individual responsibility to create and sustain change at a wider level. Changes in policy, practice and broader narratives surrounding dementia and being care experienced were identified as key.

Many beneficiaries regarded the power of telling their own stories as their key tool in creating and sustaining transformational change.

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<sup>7</sup> Hickey and Martin, (2002) Relocating participation within a radical politics of development: critical modernism and citizenship [in] Hickey, Mohan *Participation from Tyranny to Transformation*. Zed Books, London.

<sup>8</sup> Ahmed, S. (2004). *The cultural politics of emotion*. Edinburgh: Edinburgh University Press.

Many of the beneficiaries who took part in focus groups and interviews had shared their experiences with others in the hope that this would lead to changes in attitudes, practices and policy. For example, a beneficiary involved with STAND highlighted the value of holding intergenerational discussions about dementia. It seemed that both the children and the beneficiary gained a lot from the educational encounter recounted here.

*Amazing. Children have been, yeah, it's had a huge impact. We did (primary school), and at the end of the session, a little girl came up to us and said, excuse me, she said, that was, my granny had dementia and all sorts, and she could actually relate to it, so it was fine. And to be honest, some of them must have been looking up what dementia was before we'd arrived, because we'd ask them questions, and they'd give all the answers, which was brilliant. Yeah, this little girl came up and said, that was absolutely amazing, my granny's got dementia, blah, blah, blah, and she said, can I sing you a song. And I thought, yeah, on you go, like. So she sat down in the middle of the class, got a little ukulele out, and started singing a Lewis Capaldi song. And within five minutes, the whole class were singing the song. And you're sitting there thinking, wow, you know, what an amazing feeling. (Richard, person living with dementia, 57M)*

However, beneficiaries also expressed concerns relating to the sustainability of this impact, especially in relation to broader attitudinal and cultural changes. For some beneficiaries there was frustration that the responsibility for changing attitudes appeared to rest with them. Perhaps more importantly, they argued that they could not personally sustain the repeated sharing of their stories and therefore of the negative impact this had on them.

As such, it is important to analyse the views of those who accepted the enormity of the challenge of creating sustainable change and suggested ways for this to take place. For them, the focus needed to feel more localised and that the responsibility for making and maintaining cultural and political change needed to rest elsewhere. For example, Skye shared how their Champions Board's emphasis on stigma has been adopted by the local Corporate Parenting Board. For her, this had the possibility of reaching a larger audience providing a platform for further changing attitudes and, most importantly, placed the burden of sustainable change elsewhere.

*(The stigma is) something that the corporate parenting board has taken into consideration this year, and they've written it in the plan that they're going to try and tackle the stigma around care experience in (location removed) as much as they can. (Skye, young person, F)*

In the quote below, Lucy highlights how her actions prompted a change in the assessment processes relating to people with dementia in her local area. She was supported to challenge the existing systems by staff from the Trust-funded project she was involved in. However, she further argues that such changes are meaningless unless also enacted and sustained by the professionals involved:

*I maybe said to you that having forced a meeting with the council and the hospital in January, when the mental health officer from the council was there, she was present at the meeting, and she asked me what I wanted as an outcome. And I wanted as an outcome that nobody else went through this. And I wanted as an outcome that when people were told that an assessment would be made, that a full assessment would be made and people were informed in advance that that assessment...that was going to be an assessment meeting with the carer and the individual and the social worker. And I got an email back...you know, I don't...I'm a cynic, so I don't necessarily have faith, but the email coming back came...which came back to me following the meeting was that they had taken steps to change the way that they had done things and to ensure that going forward people would be involved. But I'm...I am also very aware of how meaningless words on paper are. (Lucy, unpaid carer, 64F)*

The difficulties in achieving sustainable change in culture, attitudes and practice were therefore identified by many beneficiaries who were well aware that sustainable change can only occur if systems, organisations and people in power were held to account. However, being part of a Trust-funded project had given them the platform and opportunity to take on this challenge.

*I think it has made me a bit more passionate for changes and I suppose a lot more angry at how naive some people can be and how much some people can kind of wear their blinkers, if that makes sense, cause I think sometimes people just, you know, they don't really see the difficulties... And sometimes you can see some people around the table where you can tell they are only there because they've been told that they have to be there. They are not there to be genuinely, like, do something positive. Ehm. I think it has been a mixed bag of emotions. I think it also has given me the confidence to realise you know people can actually kinda stand up and promote change and sometimes just sometimes it does actually happen. Or you know it begins to happen at least. So that's quite exciting to see some things unfold. (Jenna, young person, F)*

Throughout the majority of the interviews and focus groups there was a note of caution regarding the sustainability of change in terms of both long-term funding of services and changes to policy, practice and wider narratives. For some, this was closely tied to the end of the Life Changes Trust.

*I think it's hard for some of the people who've been around longer, some of the alumni, not all of them, but other people I don't think understand the train crash that's about to happen... There'll be no funding, how do we fund what we do? (Oliver, person living with dementia, 62M)*

The uncertainty surrounding the longevity of what had been for many beneficiaries a lifeline and a significant network of support was a cause of anxiety for some participants. They felt that the focus of the projects they were involved in had shifted from providing activities and resources to finding future funding. In turn, they felt that this had reduced the energy and time given to the promotion of change to policies, practices and attitudes and to the efforts to sustain any changes which had been made.

*But I think we're quite lucky and we always manage to do what we have to do in a comfortable way. But I think there's always that worry that we're going to lose that funding and the Champions Boards just going to like...that'll be it. (Emily, young person, F)*

## 3.10 Champions Board case study

Champions Boards are forums created to provide young people with care experience with a space where they can meet, and work with key decision-makers involved in the design and delivery of local care services. The Trust has funded 21 Champions Boards across Scotland and there are also a number of areas with Boards which do not receive Trust funds. They are based primarily within Local Authorities and provide a platform for young people to have a deeper engagement in influencing local policy and practice.

Young people spoke about their experiences of Champions Boards, and the way these spaces shaped both their personal lives, as well as their broader communities. We talked to some of them, such as Alex, Gemma, Jenna, Niamh, Naomi and Skye, individually, and others like Blair, Brodie, Finlay and Tyler we met during three focus group discussions. With ages ranging between 14 and 26, these young people were often at different stages of their lives, some with their own children, and different levels of involvement within the Boards. Some of them had moved from being a young Champ to a staff position, using their experiences to guide other young people. In this case study, we draw together findings to explore notions of transformation and sustainability in change for the young people with care experience.

### **‘I feel like Champs is one big family.’ (Brodie): The transformative effect of companionship and support**

A sense of Champs Boards being a *‘chaotic family’* (Blair) was repeatedly voiced by young people. Skye recalls how, before the pandemic, they would meet and play games, do *‘fun stuff’* and share food – sometimes bringing ingredients and cooking together. She told us how such social activities would always accompany discussions on housing, education and employment.



As lockdown initially put a stop to this, they *‘gave themselves a week to try and figure [things] out’* before *‘moving everything onto Zoom’*. Ever adapting, they replaced their usual *‘big Christmas meal together’* with delivering Christmas dinners to all the Champs and having Christmas lunch on Zoom where they sang Christmas songs.



Niamh recently had a baby and recalls how a friend from Champions Board provided her with much needed housing help, and how that inspired her to later advocate for placements for young mothers and babies herself. When asked what he thought of the term 'transformation', Brodie responded that he felt that it described his experience, as the Champions Board is a *'group of people that actually understand you (...) and actually care'*.

The empathy afforded within the context of the Champions Board was often described as a powerful factor arming young people with a confidence for many challenging life situations.

*I always thought, oh, I couldn't do that, I'm not clever enough. And then, like, got this job [within the Champions Board] and, like, it just helped me so much. (Niamh)*

A particular trip that the young people with care experience enjoyed was when their Champions Board visited the Colomba 1400 centre on the Isle of Skye for five days. During this trip they focussed on cementing the values of the Champions Board and participated in teamwork activities.



*When I first came here I was shy, and I went to Colomba 1400 and my confidence built up and I'm more confident now than I am used to be. (Naomi)*

### ***'It doesn't have to be like this' (Film: Stigma): counteracting stigma and changing perceptions***

Many young people who attended the Champions Board told us how they were working towards changing and transforming the way in which people with care experiences are perceived.

When the members of the Proud2Care Inverclyde Champions Board filmed 'Stigma', they focussed on portraying how the stigma associated with being in care becomes a burden, weighing young people down with harmful stereotypes. Several young people voiced the same worry: Brodie mentioned how young care experienced people are seen '*as criminals*', with Blair noticing the assumption that it is always the child that did something '*wrong*', and never the parent.



Tyler was adamant they had to '*do something to make people aware how stigma can affect us*' and disperse inaccurate presumptions. 'Stigma' was one of the initiatives.

*The feedback from the videos was encouraging and reinforced the idea that the changing the minds of people was possible. (Finlay)*



Skye told us that they also gave corporate parenting training to housing officers, teachers, teaching assistants and head teachers in their community to explain what corporate parenting is, to '*give them the statistics*', and to '*make sure they know (...) that care kids aren't bad.*' Jenna shared the same views, saying it was important to educate people that '*being care experienced isn't just because you're a rotten apple*'.

As she remarked, the most important thing for her was '*finding out where I belong and finding my place within that new society*'. Indeed, several Champions Board members we talked to felt hopeful that the work they invested in and the resources created could transform how young people with care experience are perceived in Scotland.

## Empowered to inspire sustainable change

When asked what image would best describe the Champions Board, Alex listed *'fireworks, lots of colours and stars in the sky, us reaching our dreams, ambitions and what we want to achieve'*. Being actively involved with the key decision-makers and service leads equips young people with necessary skills and opportunities to practice them in real life settings, for example, like Jenna, helping design a housing booklet, organise cooking sessions, implementing an app for care experienced people, and coordinating the donation of forty Christmas trees.



*It's good to be part of like making change and like influencing like local government to make changes to...for care experienced young people and ensuring that our voices are always at the centre. (Gemma)*

One of Jenna's biggest success stories was getting the local council to donate fifty phones to those young people who needed them. As she mentioned, without the phones the young people found it difficult to keep appointments and stay connected with their families and other Champs. She was very uplifted by the profound change this made to fifty young people, and the way her determination made it possible. While the work of the Champs resulted in many tangible and material outcomes for young people, it also affirmed to some of the attendees of the Champions Board that young people could affect substantial and transformational change.

*It's given me lots of confidence and (...) if it wasn't for Champs I don't think I would've had the confidence to, like, pass my driving test and, like, my house fixed and, like, I would not be where I am today. (Niamh)*

Given this, the Champions Board in Inverclyde further created a promotional video called 'Alice in Careland' in order to promote the Champions Board and:

*to let others know that there are others out there and you can go and talk to and there is always people in the same situation and or is similar to you. (Brodie)*



*I realised how powerful, I suppose, that young people could actually be in these meetings and the suggestions that they're putting forward.*  
(Jenna)

### **Reflections on being involved in Champions Boards**

As young people reflected on their participation in the Champions Board, they acknowledged the opportunities it gave them to influence policy and practice that, in turn, affected the lives of young people with care experience.



*'A shooting star' as it 'represents change (...) like the shooting star is pinging across the sky, it's aiming towards (...) change that we want made (...) towards a fairer place to grow up in Scotland'.* (Gemma)

Many young people felt these personal experiences of empowerment had fuelled a more sustainable change for their own future and that of other young people with care experience.

With strong bonds built on shared experience, the Champions Board provided them with a sense of camaraderie, belonging and support which for some was particularly important during the COVID-19 pandemic. As young people grow and mature, the Champions Boards also change but questions remain about their future.

*It's getting better all the time, and it's just growing and getting stronger (...) transforming into a bigger platform...if I had a magic wand I would wave it and (...) sustain the Champions Board with funding to continue for as long as it needs.* (Skye)

## 3.11 Conclusions and lessons drawn

This section has highlighted that, for most beneficiaries, the Life Changes Trust has been successful in funding services which address its five overarching aims. It has also illustrated the **overlap and interconnectedness of each of the five aims** from the perspective of beneficiaries and has presented the many positive experiences they have had of both the Life Changes Trust's work and that of the projects and programmes it has funded.

Across the three beneficiary groups there were differences in relation to how the Life Changes Trust as a funder featured in these experiences. In some cases, the Trust worked directly with the individual/groups, whereas for others, the Trust was perhaps one of several funders contributing to the service they were engaged with. For the remaining participants, the Life Changes Trust were viewed as a step removed from the group or project itself, leading beneficiaries to a sense of not minding who the funder was as long as funding for their project was available and continued.

It may be argued that given that data collection occurred during COVID-19 restrictions, some of the positive experiences and the reliance on the Life Changes Trust projects observed in the data resulted from the extreme cuts in delivery of other services over this period. At the same time, the reported continued presence of the Trust throughout the pandemic and its ability to adapt quickly to provide virtual spaces of support for beneficiaries has had a clear, positive impact, with some examples of increased participation levels as physical travel to activities and groups was no longer a factor. This could point to the need for a certain re-definition and expansion of the concept of 'community' post-pandemic, with new shared spaces created online.

Data highlighted the **diverse demographic characteristics and experiences** across and between beneficiary groups. Despite the concerns raised by the Trust's staff as outlined in Section two relating to the links between young people with care experience, people living with dementia and unpaid carers, this section has highlighted that **many experiences (at an individual and structural level) and feelings were shared by people in across all three groups**.

Importantly, the data highlight that the five aims originally identified by the Life Changes Trust and which underpin their approach to funding, resonated with members of all three beneficiary groups. These findings raise a broader issue emerging as a gap in the data relating to the limited opportunities created by the Life Changes Trust, perhaps partly as a result of the pandemic, to bring together the three groups and/or projects.



Whilst some reference was made to links between people living with dementia and the carer group, there appeared to be no connections made by the Trust between these two beneficiary groups and young people with care experience.

All groups talked about the value of home and the need to belong. The emphasis they placed on having access to spaces where they could feel accepted and valued was striking. Evidence from across the datasets illustrated how **Trust-funded projects provided such spaces**. Furthermore, evidence pointed to the role of the Trust in helping to make places homely and the ways in which this significantly contributed to the sense of having a place that 'suits me and my needs'.

However, it appeared challenging for Trust-funded projects to fully counter the **wider structural constraints** affecting the beneficiary groups. This was evident in accounts of the lack of housing for young people and the fears of losing one's home provoked by the paying for social care. Relevant financial implications relating to home and place are harder to discuss across groups because we know that there is likely to be a class bias in who comes forward to participate in research/evaluation. However, it was clear that economic and educational barriers to accessing the necessary services and resources also remain.

The notion of independence was central to many of the services which the Life Changes Trust funded. As a term, its meaning was explored in many of the evaluation reports considered in the secondary analysis as well as in interviews and focus groups. The Trust's aim of supporting people to 'be as independent as possible' was the only one of the five aims where there appeared to be marked **differences between the three beneficiary groups** in relation to what this term meant to them. The data highlighted that Trust-funded projects recognised these differences.

To ensure that people got 'the help they need when they need it', **'need' had to be understood as dynamic and ever-changing**. This was challenging for some Trust-funded projects and meant that for some beneficiaries their involvement with services was time limited. Beneficiaries talked positively about projects and programmes which changed with them, or which offered flexibility. Interestingly, COVID-19 restrictions forced a number of projects to review the delivery of service. This appears to have worked well for many of the people we spoke to. At the same time, it was the **relationships which had been established through involvement with services that were often most critical**, and it is not surprising that beneficiaries feared that these relationships would be severed by the end of funding.

All beneficiaries were aware of the way they were **labelled by others** and how these labels had impacted on their lives or lives of those around them. For some of the younger people with care experience, there was a sense of moving beyond such labels, and being seen as an adult independent of care-experience status.



Trust-funded groups created spaces where young peoples' specific needs were recognised, and support was given in a non-identity defining and non-stigmatising way.

For unpaid carers and people living with dementia, there was often a need to 'lean in' to the label and try to reframe what it meant to experience dementia. Their focus was often to enable others to feel more hopeful following diagnosis.

A push for change in attitudes, policy and practice was evident across all datasets. It was interesting that in relation to the final aim of empowerment and 'being inspired', the majority of beneficiaries related this to taking on the **responsibility for creating change**. For some beneficiaries this was experienced as energising and empowering. Others reported feelings of ambivalence; they wanted to push for change, but at the same time, felt that the responsibility should rest with others. There were also mixed experiences among beneficiaries of **sharing their stories** as a catalyst for change.

Sharing stories amongst peers or to wider audiences was a common experience of both those attending Trust-funded projects and those with direct involvement with the Life Changes Trust itself. Some beneficiaries described feeling unburdened and more powerful for having done so; others felt depleted and more defined by their beneficiary status. The way people have shared their story may have changed over time with the Trust. In the early years, the feeling of being unheard and cautious of trusting people to share their story effectively may have been greater, with a need to 'cut through' and be seen while now people seek to be seen as a whole person.

Our evaluation provides excellent examples of empowerment and how beneficiaries have been able to use their voice to push for change, to influence others' thinking and to challenge stigma. Yet, with this comes a label and identity that many may choose not to take on, or in some cases actively avoid.

The approach taken by the Life Changes Trust to how services should be run placed a significant emphasis on the **involvement of beneficiaries in the planning and delivery of services** as well as requiring services to operate from a relational perspective. This has clearly been successful in generating places where beneficiaries feel safe, listened to and respected. Beneficiaries offered powerful accounts of being supported by services and perhaps most significantly by others who were attending the service. It seemed crucial to many that they did not only have this experience but should be able to offer it to others.

This section has shown that, from the perspective of beneficiaries, the Life Changes Trust has been effective in working with both beneficiaries and providers to create services which offer helpful, relevant support for people from all three beneficiary groups. The data does, however, raise some interesting considerations to take forward to better support sustainable change.

The needs of beneficiaries are not only diverse but change over time. As such, services need to be supported to be dynamic and responsive in how they deliver help and support.
Beneficiaries value the security that long-term funding provides. Short-term funding creates anxiety and takes time away from current service provision and activism. Alternatively, specific staff posts need to be funded that have a fundraising role and to be in place for the duration of the funded period to free project staff and beneficiaries to focus on the projects themselves.
Individual awards have had a huge impact and were referred to by a significant number of beneficiaries. Without exception, beneficiaries spoke positively about their experience of applying for and receiving awards, as well as of the transformational impact they felt the awards had had on their lives. For many, it was not just the material change that the awards made to their lives but rather the experience of having their needs met with such openness, flexibility and care. The Life Changes Trust should prioritise the learning gained from introducing the awards and seek to embed them within a continuing organisation.
Being seen not only as a recipient but as an expert and a contributor within a project is crucial. Learning gained by the Life Changes Trust in facilitating co-production should be promoted and shared with other organisations and funders.
Many lessons can be learned from the Trust's practices in terms of making people feel heard, valued and respected. We notice this attention may be particularly meaningful and empowering for (older) women who are unpaid carers, young people and people from minority ethnic groups. These are the groups that already face various disadvantages and may lack social and legal influence. However, there is no clear blueprint for how to achieve this across settings. It seems that a nuanced, comprehensive approach to seeing people as complex individuals with many different identities and needs is needed. Funders need to recognise the importance of these approaches, but the people working directly with beneficiaries need to embody them.

The figure below illustrates the next step in constructing a logic model of the Life Changes Trust by adding the process and short-term outcomes evidenced within this section of the report. Longer-term outcomes are considered following the next section where the focus is on wider impact in the policy and practice landscape in Scotland.

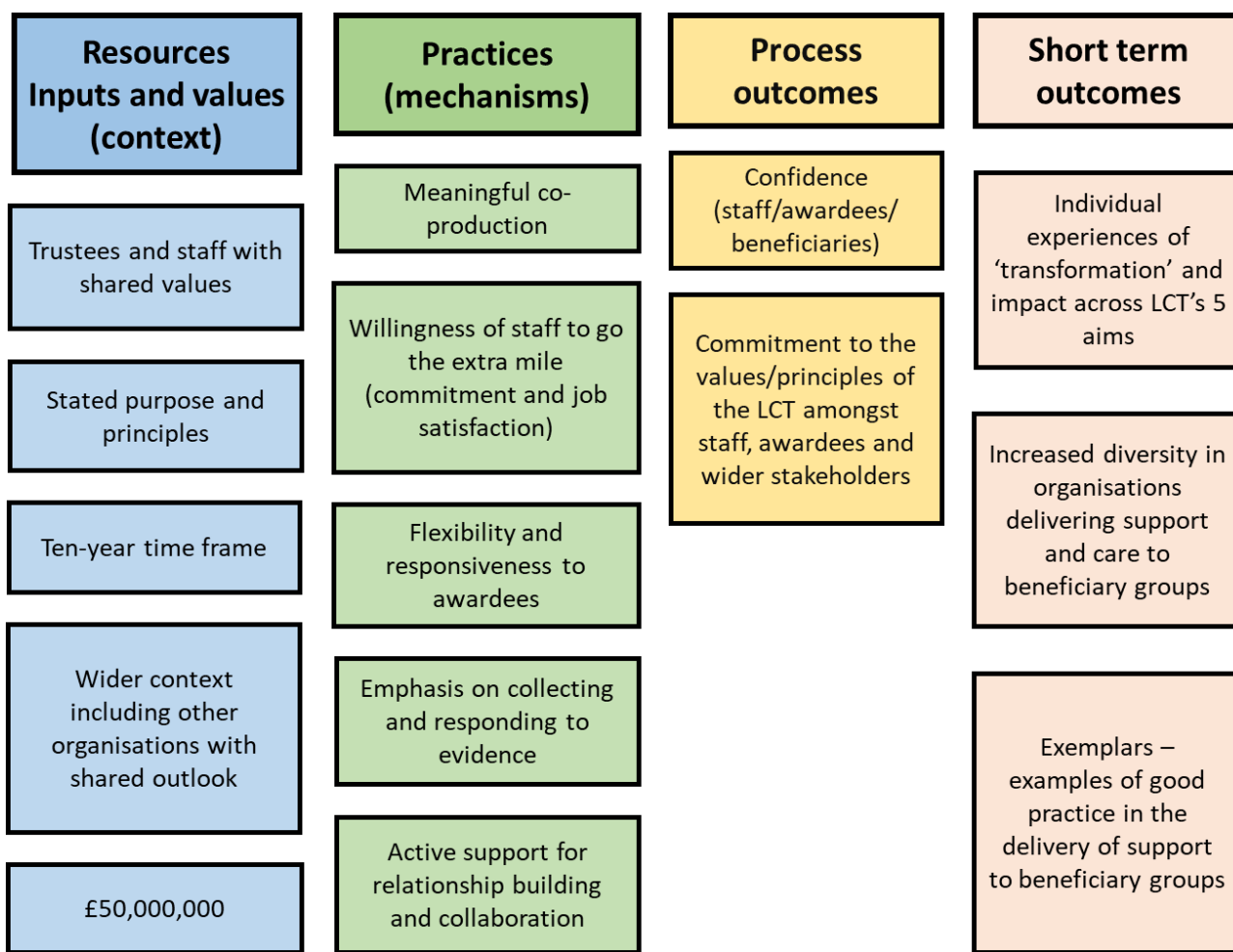


Figure 3.1 Logic model stage two

## 4. The place and impact of the Trust in the wider policy and practice context

### 4.1 Introduction

This section brings together data from interviews and online surveys with Life Changes Trust awardees and stakeholders and from the secondary analysis of monitoring and external evaluation reports to explore the role and impact of the Trust on the wider policy and practice context in Scotland. Data from the Trust beneficiaries are also included to further illustrate impact.

These multiple data sources help to draw up a picture of the impact of the Trust, and how far these impacts have extended beyond those for individual beneficiaries to influence the wider policy and practice context across Scotland for the three beneficiary groups. The section starts by discussing views of, and evidence for, the wider policy and practice impacts of the Trust's work, before reviewing evidence regarding the likely sustainability of these impacts, and for the Trust's contribution to transformational change in these arenas for the different beneficiary groups.

In this section identifiers for awardees include a letter denoting the beneficiary group their project supports (D, C, YP and a number to distinguish individuals); report extracts include the position of the person making the comment, if known, and the name of the report; and beneficiary quotes are identified with a pseudonym and include the person's gender and beneficiary group.

### 4.2 The impact of the Life Changes Trust on local and national policy

The following sub-section draws together evidence to review the Trust's impact on policy at organisational, local and national levels. The secondary analysis of reports detailing Trust-funded activities examined the degrees of impact on organisational, local, and national policies in relation to the three beneficiary groups.

Impact on policy, for the purposes of the analysis, included examples where activities of Trust-funded projects interacted with policymakers or groups involved in influencing policy at:

- organisational level (e.g., within the wider organisation a project was located within)
- local level (e.g., at community, local authority or regional level, such as engaging with local councillors or leading to changes in local authority policymaking)
- national level (impacts on policy at national governmental levels, such as national dementia strategies or policy for young people with care experience, or in organisations that engaged with groups at national level)

The research team acknowledged the difficulty of truly assessing the extent to which specific activities contribute to changing policy, given the multiple influences on policymakers and the many actors in this sphere – for example, it is very difficult to disentangle the influences of the Life Changes Trust from that of the Independent Care Review. However, the report draws on evidence from across sources to demonstrate the different ways in which the Life Changes Trust was believed to have contributed to policy change.

## **Influencing policy at local and organisational level**

There was strong evidence that Trust-funded projects had influenced policy change within other organisations. The development of more inclusive, co-produced, and person-centred activities by projects were supported by changes in organisational practices and the internal policies underpinning them, or in the organisations projects were collaborating with. For example, the Proud to Care project has engaged with a number of different organisations and stakeholders, producing differing outputs from the toolkit such as 'A Guide for Health and Social Care Providers', 'A Guide to Pride', and the MECOPP informal caring briefing. This has enabled the project to extend the impact of Life Changes Trust funding to organisations they collaborate with. The recommendations, briefings, and toolkit could potentially contribute to broader learning and influence future policy within the wider sector.

Some projects engaged in influencing activities which brought young people with care experience into contact with organisational policymakers. These were described as having transformed attitudes among policymakers and organisations, leading to them reporting that they would change their priorities as a result.

*We've seen quite a culture shift now working within the (organisation) – participation has always been important, but this project has really paved the way. We're currently in the process of creating a participation strategy for the organisation and embedding that and looking to recruit people with lived experience. (Project staff, Staff, Relationship-Based Practice and Policy Interim Report, p. 26)*

While views among stakeholders interviewed for this study on the impact of the Trust on organisations providing support for young people with care experience were generally very positive, they did raise a few queries about aspects of the Trust's approach. For example, there was some diversity of opinion on how 'transformational' an approach the Champions Boards actually represented. While one view was that they had normalised the involvement of young people with care experience in conversations about care, another was that the '*jury was still out*' on whether they represented a new way of doing things, or whether they are imposing adult ways of working on young people:

*So often what we do is we create images of ourselves as bureaucrats...so the Champions Boards kind of mirror what Councils do, in terms of committees and things... If it was really young person led, what would it actually look like? ... And a lot of our young people can't actually interact with it because their lives are too disjointed or their lives are too distressed. (National Stakeholder 14)*

Local level policy influences related to the ability and impact of Trust-funded activities to influence policy at regional or community level, such as policies enacted by local authorities, or organisations that were active across a locality or region. The small scale of many projects often led to them focussing more on local rather than national policymakers, as they felt they had more potential to influence local decision-making. For example, the reports on the Storytelling Sessions for people living with dementia and unpaid carers produced a number of priorities to inform local policy and practice based on their local circumstances. As a result, policy priorities differed across regions, with some groups focussing on availability of services while others focussed on promoting greater participation in the local community.

Awardees from the Young People with Care Experience Programme provided a number of examples of Trust-funded projects both changing local policy and being incorporated into wider Council or Health and Social Care Partnership strategy.



Champions Boards were seen as playing a significant role in increasing awareness of young people with care experience at local authority level, with specific examples given of Champions Boards leading to change in local policy. For example, one interviewee described how a Champions Board had been able to work with the local Through Care Team to evidence the need to increase care leavers' income, which they felt had had a 'massive' impact. The same Champions Board also highlighted disparities in the Christmas present budgets for children in foster and residential care in their local authority, which led to changes in local policy related to this. Champions Board staff reported that local policymakers believed that their engagement in the Champions Boards would lead to changes in how they approached future policy-making, as well as changes in relationships between themselves and young people.

*I certainly have increased my understanding of the issues and been impressed with the confidence and ideas generated from our young people. (Corporate Parent, Champions Board Scorecard Report 2020, p. 21)*

Other examples of local policy influence in relation to young people with care experience discussed by awardees included evidence from a Trust-funded pilot to increase access to leisure activities for young people with care experience being used to influence the Health and Social Care Partnership and Council to commit to rolling the programme out city-wide.

There was greater diversity of opinion among those working across the dementia field, who were interviewed for this evaluation, about the Trust's impact on local policy. One view was that the work of the Trust for people living with dementia and unpaid carers had focussed more on communities and individuals and had impacted less on either services or policy, although an alternative view was that the Trust's work at a local level was cohering into something bigger.

*There is a cumulative impact of the local work that they have been doing, and I think it is important not to underestimate that and not to just focus on...the national stuff... bringing people together across those different communities and the cross fertilisation and creation of that community has meant that they have been able to have much wider reach, and there has been learning from where communities have got involved in local strategy and local delivery. (National Stakeholder 8)*

In Aberdeen, as a result of the pilot project the Dementia Enablement Programme (DEP), staff were represented on Aberdeen City's Health and Social Care Partnership's Integration and Housing Committee and the Independent Living and Special Provision Strategic Working Group. An Aberdeen organisation stated that "*DEP has opened doors for us*", in relation to the DEP enhancing awareness and recognition of the role that Care and Repair can play in supporting dementia.

There is also evidence that the DEP had a wider impact on policy and practice within Care and Repair organisations. In one area, a focus on dementia has been embedded into Care and Repair's strategy, and five other Care and Repair services in the same locality mirrored elements of the DEP in their service.

Further examples of local level policy change are in the local dementia strategies developed with support from the Life Changes Trust in Aberdeen and Orkney. There is, therefore, evidence of significant local policy changes relating to people living with dementia as a result of Trust-funded projects.

However, evidence also suggests these changes are somewhat fragmented and isolated within specific organisations, geographical areas, or communities. Whilst the Trust has made a number of process and policy-based recommendations to Local Authorities, for wider systemic change to occur, the enthusiasm of the Trust, the beneficiaries, and stakeholders requires universal policy support. Without this, individuals and organisations will be limited in achieving broader change beyond the reach of their individual networks.

## **Influencing policy at a national level**

The secondary analysis of evaluation reports provided evidence that Trust-funded projects in the Young People with Care Experience Programme had also made progress in terms of engaging and influencing the thinking of national policymakers. The evaluation reports provided evidence of policymakers beginning to 'change the questions' regarding young people with care experience, with such discussions being fed into national policy planning such as the Independent Care Review in relation to young people with care experience.

*The focus has begun to shift however to the agency, capacities, capabilities, hopes, dreams, and human rights of young people as a way of promoting more positive futures. The recent Independent Care Review reflects this. (...) The Advisory Group has helped pioneer a more forward-looking and positive agenda. (Life Changes Trust Advisor, Evaluation of the Life Changes Trust Advisory Group, Interim Summary Report – February 2021, p. 5)*

Both the secondary analysis and interviews with awardees identified specific positive examples of the perceived influence of Trust funding on national policy, particularly for young people with care experience. For example, Who Cares? Scotland's end of year report from 2019 gives examples that demonstrate the impact of its Life Changes Trust-funded activities on Scottish Government policy in securing continuing and extended support for young people with care experience from statutory services.

*We challenged the First Minister and the Chair of the Independent Care Review to deliver on their promises of transformational change made over two years ago. We were heard, partially, with a number of our recommendations becoming law within a matter of months. (Who Cares? Scotland 2019 End of Year Report, p. 3)*

Another Life Changes Trust-funded project with young people with experience of the Justice System reported influencing the Youth Justice Strategy for Scotland to include a participation strand.

*There is now, you know, a participation strand in the Youth Justice Strategy for Scotland, which is amazing, amazing, amazing, that that is even, that that's there, that was quite hard-won, so we are proud of that, and young people co-produced that as well, which is great. (Awardee YP2)*

Many of the young people with care experience interviewed for this evaluation discussed the importance of voice and explained their role in influencing policy and practice implementation. Attendees of Champions Boards, for example, spoke about how they felt that some policy changes had been made which took the experiences, perspectives, and needs of young people with care experience into account, for example with regard to changes in council tax payments for young people with care experience.

*It was good to see, like, that change being made because it was one that needed to be made because there was a lot of, like, care experienced people falling into debt because of council tax and, like, I know that they can't abolish like rent, but like it's good as well that the government is now introduced that under 22's don't need to pay council tax, which is good, nobody...like I got my flat when I was 20, and that was the year that council tax exemption got put into play. (Gemma, young person, F)*

The final evaluation report of the Champions Boards approach provides evidence of a circular influence between their work and The Promise, which is responsible for implementing the findings and the recommendations of the Independent Care Review in Scotland. The Champions Boards were heavily involved both in the Independent Care Review and The Promise, and some young people previously involved with the Champions Boards were subsequently employed as Promise development workers. However, evidence suggests not only that the Boards and the Promise influenced each other, but their combined influence helped one build the foundations to the other and vice versa, this resulting overall in the care experienced agenda becoming more prominent.

*Many pointed to the role of the Trust's grant funding in building a strong foundation from which participation and engagement with young people with care experience can be built, in the wider context of The Promise. Many highlighted that The Promise consolidated support for a Champions Board type approach, and that Champions Boards meant that the work on The Promise is not starting from the beginning. (Evaluation of the Champions Board Approach Final Report, p. 97)*

Some partners of the Champions Boards highlighted that a wider context with a focus on children's rights, including The Promise, is what really enabled them to listen to children and young people and implement the ideas they suggested. The need for a wider systemic change at a policy level to make sure that the investments of the Trust are truly impactful is particularly evident here.

Projects to support young people with care experience also empowered them, so that they felt that they could actually influence the decisions of those in power.

*'Cause very often for many people who are in care, there aren't people around to set those expectations. You're quite powerful, you could really do stuff. We think you might be able to change this thing. That isn't something people hear a lot but because of the investment from the Life Changes Trust, you had an organisational culture that started to be about actually no, you can do that. That is something you can achieve. (Awardee YP7)*

The majority of monitoring and external evaluation reports on Life Changes Trust-funded dementia related projects focussed on evidence on improving local conditions for people living with dementia. Although such evidence was provided less frequently when compared to evidence of improving local practice, a number of Trust-funded projects also provided evidence to demonstrate the role of their work in informing national policy discussions across the three beneficiary groups.

However, there were notable examples of projects that did provide evidence for their role in informing national policy including the Scams Protection and Prevention project, whose work influenced the 2021 Trading Standards Scotland Consultation, and the Scottish Government's Scam Prevention, Awareness and Enforcement Strategy 2021-2024.

*At a national level, project partners attended the Scottish Dementia Working Group and Cross-party Working Group on Dementia. Working within these structures project partners were able to provide input to the forthcoming national Scam Prevention and Dementia Strategies, with prevention of financial harm proposed in the latter. (Evaluation of the Scams Protection and Prevention Project Final Report, p. 15)*

A report published by the Trust summarising learning developed across the wide range of Trust-funded projects was also submitted as evidence in the 2020 Independent Review of Adult Social Care in Scotland. This report summarised evidence learned from a number of the projects reported on in this secondary analysis, particularly arguing for the adoption of a whole life and human rights-based strategy for Scottish adult social care in the future.

*A whole life approach to dementia means that statutory organisations should look across all statutory portfolios to determine whether there are changes that can be made that would help reduce or delay the requirement for social care...In our experience, the role of housing is often overlooked in social care planning by Integration Joint Boards. In 2016/17, the Life Changes Trust funded a report on housing and dementia. The Trust had organised a number of events bringing together housing practitioners, health and social care professionals, the private and the voluntary sector to help identify housing's contribution to supporting people with dementia...The final report entitled 'Being Home' was launched at the Scottish Parliament. (A Vision for a Whole Life approach to Social Care in Scotland November 2020 report, p. 33)*

The Rights Made Real in Care Homes programme evaluation report noted that the national debate was changing towards greater engagement with people living with dementia, including those with advanced dementia or care home residents in decision-making about their lives.

The evaluation report for TIDE, the 'Together in Dementia Everyday' network for carers of people living with dementia, was one report which discussed in detail the methods they had used to influence both practitioners and policymakers. For example, TIDE described its members attending or hosting events with MSPs and MPs. These activities led to significant engagement with policymakers, although again it was unclear at this point in time whether these consultations and influencing activities had led to significant policy change.

The Trust's large investments in BOLD and About Dementia were seen by national stakeholders interviewed for this evaluation as key to extending and enhancing the Trust's impacts at the level of national policy and decision-making. These were still in the relatively early stages of operation at the time of writing.

About Dementia is the key Life Changes Trust-funded project tasked with influencing policy. While staff from About Dementia, interviewed for this evaluation, reflect that they are still at relatively early stages of influencing national policy, they also cited examples of how they are developing policy links and starting to have real input to emerging policy agendas. This included, for example, contributing to the Scottish Government Dementia and COVID-19 Action Plan and developing avenues for its members with dementia to feed into other policy developments (such as the recent Review of Adult Social Care) at national and local levels. They also felt that the Life Changes Trust has supported them to develop strategic relationships with policymakers and 'get into rooms' they would not otherwise have been in.

Findings from interviews with national stakeholders, conducted in year 1 of this evaluation, found a perception that it was easier to identify impacts of the Trust's investment on national policies in the young people with care experience field than in the dementia field. With respect to young people with care experience, while disentangling the impact of the Trust from other factors influencing the policy landscape was difficult, the Trust was seen as having helped maintain and, perhaps, accelerate a momentum for real change in the care system.

Awardees who took part in interviews with the evaluation team also commented on the perceived policy impacts of the Trust. Across the different beneficiary groups, the awardees also felt there was more confidence around the Life Changes Trust's perceived influence on national policy for the Young People with Care Experience Programme, with influence on national dementia policy seen as a work in progress.

*I don't get the sense that the Life Changes Trust have got a huge profile at national policy level. (Awardee D10)*

These findings also relate to the timing of policy development within the Scottish Government, with the Independent Care Review taking place at a key point in the Life Changes Trust's timeline while the fourth national Dementia Strategy has been put on hold, replaced at the moment, by the Dementia and COVID-19 Action Plan. The Life Changes Trust is noted in the plan and also co-chairs the Communities sub-group from Commitment 11 of the plan. Awardees did, however, identify more perceived progress at a local level, citing the way that Dementia Friendly Communities have become embedded as a community planning priority.



There were unresolved questions in many of the monitoring and external evaluation reports reviewed regarding how far such policy influencing undertaken by Life Changes Trust-funded projects led to actual and meaningful policy change, particularly at a national level. While it is likely that some of the forms of policy influencing listed above will have led to meaningful policy change, it is harder to demonstrate evidence that these forms of engagement themselves had a causal effect in leading to policy change, or the precise extent to which they contributed to the wider evolution of policy in relation to young people with care experience.

## **Supporting co-production in policy influencing work**

Over the lifetime of the Life Changes Trust, funded projects increasingly made co-production of project activities with beneficiaries a key priority. Such approaches sought to recognise and build upon expertise gained through lived experience, facilitating beneficiary-led project activities or supporting greater forms of advocacy among beneficiaries. Across these projects, a key feature of practice was the transfer, at least to some degree, of power to beneficiary groups, for example regarding decision-making about project activities. This transfer of power within organisations varied, from greater degrees of consultation through to true 'citizen control' with beneficiary groups making core decisions. The focus on co-production between various stakeholders involved in a project also illustrated the desire to make project activities as inclusive as possible.

Much of the discussion on influencing activities in both the monitoring and external evaluation reports and interviews with awardees indicates that the main focus of much of the influencing work carried out by Trust awardees appeared to be encouraging both extended support for and more inclusive forms of engaging with the three beneficiary groups. Such engagement had the goal of ensuring that beneficiary voices were not only listened to in policy-making but were at the centre of decision-making processes at policy level. Findings from the year 1 survey of Trust stakeholders found that around two thirds of respondents working in the dementia field felt the Trust has been successful in increasing the influence of people living with dementia over local decision-making. For unpaid carers this figure was just over half, while for young people with care experience this was higher, at 70%.

According to young members of the Trust Advisory Group, young people with care experience were able to fully participate as equals, contrary to other experiences where they felt they were 'put on a platform' but not necessarily supported and offered development opportunities.

In particular, the grant management was framed as a tangible example of 'share of power' in the evaluation, as young people and project staff were enabled to 'define their own rules' for their use. The flexibility of grants was also praised in the Rights and Equalities and Empowerment grants evaluation report.

*The beauty and the challenge is how much the Trust have given...have trusted us to kind of guide it. But also, that's quite scary because it's like, there's no rules. Like, you've got to make them up as you go along. But actually, the young people and the staff have been really good at helping to kind of shape that. (Project staff, Rights and Equalities – An interim report on the evaluation of the Rights and Equalities Initiatives and Empowerment Grants of the Life Changes Trust, p. 24)*

The monitoring and external evaluation reports and interviews conducted directly for this evaluation do identify a number of challenges to engagement and policy-influencing work. The TIDE interim evaluation report described how some carers found engagement with policymakers daunting, with issues such as lack of confidence limiting the number and willingness of carers to engage at this level.

*...not everyone wants to do any type of influencing. I think a lot of people are also quite scared...that we're selling it almost at a level that's too high... 'Influencing opportunities', 'involvement network', a lot of people don't know what that is. And don't want to find out either... Often, I think... 'Why would I do this? Why would I go along?'" (Staff member, TIDE Interim Evaluation Report, p. 49)*

As a result, much of TIDE's attention in relation to influencing activities focussed on raising confidence and empowering unpaid carers to feel like their voices were important in conversations about how best to support carers. A young person with care experience shared a similar note of caution in an interview for this evaluation.

*I think for a young person who, perhaps, wants to try participation for the first time, and they need more of the social aspect of it, and a soft start, I don't think the group would be best for them. Because you'd need to be able to, if not hit the ground running, you'd need to be able to hit the ground jogging, I think, and that's just because the momentum that the group's got, the profile that the groups got. And it is quite intense, real work, for a completely new young person who maybe hasn't done anything like that, it might be a bit too much for them. (Kaelyn, young person, F)*

Some organisations also questioned how they could meaningfully influence policy given their relatively small size, as well as how they could determine whether their engagement led to actual policy change. The difficulties of tracking through from investment to definite policy change were acknowledged by practitioners.

*Policy reach is limited, as might be expected given the level of investment. Nonetheless, where policy impact was a clear focus of the project, evidence of reach was there (e.g., young person with disabilities speaking directly with politicians). None of the projects were able to track impact from dissemination through to actual policy/practice change, but that would represent a large commitment given the small scale of the investment. (Care and Equalities – An interim report on the evaluation of the Rights and Equalities Initiatives and Empowerment Grants of the Life Changes Trust, p. 19)*

Another awardee from the Dementia Programme felt that time is needed to build up a reputation before others will automatically consider and approach the project for input on questions of policy or legislation. They also reflected on the challenges of balancing the desire to influence policy with other more practical aspects of running an organisation or delivering services, which can lead to organisational resources being spread thin. Another barrier to influencing policy more generally was identified in the impact of levels of public interest surrounding different issues on the political appetite for tackling them. For example, one awardee explained that unpaid carers of people with dementia felt that there was not much sympathy among the general public for them.

*So I think it's, that's the thing, how can an organisation like the Life Changes Trust create a transformational change, if voters don't, you know, if they don't feel that people care about it. (Awardee C2)*

Although there were many examples of positive perceived impacts of the Trust on co-creation in the practice of organisations it funded and beyond, there were also some comments regarding the limits to and challenges around achieving true co-production in practice beyond the work with the Trust. For example, some young people and people living with dementia described limits to their role and frustrations when their involvement was seen as tokenism or people paying 'lip service' to involvement processes. One participant described her annoyance at feeling things were not really in their control.

*...they're working quite quickly on trying to design how they're going to make children's services and social work amazing. But I don't know. I don't know if it's just one of these things that's been published and like my review, it'll be a big thing at the start and then it'll be (...) But it's annoying because it's not us that has it in our hands, it's more like local authorities and health and education and things like that. (We are) a tiny wee part of it. (Emily, young person, F)*

In summary, looking across the various sources of data considered in this section, there is clear evidence of the Trust's influence on *organisational* policy in funded organisations, as well as concrete examples of significant influence on local policy, for example through key initiatives such as Dementia Friendly Communities and Champions Boards. There is also growing evidence of the Life Changes Trust's influence on national policy, although at this point in time, this is most evident for young people with care experience. For people living with dementia and unpaid carers, while it was less clear that Trust activities had led to concrete policy change, it was clear that significant influencing activity has taken place and there are encouraging signs of national policymakers engaging more broadly with different organisations and with people living with dementia.

## 4.3 The impact of the Life Changes Trust on practice

As well as influencing policymaking in relation to the three beneficiary groups, there was evidence that Trust funding has had a number of impacts on practice, in terms of:

- how activities taking place within projects were delivered
- how the delivery of these activities changed over time
- the impact of changes to activities for beneficiaries

As with policy impacts, it is challenging to definitively disentangle the impacts of the Life Changes Trust on practice. While both the secondary analysis and primary research for this evaluation highlight examples of practice within Trust-funded organisations that align with the aims of the Trust, it is not always straightforward to assess the extent to which these practices can be attributed specifically to the impact of the Trust. For example, a number of projects such as TIDE and DEEP, the various Dementia Friendly Community initiatives, and Who Cares? Scotland used the Life Changes Trust funding to extend their activities, in which they applied their pre-existing attitudes and participatory, person-centered, and rights-based approaches to their projects. In such cases, funding will have enabled the projects to increase their reach, but because they are likely to already be adopting or have principles aligned with the Trust, it is arguably less clear that they have fundamentally changed how they delivered activities.

The online survey of Trust-funded awardees asked what level of impact they felt receiving funding from the LCT had across a number of areas, each of which was intended to capture aspects of the Trust's core aims and remit.

Awardees were most positive about the impacts of funding in terms of 'creating opportunities that would not otherwise have been available' for beneficiaries, especially for people living with dementia and unpaid carers and 'changing the way other organisations approached working with' beneficiaries – indicating the positive impacts of funding both on extending services for beneficiary groups and on wider practices within funded organisations.

However, awardees, while still positive about this, were somewhat less likely to feel that receiving funding had 'a great deal of impact' on 'changing the way professionals approach working with' these groups. This indicates that, unsurprisingly, the Trust is seen as having less reach in changing responses among practitioners more widely, beyond the organisations it has directly funded.

This sub-section will present the key themes emerging across the evaluation project relating to the domains of impact of the Trust on practice within funded projects as well as their wider impacts on practice.

## **Knowledge and understanding – shifting mindsets and increasing confidence**

For the Dementia Programme, interviews with awardees highlighted the impact of Trust funding on organisations' understanding of dementia as a key impact, especially in organisations where this wasn't their core focus, but where Life Changes Trust funding had enabled them to develop specific services for people living with dementia. An important part of this was being able to develop understanding of dementia among staff within their own organisations.

*They did quite a lot of extra, like making sure that I was prepared for what the project would involve and things like that, and making sure that I had thought about everything that needed to be thought about because it's such a new area for us and for me as well. They kind of suggested different organisations that I could get in touch with that might be interesting sessions or could assist with training and things like that as well, which was really useful. (Awardee D2)*

The process of raising dementia awareness at individual, organisational, community, and policy levels has had a positive impact on the sustainability of projects. Raising awareness has taken various forms, including events, community integration, social media activity, and multi-agency networking.

Networks have also been established where families have been made aware of services, and vice versa. The secondary analysis shows that there is significant evidence - obtained from qualitative interviews with staff and stakeholders - that at least five dementia funding programmes, encompassing 54 projects, put effectively into practice collaboration and multi-agency working, creating sustainable partnerships at practice and organisational levels. In Aberdeen, there was evidence that the Trust-funded Dementia Enablement Programme (DEP) had a wider impact on practitioner attitudes within other Care and Repair organisations, with five other Care and Repair services in the same locality mirroring elements of the DEP in their service. The Care and Repair handyperson involved in setting up a Men's Shed project - another project, that was not funded by the Trust - was also encouraging it to be dementia friendly, highlighting the wider impacts of the Trust's funding on staff knowledge and confidence, and by extension the organisation's wider work.

*If it hadn't been for this project, then this handyperson wouldn't have had the confidence to work with people with dementia. (Care and Repair manager, Evaluation of the Pilot Dementia Enablement Project, p. 37)*

For organisations and staff that had received Trust funding, training and development opportunities accessed through the project and their links with the Trust had increased levels of knowledge and awareness of how to adapt their practice to be more inclusive to the needs of their beneficiaries.

*I've learned a lot in doing this, things that I definitely didn't know before and obstacles I didn't know were obstacles before. (Project Lead, Scottish Dance Theatre, Relationship-Based Practice and Policy Interim Report, p. 16)*

*I just want to go back (to my organisation) and energise everyone! (Practitioner, Community and Dementia: Creating Better Lives – Lanarkshire Storytelling Sessions Reports, p. 23)*

*...during the training sessions, many attendees quickly begun to suggest possible practical ways their organisation could improve their inclusivity. (Proud to Care LGBT Dementia Project Report, p. 10)*



Awardees reported that the Life Changes Trust had helped them think more about inclusion of people with dementia and to have the confidence to present themselves more explicitly as a rights-based organisation in relation to working with people with dementia and other groups.

*It has made me feel a bit stronger actually, about saying we are a rights-based organisation. I mean, I did say it before, but working with a funder like that and hearing them say it very clearly, it is quite empowering. (Awardee D3)*

In the context of the Young People with Care Experience Programme, the Relationship-Based Practice and Policy evaluation found that shared training opportunities supported a shift in mindset about the duties of Council employees as Corporate Parents and their responsibilities towards young people.

This resonates with the Champions Boards Scorecard Report which reported findings from a survey of 260 Board members and Corporate Parents, showing that Boards had helped Councils and Corporate Parents understand young people with care experience well, and that the services were better meeting young people's needs as a result of their influence (85% of responses). This includes increased awareness of trauma, experiences, needs, and opportunities available for young people with care experience. However, a more consistent commitment, attendance, and active participation in decision-making was still required from Corporate Parents.

*Corporate Parents have a massively increased understanding of CEYP and trauma. Practice across the board is more trauma-informed, particularly in education and housing... Young people have been so important influencing this by building relationships and telling their story. (Survey respondent, Champions Board Partnership Scorecard Results 2020, p. 21)*

Over time, case-to-case changes can contribute to broader cultural shifts which reduce stigma within both geographical communities and communities of interest which extend beyond physical locations. For example, the Rights and Equalities Initiatives and Empowerment Grants evaluation report presented evidence of mindsets towards young people with experience of care and homelessness shifting at a community level.

*We've opened it up to older people, we offered people to come in. We have an engagement with a local church where the people from the local church...we have good relationships with the church. They sort of accept us within the community now as well, and temporary accommodation being in some communities can be quite stigmatised... (Empowerment Grant project staff, Care and Equalities - An interim report on the evaluation of the Rights and Equalities Initiatives and Empowerment Grants of the Life Changes Trust, p. 15)*

On the other hand, the Champions Boards Scorecard Report acknowledged how, although it is reported that the awareness of young people's needs and issues improved at an organisational level, inequality and stigma affecting young people with care experience is still structural and complex, and it might take many more years to make a significant impact.

## **Putting co-production approaches into practice**

Alongside the co-production of policy, the shift towards putting co-production into practice was also a clear feature of projects funded later in the life of the Life Changes Trust, building on the initial learning from earlier projects. A number of reports from projects conducted between 2019 and 2021 referred to co-produced approaches becoming an increasing priority or being seen as part of the legacies of projects.

Some approaches, such as the Storytelling sessions delivered by the Village Storytelling Centre, gave people with dementia and unpaid carers the opportunity to share their experiences of accessing support in their communities, both from statutory agencies and activities provided by third sector organisations. Sessions were held within thirteen Health Board areas and gave participants the opportunity to say what was important to them and to share their experiences of local services. Sessions were also set up to provide space for staff and volunteers to contribute, this addition was requested by people with lived experience as it was felt a collective view was important to inform this work. Many of the experiences shared were negative, particularly in relation to the abilities of statutory sector organisations, which were described as being unresponsive to queries, not effectively signposting people to appropriate services, and failing to understand or respond to the needs of people with dementia. Conversely the reports also noted where experiences were positive and cited examples of what had worked well and could impact future approaches.

*I'd have liked a reply to a phone call or an email. Not having to phone every day for a week or a fortnight to get a response from social work or a district nurse. Not endlessly telling the same story over and over again to different people. (Unpaid carer; Forth Valley Storytelling Sessions Report (VSC), p. 4)*

Whilst often difficult to hear, such reports detailed challenges in accessing support for people living with dementia, and in response detailed a list of priorities to address such challenges and how they could potentially be overcome. Reports for each of the thirteen areas collectively provided, in total, 95 local priorities focussed on improvements in policy and practice for each Health Board area. Priorities across the areas included the need for clear pathways through services (including post diagnostic support), the importance of peer support, timely diagnosis, reductions in stigma and isolation, and greater consistency in information provision and sharing.

Co-production approaches also went beyond collecting views of beneficiaries in order to drive service improvement, moving towards models which instead involved beneficiaries as equal partners, or went even further by ceding control over decision-making to beneficiaries. Exemplars of such projects included the Aspirational Awards for young people with care experience and Individual Awards scheme for people affected by dementia, which gave their respective beneficiaries full control over how awards would be spent with few to no restrictions.

In giving recipients total freedom to choose and fund activities that individual beneficiaries felt would benefit them, both of these programmes provide examples of practice innovations that the Life Changes Trust's funding models allowed to develop. Such claims were also made by other projects across all three beneficiary groups, who felt that a key outcome for future learning was the impacts of such co-production approaches.

*A significant part of the Trust's legacy may be around including the voice of care experience – both via the Advisory Group and the local Champions Boards. This work will leave behind a group of ambassadors for co-production who will take these experiences forward in their different ways. (Evaluation of the Life Changes Trust Advisory Group – Interim Summary Report, p. 5)*

*It took time to recruit staff, to engage with people affected by dementia, garner their views and respond to these. Indeed, if we were to do it again, we would give more time to ensuring all partners are truly involved, people living with dementia and their carers, in setting their priorities for creating a DFC. (Organisational member, Dementia Friendly Communities - Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland, p. 34)*

Such approaches sought to recognise and build upon expertise gained through lived experience, facilitating beneficiary-led project activities or supporting greater forms of advocacy among beneficiaries. The awards schemes for both people affected by dementia and young people with care experience identified ceding control, flexibility, and trust as essential to their success.

As with co-produced approaches to policy development, a key feature of practice was the transfer of at least some degree of power to beneficiaries, for example regarding decision-making about a project's activities. This transfer of power included greater degrees of consultation or true 'citizen control' with beneficiary groups making core decisions, such as how to spend their grants or the criteria to assign individual awards. The focus on co-production between various stakeholders involved in a project also illustrated the desire to make project activities as inclusive as possible.

For young people's services, awardees reported greater recognition of the role young people can play in organisations and how their views are taken on board, extending beyond their role in projects directly funded by the Trust. For example, one organisation described how their partner in a Trust-funded project had made a subtle but important change to the name of their service to put 'children and young people' at the start of their title as well as developing a participation strategy that now includes the appointment of young people with care experience as participation workers. Another awardee reported that their organisation now includes young people in all recruitment activities. There was also evidence of an awardee taking ideas from the Life Changes Trust, such as the Aspirational and Individual Awards, and seeking to incorporate in their own practice:

*So, we're looking at micro loans, we're looking at the grants awards. We're exploring what those options might be because we do think there's some value to kind of bringing in that business element as well. So, we're currently scoping that out with a view to commencing that in April. And certainly, it was a trigger of a conversation from attending that (Life Changes Trust) event. We may have got there anyway, but we probably... it helped formulate the thinking really. (Awardee YP8)*

There is optimism that co-production practices pioneered within some of the projects, such as the Champions Board will have a lasting impact.

*The achievements made by the Champions Board are seen as crucial and a new way of working and something which will be in place forever. (Respondent, Champions Board Partnership Scorecard Results 2020, p. 25)*

The adoption of participatory and co-production approaches in organisations with Life Changes Trust funding was further evidenced by beneficiaries who reported an increase in the practices of participation and co-production in projects across all beneficiary groups and observed co-production becoming part of practice in other organisations. The Life Changes Trust was credited by young people with care experience as providing a 'role model' for the sector and by an awardee as 'raising the profile of participation'.

*I see more people talking about co-productive work...I've seen other charities start to pick up the model of the (Life Changes Trust group)... I don't know if they'll do the same thing, but I've seen them start to pick up genuine co-production through seeing how we work. (Bradley young person, M)*

From analysis of reports, significant attempts had been made to embed co-production and participation in decision-making, the benefits of which were evident in the testimonies of beneficiaries and stakeholders. Detailed examples of such co-production practices are provided in the evaluation report for the Rights Made Real in Care Homes programme, where residents were involved in decision-making over staff and activities, and services were reportedly tailored towards their individual needs. This resonates with the peer mentoring projects for young people, where the majority of projects used a mentee-led matching process and goals for the mentoring relationship were self-identified by young people with their mentors.

## **Supporting networks and knowledge exchange**

A further key feature of practice development among Life Changes Trust-funded projects evident from analysis of the monitoring and external evaluation reports was the growing recognition of the value and impact of networking, collaboration, and partnerships with other organisations operating in the same space. Such collaborations were crucial in reducing repetition of effort, supporting new projects to develop their activities, coordinating with statutory organisations such as local NHS Trusts or Local Authorities, or ensuring that changes in practice were embedded in collaborating organisations.

*We saw some very positive examples of partnership working and collaboration. This includes housing teams. Engagement increased between social workers and young people. There were good signs of skills being transferred between practitioners and people learning from each other. (Home and Belonging Progress Report, p. 7)*

Evidence was also found for Life Changes Trust funding providing opportunities to develop links and networks at the community level. In the context of the Regional Grants and Dementia Friendly Communities programmes, there was a flexible approach in how grants could be spent and communities were not focussed on geography but extended to communities of interest, empowering a grassroots and community-based approach to supporting people living with dementia and unpaid carers.

By working collaboratively, and in some cases amalgamating with local community groups and venues, projects involved in the Get Outdoors Programme, such as Sporting Memories and Evanton Wood, have encouraged community members to be more inclusive of people living with dementia, whilst also paving the way for some of their activities to be sustained in the longer term. Community groups have also been supported to think about how local activities can be made dementia inclusive as standard. This increasing sense of universality promotes inclusive services for all that are intrinsically dementia friendly in the future.

*Whether you've got dementia or not in our town, you've probably heard of us, and it's a good way of sharing, frankly, just compassionate, a compassionate ethic, which is good for everyone.* (Director of Dementia Friendly organisation, An Active Future with Dementia: How Sport & Physical Activity Can Connect Us. Summary and Evaluation by Sporting Memories Foundation Scotland. Linked video evidence.)

Awardees reported that the Life Changes Trust created opportunities for sharing learning and influencing each other's understanding and practice through network meetings, conferences, and evaluation events, as well as links between Trust-funded projects being established and maintained by the projects themselves. The cross-sector links enabled by these were particularly valued.

*So I think it's really interesting to see how the Life Changes Trust has funded a cultural organisation, a big museum like V&A Dundee, alongside the really small grassroots, walking groups or support services or telephone helplines. And it shows that this network of support is gradually being stitched tighter and tighter together... Prior to this role, prior to...several years ago, I was also guilty of seeing dementia as purely a medical condition but actually it's really interesting to see the projects the Life Changes Trust have funded are not all medical projects. So I think that's a really interesting change in how people see dementia but also in the way people see the support services as well.* (Awardee D7)

Examples of the ways in which the Trust had supported networking and knowledge exchange were given from both the Dementia and Young People with Care Experience Programmes. As discussed earlier in the report, several organisations commented on the positive impact of linking up Trust-funded projects, although some felt that more could have been done to ensure links were built between projects.

Awardees talked about sharing their new learning and practices more widely with organisations beyond those directly funded by the Trust. Examples included training and other influencing activities such as participatory performances by young people for social workers and young people making films to provide training for the police and housing services to inform how they work with young people with care experience. In developing activities for people living with dementia, several projects reached out to new individuals, organisations, or groups they may otherwise not have worked with.

For example, forestry projects were not only able to extend their reach to more people with dementia, but also supported engagement with other dementia-supporting organisations they might otherwise not have worked with, leading to changes in attitudes and practice across partnering organisations.

As a result, there is the potential that practice changes could be felt beyond Trust-funded organisations, although there are challenges collecting evidence to demonstrate that this took place. Figure 4.1 illustrates the networks formed using social media by a Trust-supported project led by Paths for All.





Figure 4.1 Social media map for Paths for All

Despite perceptions reported in some of the evaluation reports and echoed in some of our interviews with stakeholders that dementia projects, in particular, could sometimes be in competition with each other, a strong focus on collaboration was nonetheless apparent across many of the Trust-funded projects, with such collaboration being enhanced through Life Changes Trust knowledge exchange activities.

However, projects who tried to engage with statutory agencies such as local authorities or individual GP surgeries did report problems in making the initial links, and then sustaining their relationships with them over time. As an example of the impact difficulties in liaising with statutory services could bring for projects, one peer support project (the ENABLE Cuppa Club) described difficulties in engaging with GP surgeries, who were thought to be a gatekeeper to informing their main beneficiary group – people living with dementia and intellectual disabilities. In part due to difficulties in promoting the project through GP surgeries, the project struggled to make contact with these beneficiaries, which contributed to the early closure of the project. Projects for young people with care experience also experienced similar difficulties in terms of building relationships and networks with statutory agencies.

*The structures and systems in place in local authorities have presented challenges and meant that progress with some of the projects has been slower than hoped. These issues could continue to affect the Home and Belonging initiative over the coming years. The Life Changes Trust should consider how it can support projects to build these relationships in Year Two and Year Three. (Home and Belonging Progress Report, p. 8)*

In terms of collaboration at a wider, national level, awardees from the Dementia Programme and national stakeholders working in this field interviewed in Year 1 of the evaluation suggested there have been some ongoing challenges around maximising the impact of the Trust on the wider dementia sector. One view was that the Life Changes Trust had gone 'above and beyond' in their efforts to bring people together at a national level, but that it has not always proved possible to sustain engagement from other stakeholders in the dementia sector.

Others, as already discussed in Section two, felt that some organisations in the dementia community have felt alienated from the community of Life Changes Trust stakeholders. Several awardees commented on what they perceived as the particular challenges of bringing the dementia sector together.

*I find that the health and social care services (including research) that has been set up to deal with people living with dementia and unpaid carers is full of politics, personalities and agendas that are not always helpful to the communities they are set up to help. I strongly suspect that funding is not allocated and managed effectively, as a result. (Awardee C2)*

Another awardee also spoke of the challenge for them in trying to organise an event with input from more than one dementia organisation where there were tensions evident between them.

More widely, the Trust's arrival in an already 'cluttered' dementia landscape was viewed by awardees and stakeholders as having 'disrupted' existing structures and groupings working on dementia. Sharply divergent views were expressed on whether or not this disruption had been welcome or divisive. On the one hand, there was a perception that the Trust had helped to open the dementia sector in Scotland up, both by challenging ideas about how best to support people living with dementia, and by including organisations who may previously have felt excluded by established dementia networks in Scotland. On the other, it was suggested that the Trust has, at least in part, duplicated existing structures, which was viewed as inefficient and having contributed to competition rather than collaboration in the sector.

This sub-section has examined the ways in which the Life Changes Trust has impacted on practice for the organisations it funded and in their wider landscape. There is evidence from primary and secondary data that the most significant impact assessed was within the Life Changes Trust-funded organisations; this included the development of inclusive or specific services for beneficiaries and an increased awareness of their needs, with positive impact on practitioners' attitudes and confidence. There is some evidence of mindset shifts towards beneficiaries in the wider community, but more long-term efforts are needed to enable systemic change and address structural inequality and stigma.

Another key impact was the creation of sustainable partnerships at practice and organisational level, which to some extent improved multi-agency working and connected beneficiaries to services. Collaboration was easier amongst Trust-funded organisations, whereas it tended to be more challenging with statutory services and other organisations who did not necessarily feel part of the Life Changes Trust community, and where conflicting views on how to achieve the best outcomes for beneficiaries could be an obstacle. The Trust was reputed for being innovative, as it challenged current practice and included a new range of organisations, but in some cases was seen as having duplicated existing structures.

One view (from a national stakeholder) was that, going forward, there might need to be a 'national forum' of all organisations and individuals in the dementia field, to try and ensure people work together rather than in parallel.

## 4.4 Evidence of sustainability within policy and practice

The Life Changes Trust defines sustainability as being achieved when ***the benefits of a project, initiative or shift in culture and practice can be continued in the long term.***

Within the evaluation we found evidence of sustainability in terms of impact for individuals, discussed in detail in Section three, and here in this section have provided evidence of impact on policy and practice across Scotland. This sub-section considers evidence for the likely or potential sustainability of these impacts in terms of how projects, their activities, and their impact have continued, or plan to continue, once the Life Changes Trust funding ends. Many projects discussed changes they had made in their organisations or in their activities but ascertaining evidence to demonstrate the long-term sustainability and legacy of projects is difficult to assess until more time has passed. As part of the legacy activities post closure of the Trust, routes through which the long-term sustainability of Trust-funded projects can be assessed should be considered.

### Continuation of activities funded by the Life Changes Trust

One of the key determinants of the sustainability of Trust-funded projects related to the ability of projects to secure further funding. The Life Changes Trust had played a vital role in funding a wide variety of community projects for each of the beneficiary groups and had become one of the major Scottish funders of these types of organisations. However, this also means that as a result of the time-limited nature of the Trust this source of funding will end with its closure. Organisations therefore will need to find alternative funding from other sources if their projects are to continue beyond the Trust's lifetime.

Findings from the 26 respondents whose Life Changes Trust funding had come to an end at the time of the awardee survey helps cast light on the different ways in which Trust impacts may be sustained longer-term, and in particular on the role of funding in ensuring sustainability. In eight cases, the activities had stopped after Trust funding ended, but in 18 they were ongoing. In the cases where activities had ceased altogether, the two main reasons given were either that the project had achieved its aims or that no further funding had been available.

Where projects were ongoing, they had either been funded through another external source, or the organisation had become self-funded, or it was claimed they had become embedded within a larger organisation and no longer needed specific funding. In a majority of these cases, 'sustaining' activities did not mean simply continuing them exactly as funded by the Trust, but rather changing or expanding them, for example to cover other sub-groups (including groups outwith the Trust's remit), to cover more geographic locations, to develop cross-organisational or cross-project elements, or to change activities in response to the wishes of beneficiaries.

Awardees who took part in qualitative interviews were at different points in terms of whether the actual activities funded by the Trust were expected to be ongoing or not. However, their responses to questions about sustainability also illustrated a number of routes by which activities were likely to continue. Several organisations had already secured the continuation of activities beyond the Life Changes Trust-funded period either through securing further funding from other sources, by mainstreaming activities within the organisation's core activities or by incorporating key activities in the mainstream work of other organisations. Secondary analysis of evaluation reports indicated a similar variety in how sustainability was being achieved.

*So yeah, I mean, it's really fundable, and we've got really good evidence, but how long we'll continue to be able to get external funding for it, and then, how we need to look at it. And we have integrated, and kind of mainstreamed a lot of the work into our current work anyway. (Awardee D9)*

Awardees emphasised the value of the evidence they were required to collect about the impact of their activities as a condition of Life Changes Trust funding in securing further funding from other sources.

*But it has also allowed us at a strategic level to evidence that there is a wider benefit to young people, it is not just about the activity they are doing, it's about their confidence, their relationships, their sense of wellbeing and achievement and we have been able to evidence that at a strategic level to persuade our colleagues that we need to continue with that. (Awardee YP3)*

Some projects discussed the point that while they may not take forward the work the Trust had funded them to do themselves post project end, their broader aims were being met by other organisations, or that information and learning generated from their projects could be used in the development of other projects.

For example, the Carers Conference group had created resources for other carers to be able to set up and run their own conferences. However, there were relatively few concrete examples reported of such resources being used by other projects; to date only one other area had taken up the carers conference resources, despite personal efforts to support this process. While the conference organisers felt this was 'a shame', they did feel that there is now more of a focus on community dementia conferences and that TIDE now has 'more of a footing' itself in Scotland to be able to take similar work forward.

The organisations taking forward the legacy work of the Trust will be crucial in ensuring that resources produced by Trust-funded projects can be widely accessible after the closure of either these individual projects or more widely the closure of the Trust itself. The secondary analysis of evaluation reports found that, despite challenges associated with a lack of future funding and resources, overall, we have evidence that at least six of the key Life Changes Trust funding programmes, encompassing 76 projects for all the three groups of beneficiaries, sought to ensure sustainability to continue their activities in the longer-term. The awardee survey and interview data also provided reflections on both the impact of Life Changes Trust funding and the *likelihood*, from their perspective, that this impact will be sustained. The awardee survey suggests that, in most cases, awardees felt impacts were either very, or fairly likely to be sustained.

The Trust has developed a detailed plan for the development of local, regional, and national legacy partners to continue to support transmission of learning gained from Trust activities post its closure. For the Dementia Programme, national legacy partners involve BOLD, About Dementia, and Age Scotland. BOLD, one of the Trust's legacy projects, has also started exploring funding options to enable it to continue to support its existing network of 'partners' who have been through the BOLD programme, while also extending the reach of the programme offer outwith Scotland; ultimately the ambition was for this to become an international programme. At the time of writing this report, the Life Changes Trust had launched a £1m funding programme to identify local legacy partners, who are expected to include Meeting Centres, Dementia Friendly Community Initiatives, and Peer Support projects. In addition, Regional Learning Hubs have been established supporting the Trust's Regional Small Grants Programme.

For projects supporting young people with care experience, a £2.5 million legacy programme has launched, which will include the development of a National Leadership Network to bring legacy partners for the Young People with Care Experience Programme together to focus on leadership in all its forms.



Wider legacy arrangements include a partnership with the Robertson Trust and other organisations to develop the Each and Every Child Initiative to reframe the narrative around the care system and the children and young people in that system, tackling negative attitudes. A Creativity and Care Experience funding call will invest in a collaboration to create a national legacy initiative which will support inclusion through creativity.

Finally, the Scottish Throughcare and Aftercare Forum (STAF) will support the development of a learning channel which will host and further develop all of the Trust's learning resources. There is also a linked Digital Skills element to this work, which will be delivered by a further collaboration of organisations working across Scotland, aiming to make a contribution to tackling the digital divide whilst continuing to be aspirational for young people with care experience.

This programme of legacy activities has been shaped by a panel of young people with care experience and will continue to involve young people with care experience as the key decision-makers, setting the direction and ensuring there is accountability to people with lived experience.

## Sustaining participatory approaches

As evidenced throughout this section, one of the key impacts of the Life Changes Trust has been in the adoption of participatory and co-production approaches by Trust-funded organisations and projects. Examples were evident within the secondary analysis of evaluation reports of Trust-funded projects, with a high proportion of projects being inspired to adopt and sustain participatory approaches in their organisation. For example, the North East Angus Care Home Improvement Group, within the Rights Made Real in Care Homes group, changed their recruitment practices in line with residents' preferences.

*Residents need to be involved in appraising the people who'll be looking after them. They have the right to be able to size up people's levels of caring and compassion. That is our starting point...residents expressed their preference for staff who have manners, which became a criterion that future staff will need to meet. (Project Manager, Recognising, respecting and responding: promoting human rights for residents of care homes in Scotland, p. 29)*



At one care home involved with the Rights Made Real in Care Homes programme, the team developed a set of cards (the “Chatterbox”) to ensure that learning sessions could be shared and discussed with those unable to attend. At another care home, within the same programme, anticipatory care discussions were embedded into six-monthly reviews and work has been undertaken to ensure that anticipatory care planning conversations are meaningful for people living with dementia.

Community groups who became involved in Dementia Friendly Community initiatives have also been supported to think about how local activities can be made dementia inclusive as standard. This increasing sense of universality promotes inclusive services for all that are intrinsically dementia friendly in the future. There is also evidence across the projects of the lasting impact of co-production practices in the Young People with Care Experience Programme.

*Young people definitely have the reins. It is about empowering them. What they have done is really special.* (Partner, Justice sector. Evaluation of the Champions Board Approach Final Evaluation, p. 90)

## What supports sustainability?

Analysis of the multiple data sources discussed in this section highlighted several mechanisms that supported sustainability in continuing work and impact. These included embedding activities in communities, through partnerships with other organisations, and the development of toolkits and resources that support knowledge exchange.

A number of projects across the various programmes sought to enhance the sustainability of their projects through partnerships with other organisations within their local communities. For example, the Life Changes Trust’s Young People’s Advisory Group developed wider linkages with other projects funded by the Life Changes Trust to ensure that impact from its activities could be spread and sustained through other organisations.

*In part, the inclusion of wider voices is achieved through the Group’s wider networks across the care community, including linkages with the Champions Boards. Wider engagement is also achieved through the varied grants programmes, where different young people are beneficiaries.* (Life Changes Trust Advisory Group Report, p. 10)

Several projects from the Dementia Programme also demonstrated benefits to sustainability through collaborative working.

By working collaboratively (and in some cases amalgamating) with local community groups and venues, projects such as Sporting Memories and Evanton Wood have both encouraged their partner organisation to become more inclusive of people with dementia, and in doing so have paved the way for some of the activities to be sustained in the longer term.

Pre-existing projects such as Evanton Wood were viewed as particularly sustainable given that they were already physically embedded within their communities, meaning these relationships were already in place. Among project participants there was also evidence to suggest that the friendships developed within projects will continue resulting in ongoing peer support.

Examples of building such social relationships included beneficiaries starting to meet informally, independently of the project activities. Some of the friendships built through participation in project activities had important implications in terms of sustainability by ensuring the strong informal support networks could flourish within projects and continue within the participant's everyday lives outwith project activities.

Examples where such engagement took place included the Get Outdoors programme, in which a wide range of social activities and friendship groups evolved from the project, as well as the TIDE and DEEP networks, which both became focal points for the social lives of those who attended, alongside their advocacy roles. The beneficiaries involved in the Get Outdoors projects also described looking forward to continuing with activities in the subsequent years.

*We think about going on trips and doing outdoor activities more since working with Froglife. We like going to the allotments, seeing what's growing and meeting different groups and people who are there. We will be doing even more of it next year. (Project staff, Get Outdoors Programme Evaluation Report, p. 34)*

Several of the funded projects sought to embed toolkits and practice guidance within their evaluations and project outputs, demonstrating a commitment to sharing knowledge which could support others to develop similar activities once funded projects have ended.

For example, the Proud to Care LGBT Dementia Project developed a toolkit for practice with the Care Inspectorate with input from Alzheimer Scotland, Hillcrest Future, and Scottish Care providing support. Similar toolkits were also developed by LGBT Youth Scotland Care Experienced Youth Commission to support organisations in their plans to engage with young people with care experience from LGBT backgrounds.

Such tools could support young people with care experience to become more involved in service design or planning.

*Even at the early stages of exploring the impact of the Workforce Development initiative, these examples indicate how young people with care experience are being involved in or influencing service design and planning. Through these activities there is improved awareness of the needs and aspirations of young people with care experience, and there are clear examples of specific changes to policies, protocols and practices. (Designed by Society – Co Design Crew Report, p. 26)*

Projects within the Get Outdoors Programme also developed 'hints and tips' for other projects and practitioners, sharing their learning from setting up outdoor initiatives and providing practical advice on how to support people living with dementia and unpaid carers to participate in outdoor activities. Since concluding in 2019, Aberdeen Council of Voluntary Organisations (ACVO) has produced two dementia toolkits; one for ethnic minority communities looking to access dementia support and the other for practitioners which focussed on tailoring dementia services effectively for people from European Ethnic Minority (EEM) communities. The ACVO continues to contribute to the development of the local dementia strategy in Aberdeen.

At an organisational level, there was evidence of some project activities being sustained through links with other organisations post Life Changes Trust funding. For example, the majority of Dementia Friendly Communities had adopted their own different strategies for securing longer-term funding, often developing from partnerships that had been important during the Trust-funded period. In total, 38 Dementia Friendly Communities continued in some form beyond the end of the Trust funding. Other organisations had also stepped in to support some of the projects; for example, Alzheimer Scotland in Glasgow has adopted approaches and activities from Froglife after collaborating with them, and in Lochaber, the Dementia Enablement Project (DEP) has been absorbed into the Care and Repair team, ensuring activities started and developed by DEP would continue.

## **The impact of the early closure of the Trust**

There was a shared feeling that the Life Changes Trust will be missed by many awardees.

*We have got really strong relationship with our organisations, we have similar values, the people in the teams have similar values, they have challenged us in good ways and vice a versa, I think some of the work we are doing has influenced how they do things as well, so we will miss the Life Changes Trust as an organisation, but the relationship we have with the people we will miss as well. (Awardee YP2)*

*But I think for me it's clear that the Life Changes Trust going does leave a gap. Not just in terms of funding, but in terms of understanding. (Awardee YP7)*

A key part of concerns expressed was related to the gap in funding that some believe will be left once the Trust closes. An awardee from the Young People with Care Experience Programme saw wider risks alongside the closing of the Trust, including the reduction in funding from Europe and the lack of a specific Scottish funder, while another noted that many more organisations will now be going directly to the Big Lottery Community Fund to fill the gap left by the Life Changes Trust. Others in the Dementia Programme noted the lack of funders that have a specific focus on dementia and questioned whether there may have been more scope for smaller projects joining together to make joint bids.

*And isn't it a shame, then, that they are closing the year early? Because for a fixed year, some of that could actually have been worked on, in terms of the sustainability plans, particularly with a lot of smaller projects. (Awardee C1)*

Some organisations were less confident than others that they would be able to secure more funding to continue activities in ways they felt were needed. One view was that the closure of the Trust will leave a gap for activities that might not fit as easily into other funding schemes, including organisations that were not directly focussed on dementia but had been supported by the Trust to expand their work to include people with dementia.

*We applied for that and then we have got another funder that we are going to send a request to as well and I spoke to them at the start of the year and they were really keen. Generally, I think it is a bit slim-pickings unfortunately, so there is not very many options for like charities like us to work with people living with dementia out there. I think that is a real shame because we have done the work, we have shown that it works really well. (Awardee D2)*

The Trust was widely seen as playing a vital role in funding a much wider variety of community-based projects for beneficiaries than would have been available had the Trust not existed.

However, there was evidence to suggest that the closure of the Trust may limit opportunities for funding for many of the organisations and projects providing support to the beneficiaries. Therefore, ascertaining sustainability and legacy of Trust-funded projects beyond its closure will be vital in continuing the momentum that Trust funding has enabled in Scotland.

## 4.5 Conclusions and lessons drawn

Evidence across the project demonstrates that the Life Changes Trust, through its funded programmes and projects, achieved **impact across Scotland for policy and practice**. Across the evaluation there was significant evidence to suggest **new organisations had entered the space** of support for people living with dementia, unpaid carers, and young people with care experience as a result of Trust funding.

Findings from the evaluation demonstrate **impacts on policy and practice at local and national level**, although the level of impact and degree to which impacts might be sustained in the long-term was less certain and varied according to beneficiary groups. For young people with care experience these impacts included both actual policy developments and significantly higher awareness among local policymakers. There was evidence that Trust-funded projects had directly influenced current national policy for young people with care experience.

In relation to people living with dementia and unpaid carers, there was significant evidence of **policy influencing activities**, although there was less evidence for direct impact on policy-making at national level. The evaluation does demonstrate extensive community engagement and close collaborations with local policy actors. There was also strong evidence for influencing in terms of promoting person-centred, rights-based, and co-produced activities. There was clear evidence of influencing work with and by people with dementia and unpaid carers that is well placed to influence national policy in the future.

At an organisational level, the impact of the Life Changes Trust projects was clearly evidenced in policy and practice. There was evidence of **widespread and significant learning within organisations** regarding the needs, wants, experiences, and perspectives of beneficiaries, which led to significant and in some cases transformational change in the services and attitudes of organisations. Reflecting the central role of beneficiaries in Trust-funded projects, meaningful co-production was a practice related change that was well evidenced from local community organisations through to regional or national scale actors, and which led to significant transformational results.

The evaluation also demonstrated the ways in which both Trust-funded projects and their impacts have been or are likely to be sustained. Many projects reported continuation of Trust-funded activities in some form; supported by funding from different sources, mainstreaming activities, and working with others to support sustainability. Lack of funding was the main barrier to the continuation of services and the early closure of the Life Changes Trust had led to concerns among a small number of projects who were likely to face significant funding challenges affecting sustainability of both projects and learning generated from funded activities. The data also raise some interesting wider considerations around sustainability to take forward.

The work discussed in this evaluation demonstrates that meaningful co-production takes time and resources. This work needs to be prioritised, supported, and resourced by policy at national, local, and organisational levels. An understanding is required of the time needed to embed changes in policy and practice.

Networks, partnerships, and community working were key to achieving sustainability, and this was evident at organisational, local, and national levels. Informal networks among group participants and in communities were also shown to be influential and helpful in sustaining projects and activities. Collaboration with statutory agencies was found to be more challenging.

Investment is needed to ensure the resources developed by projects and by the Life Changes Trust itself are updated and kept current, especially in terms of links to active projects and examples of Life Changes Trust-funded work. The Life Changes Trust legacy projects have a key role to play in this and in knowledge exchange work to support dissemination of these resources.

The Life Changes Trust legacy projects, those already funded and those still to be announced, will be key to continuing work with national and local policymakers to influence policy at local and national levels going forward.

The figure below provides the next stage of the logic model, adding in the outcomes and outputs from this stage of the report. This section has provided evidence to underpin significant and important outcomes from the Trust's work and these are summarised in the 'outputs and resources', 'short-term' and 'mid-term outcomes' included in the figure.

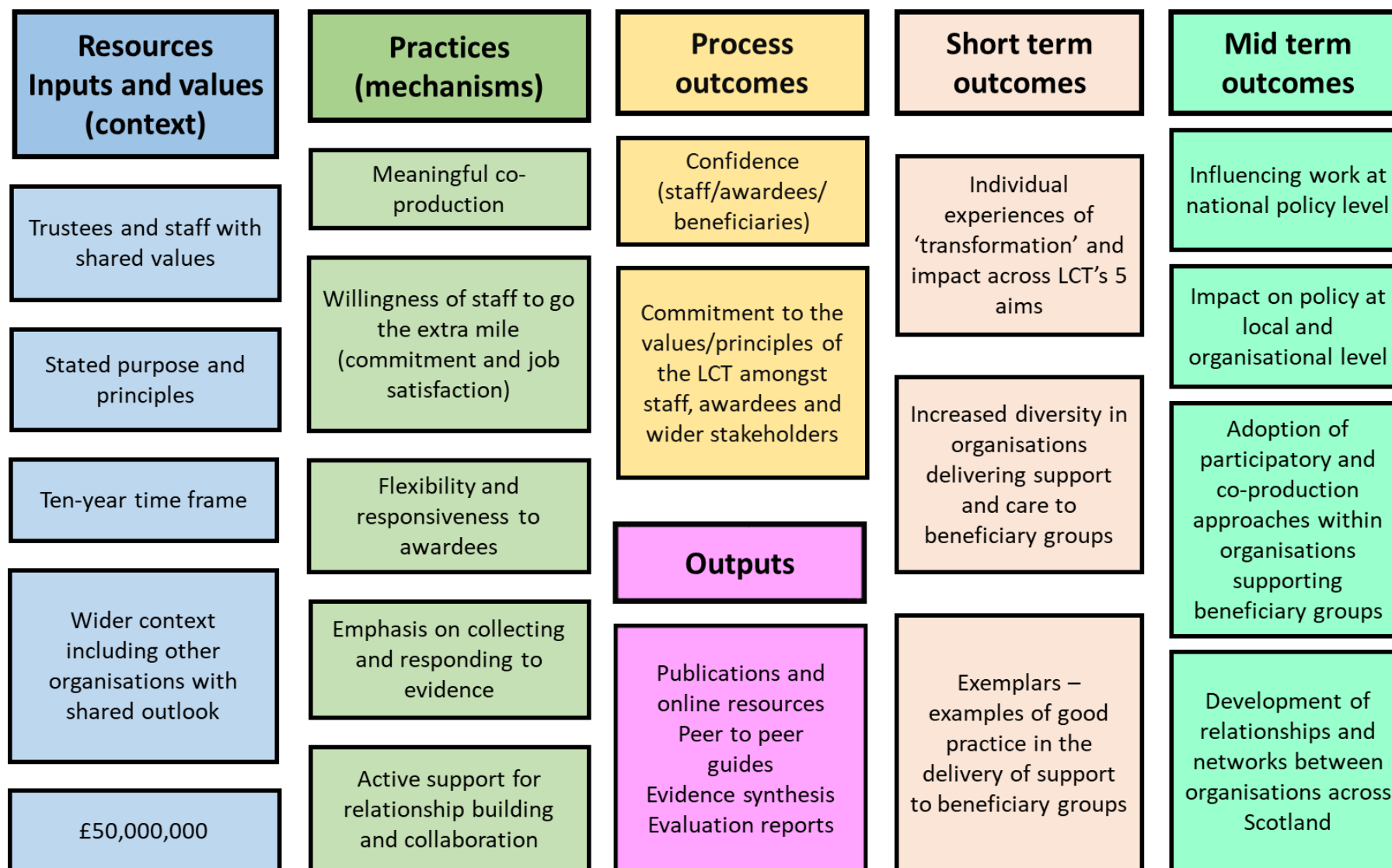


Figure 4.2 Logic model stage three



## 5. Key lessons, implications, and recommendations

### 5.1 Introduction

This section provides conclusions from across both the process and summative aspects of the evaluation and points to the key lessons that can be drawn from them. The summary of the process evaluation reflects how the Trust has worked and what it has achieved by working in this way. This discussion is followed by a consideration of the key findings on impact, focussed particularly on transformational change, sustainability and legacy. The section also highlights a number of key questions that remain at the end of the evaluation, providing issues for consideration in future work and policy focus among the Trust's legacy investments and other partners and stakeholders. We conclude with two pieces of writing from our community researchers in which they consider the legacy of the Trust in relation to the current 'state of play' in policy and practice, as they see it.

### 5.2 How the Trust works to achieve its aims

Across the evaluation, four main themes emerged in relation to HOW the Trust achieves its aims. These themes also reflect core elements of the impact the Trust has had for both beneficiaries and the wider policy and practice context.

- Placing the person with lived experience at the centre – focussing on empowerment, involvement, co-production and voice.
- Emphasising relationships – building, supporting, nurturing and valuing relationships, with beneficiaries, awardees and other stakeholders.
- Learning – valuing evidence and using this to support knowledge exchange and influencing work as well as strengthening sustainability of projects.
- Taking an investment approach – investing substantial time, effort and resources.

## Lived experienced at the core

The importance of lived experience resonated across the evaluation. This was evidenced through the beneficiaries' direct involvement in the work of the Trust as members of the Advisory Group or assessing funding applications; the types of projects funded by Life Changes Trust; consistent work with awardee organisations to help them adopt more participatory practices; and support for beneficiaries to drive the changes that are needed in the wider landscape of policy and practice. Significant investment was made by the Trust in this aspect of its work in time, resources and staff effort.

Benefits to beneficiaries were clearly evidenced in the evaluation, being involved in meaningful ways with the Trust and Trust-funded projects had significant, positive impacts for people from the three groups. For some beneficiaries this translated into concrete support through activities such as leadership training, whilst for others it was the opportunity to build slowly to ever greater active involvement. The Trust's focus on voice, empowerment and participation is strongly reflected in the types of project funded and in the work that those projects achieved and will continue to achieve in the future. Further, impacts evidenced on policy and practice often also related to adoption of participatory practices and more meaningful engagement with beneficiaries.

It is evident in the evaluation that the Trust has worked hard to have a range of voices present and to recognise diverse experiences within each beneficiary group with projects encompassing many different groups of people. It is important to note, however, that there were limits to this engagement and that structural barriers remain that continue to pose challenges to wider engagement.

It was clear from the evaluation that the focus on lived experience and voice needs to extend beyond the Life Changes Trust and projects directly engaged with the Trust. If stakeholders and organisations in the wider policy and practice context do not adopt these practices in a meaningful way, then progress will be limited. The work of the Trust has made significant headway into these arenas, as evidenced within this evaluation, but it is vital the legacy partners continue this influencing work.

## Relationships

The word 'relationship' is peppered throughout the evaluation. In many ways, this finding fits with the growing recognition across the health and social care sector of the value and importance of relationships and relational practice.

However, what was striking in this data were the nuances surrounding the notion of relationships. There was an unusual recognition of their complexity, messiness and often challenging nature. In staff interviews, as well as the secondary data, there was an awareness that relationships had to be developed and could not be assumed as a given. There could be challenges and tensions, particularly in the process of developing relationships between funded projects and Trust staff. Significantly, however, there appeared to be a genuine commitment to making relationships work and to creating authentic, real relationships rather than tokenistic ones.

The value placed on relationships was evident in beneficiary engagement, as reported in the interviews and secondary data. Many participants used family-like language to describe their relationships with the Trust and/or the funded projects. A genuine sense of belonging and nurture shone through these responses and again highlighted that 'voice' cannot be dislocated from the person who embodies it. Relationships were also an important part in how the Trust worked alongside awardees and in the wider policy and practice context, with lasting effects in the networks and communities that have developed with and around Trust-funded projects.

As with the focus on co-production and participatory approaches, resources are needed to support a relational approach in terms of time and funding. Resource was invested in relationship-making, including in staff and project development time, in travel costs, and in creating space and places where genuine communication could take place supported by consistent staffing. Meaningful and authentic relationships can only be built over time and the significant funding available to the Trust was key in enabling this approach to develop and blossom.

## Learning

The idea of the Life Changes Trust as a learning organisation emerged in the very earliest stages of the Trust's development and continues to be evident across its activities. The responses in the awardee survey, the scope and range of evidence collected within project and evaluation reports, and the manner in which evidence is headlined across its website illustrates the commitment to this aspect of the Trust's work. The Trust also demonstrates the value placed on learning from beneficiaries, seeing their lived experience as a valuable source of evidence.

As with co-production and building relationships, this approach also takes time, effort and resources. Findings across the evaluation indicate significant work for both staff and awardees attached to this process.

For staff, there is risk of burnout and stress and from the awardee perspective, there is the challenge of implementing a consistent approach to evaluation and learning across organisations with different evaluation cultures. Further, from our own experience in the field, there was evidence of evaluation fatigue amongst Trust-funded projects due to the number of internal and external evaluations taking place.

## Investment

The Trust was in a distinct and relatively unusual position in having both a significant amount of money and a limited timeframe within which to spend it. The Trust's investment approach was however also supported by the Trustees' active choice to be an 'intelligent funder'.

This notion of investment, rather than simply of 'funding', reflects the willingness of the Trust to commit time and resources to supporting their awardees and beneficiaries, as evidenced across the evaluation. The Trust adopted this investment approach in all aspects of its work, and encouraged those it supported, funded and worked alongside to do the same. They recognised that to effect change, time, effort and resources are crucial; relationships must be built, as discussed, and flexibility in changing circumstances is required.

There is also evidence of investment in beneficiaries, from the early part of the Trust, through the funding of the Advisory Group to the large legacy projects focussing on leadership for beneficiaries from all three groups. It seems clear that the particular combination of £50,000,000 and the timescale of ten years supported this investment approach and underpinned the impact and legacy of the Trust. Equally, the commitment of Trustees and staff as well as awardees, beneficiaries and other stakeholders to this approach, has been crucial in shaping and ensuring that legacy.

Figures 5.1 and 5.2 below provide a visual representation of two steps of a logic model developed across the evaluation to illustrate and explain the work of the Trust. The first figure shows the detailed analysis of the mechanisms that help the Trust achieve transformational change and the second is a summary logic model that links the context and practices of the Trust with the outcomes and legacy. Sections of this model have been included through this report to demonstrate how it was built using the full range of data from the project.

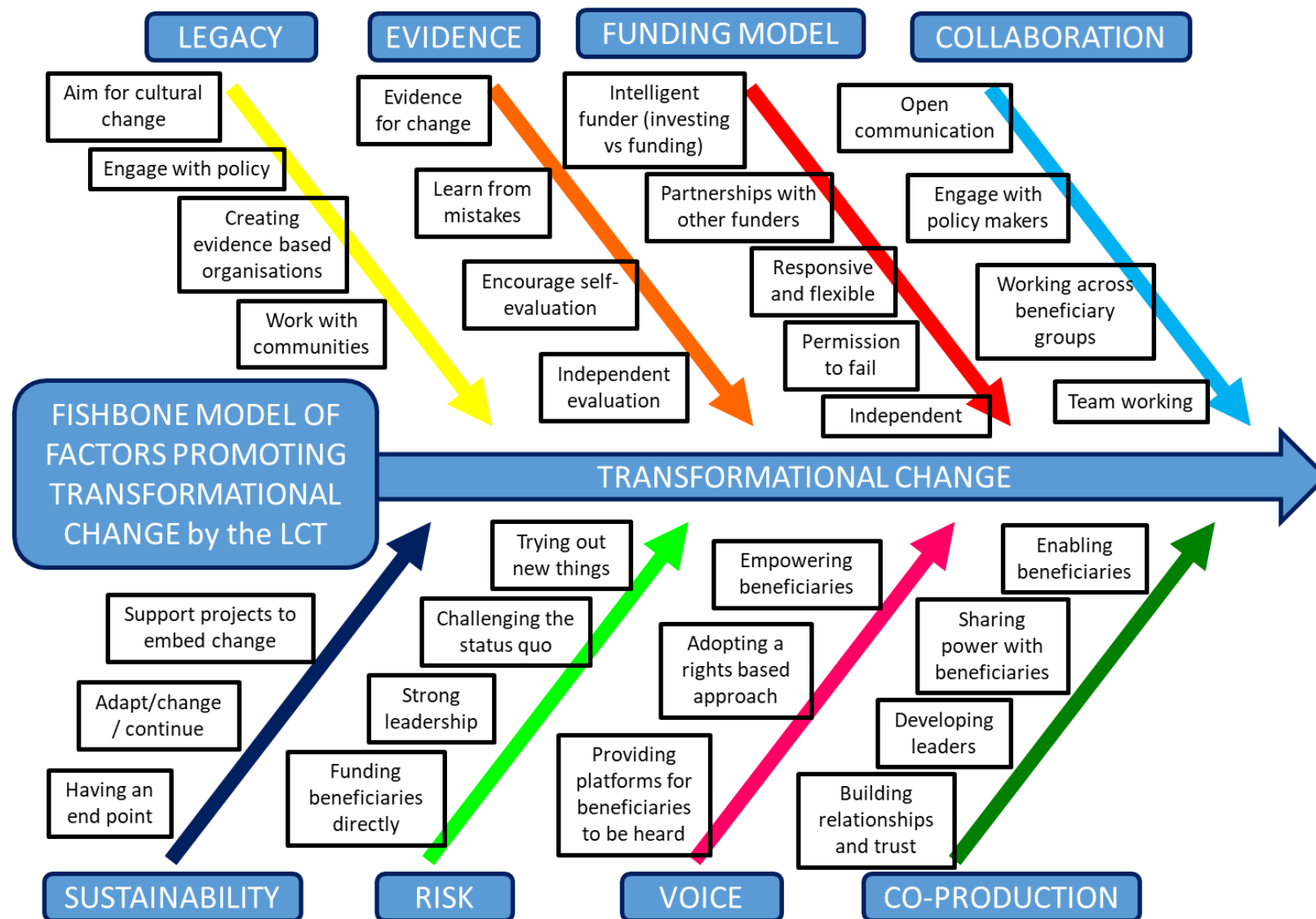


Figure 5.1 Fishbone analysis

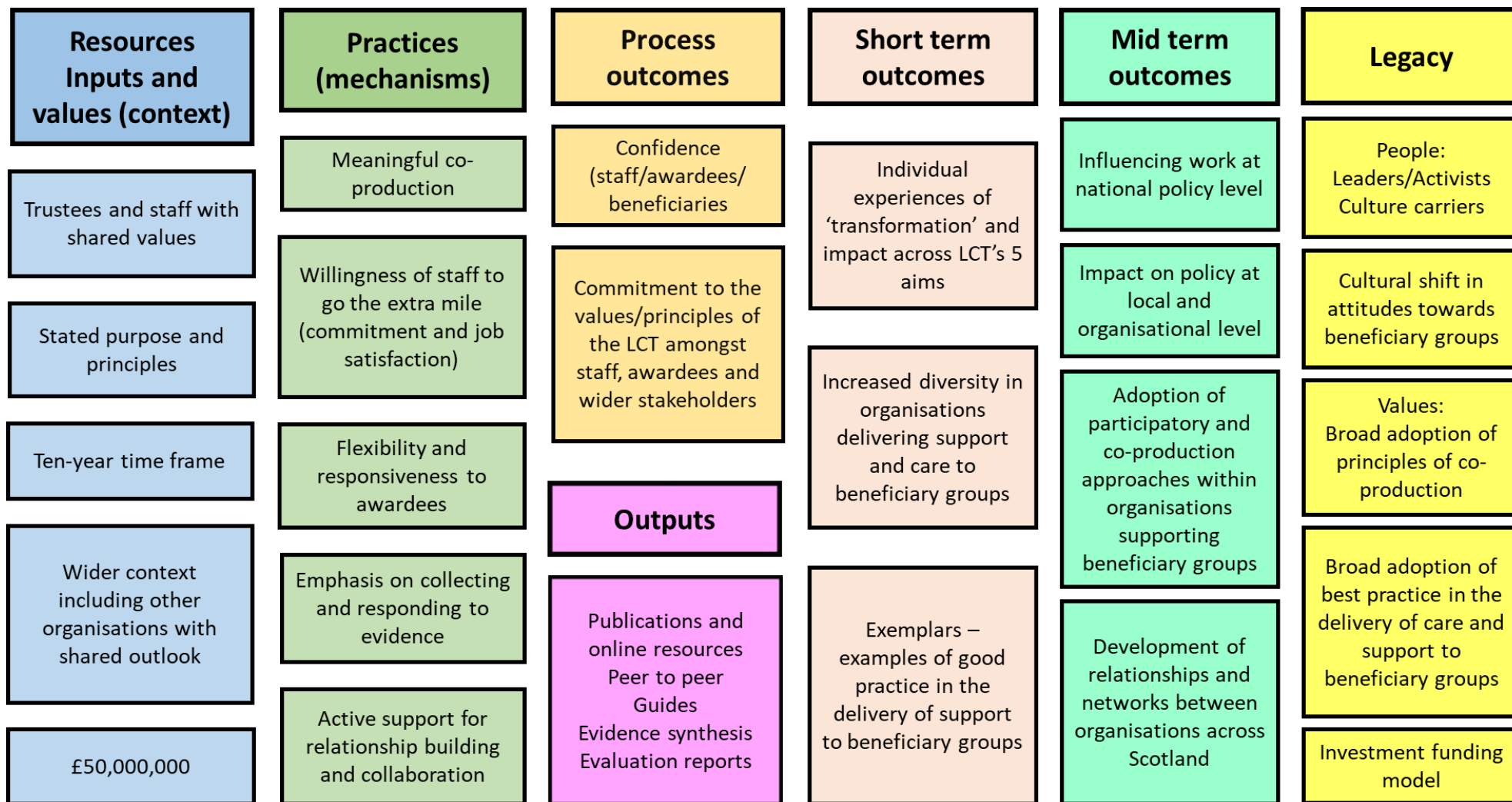
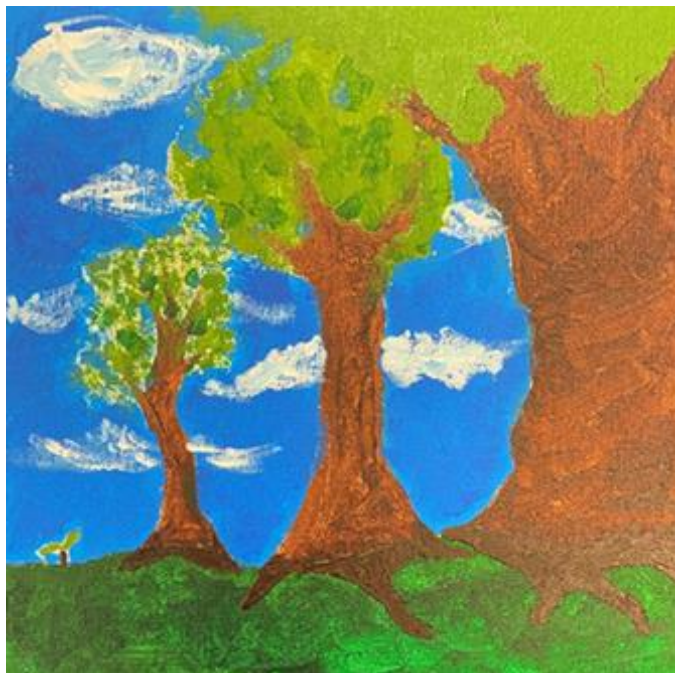


Figure 5.2 Logic model summarising the work and impact of the Trust

## 5.3 Has the Trust achieved transformational and sustainable change?

There were clear aspirations amongst staff and Trustees involved at the start of the Trust for a long-term legacy that would transform the lives of beneficiaries both during the tenure of the Trust and beyond.



*And that was definitely the hope, that the sustainability and the transformational concepts would take root and would actually happen...growing the acorn and then the tree grows and then you just have to say, right, off you go, you know, do it yourself. You know, you're brilliant now, you don't need us anymore. And that's very much what we were hoping at the beginning – we'd get to the end of ten years and people wouldn't need us anymore. (S15)*

This evaluation draws together evidence about how successful the Trust has been in achieving its aims of sustainable and transformational change and within that, how it has supported beneficiaries to experience change in relation to the five aims the Life Changes Trust has in place for its beneficiaries. The Trust's definitions and aims are included here.

**'Transformational change':** a radical change in attitudes, culture and systems which results in a substantial change for the better in the lives of beneficiaries.

**'Sustainability':** the benefits of a project, initiative or shift in culture and practice can be continued in the long term.

Alongside the five aims that the trust holds for its beneficiaries:

- I live in a place that suits me and my needs.
- I am able to be as independent as possible.
- I get the help I need when I need it.
- I feel safe, listened to, valued and respected.
- I am empowered to do the things that are important to me.



## Transformational change

Across the evaluation, members of all three beneficiary groups described a sense of having been individually changed by their participation in the Trust's own activities or in those it funded. For some, this transformation related to a growth in self-confidence or through developing new skills and knowledge, while for others this was about making friends and extending social networks.

Other beneficiaries highlighted how such individualised change had led them to greater levels of activism and involvement in creating change for the wider population. Often this involvement itself fuelled a new sense of belonging to a community which had resulted from getting involved in Trust-funded activities. For these beneficiaries such changes in the way they saw the world and its possibilities were felt to be radical and enduring. They hoped that these individual changes would result in real changes in the external world and the systems in which they had to operate.

Change was also experienced by those working for the Trust. Many talked about how their experience of working for the Trust had altered or strengthened their views and their values. There was a sense of this change being irreversible and indeed, several staff members and Trustees talked about 'next steps' and continuing to advocate and promote the work they had started at the Life Changes Trust. They saw themselves as culture carriers able to influence wider practices once the Trust closes.

For awardees, change was evidenced in their adoption of new practices, often in line with the core Trust values. Most commonly, they emphasised their adoption of co-productive practices. However, new understandings of beneficiary groups and the need to address and challenge stigma and stereotypes were also highlighted. Funded projects also shared experiences of considerable change in the ways that services are delivered.

At the level of local and organisational policy, changes were seen reflecting the participatory practices emphasised above. Several organisations had mainstreamed practices around co-production and some local Health and Social Care Partnerships had adopted Life Changes Trust project models, most notably Dementia Friendly Communities and Champions Boards and local dementia strategies developed in collaboration with the Trust.

The evaluation therefore highlighted many changes that have resulted from Trust activities from personal through to more institutional levels. Some of this change may be viewed as 'radical' and therefore 'transformational' in the Trust's own terms.

At the national level, there was (also) a general acknowledgement however that there is a long way to go in achieving transformational change across all areas covered by the Trust. Influencing change at this level is complex. However, there was a belief that the Trust had helped influence and create momentum for the current movements to radically change the care system for young people with care experience, as reflected in the establishment of the Independent Care Review and the content of The Promise.

There was also optimism that evidence produced by the Dementia Programme had influenced previous dementia strategies, and will influence the fourth Dementia Strategy (delayed due to the pandemic).

Furthermore, the evidence suggests that the Trust's work has helped influence the language used about people living with dementia and young people with care experience, and that these changes in language have laid an essential foundation for wider shifts in social attitudes towards the Trust's beneficiary groups. Evidence needs to be sought to understand the long-term impact of these changes.

## **Sustainability**

The work of the Life Changes Trust was always intended to lead to change that was not only transformational, but also sustainable beyond the life of the Trust itself. Providing a definitive answer to the question of whether the changes described in this report are sustainable arguably requires further research in the years after the Trust closes. However, our analysis suggests that sustainability will be potentially achieved through a number of different mechanisms and processes.

It is important to note however that the Trust's definition and understanding of sustainability encompasses different kinds of change. 'Sustainability' is not, therefore, reducible to projects continuing to do the same thing over time but also about changing attitudes and ways of working and sharing principles.

From our analysis of the experiences and views of beneficiaries across the three groups, it is clear that the impact of involvement in Trust projects was often long lasting and will be sustained when or if beneficiaries are no longer engaged with the project. This includes both impacts for those individuals, and the impacts of the work they undertake as activists and campaigners. For example, leadership skills will be carried forward by young people into their working lives and by people living with dementia and unpaid carers into new roles as activists campaigning for change. Beneficiaries also reported increased confidence and a greater sense of independence and ability to make their own choices following their engagement with Life Changes Trust projects.

These findings reflect notions of sustainability in terms of seeding ideas and influencing others to take forward the key principles that underpin the work of the Trust. However, there are also many examples of successes in the more direct, financial sustainability of Trust-funded investments, where alternative funding has been accessed to continue a project, or a service has been incorporated into mainstream services. As such, there was evidence of a resilience that the Trust helped to build in their awardees. Moreover, staff and awardees themselves reported improved success in their applications for funding and the confidence to innovate.

At the same time however, there was an acknowledged feeling among awardees that the closure of the Trust would leave a gap in the funding landscape, both financially and in terms of the meaningful relationships they had established with Trust staff. This loss will also be felt by beneficiaries who share concerns about the continuation of vital support and services and, for some, close relationships with Trust staff. This underlines the importance of the legacy of the Trust.

## 5.4 Legacy

One of the big questions for this evaluation was to explore the legacy of the Life Changes Trust in terms of what it is leaving behind as the door closes and what the key lessons are for moving forward. Legacy is evident in a number of ways. Most importantly through the people, networks and communities that have been supported and empowered by the Trust, but also through the practices, exemplars and resources that are left behind. People are emphasised throughout the work of the Trust; first and foremost the beneficiaries, but also the awardees and wider stakeholders, as well as stakeholders within policy and practice across Scotland.

There has been considerable work done to create and support networks and communities of practice. This focus on beneficiaries, on relational ways of working, and on investment in people and projects means that the Trust leaves a legacy of people, networks and communities to develop and take forward their aims. These people and networks will continue to enact, develop and share the principles, values and practices of the Trust. The ongoing funding that the Trust has put in place further underlines this commitment to people as a central part of its legacy. Both programmes have leadership schools: BOLD and the National Leadership Network for young people.

The Life Changes Trust staff and Trustees themselves provide another form of legacy for the Trust. As they move into new positions and networks, they will take with them the key principles and practices that the Trust has promoted.

This group act as 'culture carriers' who will help to support further change. Similarly, the resilience that the Trust has helped to build in the individuals and organisations they fund, noted above in relation to sustainability, also provides another element of its legacy. Awardees will continue to work with the Trust beneficiary groups, taking forward the learning and new practices developed during their funding from the Trust. These different groups of people will also work together to create the networks and communities, drawing in a broad range of key stakeholders, which form another part of the Trust's legacy across Scotland and further afield.

Central to this process has been the involvement of beneficiaries in sharing their experiences and working with individuals and communities to influence change from the bottom up. The Trust's work to develop and support these networks through activities such as gatherings and regional events has also been important. The legacy projects already funded and those in the pipeline have potential to form important communities of practice within the wider policy and practice context for the different beneficiary groups. Notably, About Dementia has already established significant networks of connections across Scotland that will support the continuation of the principles and values of the Trust within support for people living with dementia and unpaid carers.

The Trust will leave a wealth of evidence and guidance in the form of documents, videos and online resources that provide advice and ways of doing things. In addition, they will leave models of projects and services across Scotland that can be used as exemplars for further knowledge exchange. A note of caution remains about the need to ensure these resources remain up-to-date and widely accessed.

The Trust itself also embodies an exemplar of an approach to funding. Its responsive and intelligent approach to funding, described above, is something that other funding agencies in Scotland and further afield could usefully learn from; this will be another important aspect of its legacy.



*Recently the Deaf community have produced videos on their website, British Sign Language, and again they're working with Australia, an organisation in Australia, they're now working with them showing them what they've done. So it's interesting to see the ripples that it's not just immediately obvious and how the ripples go further apart, further away. (S27)*

## 5.5 Questions that remain

As will now be evident, the data gathered for this evaluation provided a huge amount of support for the positive impacts achieved by the Trust since its inception. However, it has also documented some of the challenges associated with a new organisation attempting to deliver on such an ambitious remit. In this final section, before we hand over to our community researchers to have the last word, we reflect on areas where we feel there are questions that are worthy of further reflection, not only among the Trust and its partners, but also by the National Lottery Community Fund and other funders who may be considering a similar model.

First, the personal impact of taking a relational approach was evident amongst staff and Trustees who invested hugely in their work, and showed very high levels of commitment to the Trust. It is not possible to evaluate or measure the impact for individuals but it seems likely that this level of commitment and engagement would be challenging to sustain over a longer period. It was noted that the Board was not able to retain members who also had practitioner roles nor young people with care experience or people living with dementia.

This reflects the level of commitment asked of this group. For any similar funding organisation, care and attention should be paid to how staff and Trustees are supported when such a strong focus is placed on building and sustaining relationships. Another consideration when adopting a relational approach is how to manage and support people when relationships end, there was a note of sadness among some beneficiaries about the end of the Trust and some concerns about ongoing support.

Second, there are questions about what happens when a new, well-funded organisation is inserted into the middle of a crowded field of policy and practice for a determined period, and then disappears.

Although this evaluation shows the Trust has had a significant cultural impact, and that this impact is likely to be sustained in various ways, the question of how the hole the Trust leaves in the landscape will be filled both financially and more broadly, is at this point unanswerable and a source of anxiety for some. The fact that the Trust was perceived to have had more impact on national policy for young people with care experience is, as already noted, partly a matter of timing.

However, it may also reflect the smaller size of this population and the more limited number of organisations involved; this smaller arena may have facilitated this faster engagement. Dementia is something that affects many more people and thus involves a much more numerous, diverse and often disconnected group of organisations, projects and people. While the Trust has developed a strong network of diverse organisations and communities within its Dementia Programme that will continue with legacy funding, there remain challenges in the integration of services and support for people with dementia and unpaid carers.

Finally, from our perspective as evaluators and community researchers, we would also like to share a note of caution around the focus on beneficiary activism. Becoming an activist is not the choice of everyone and the people who do choose to become activists often share similarities. There are, for example, more younger people with dementia among current activists than there are older people, a situation that does not represent the wider population of people with dementia. These older voices need to be heard, as do those of marginalised communities. As with all activism, it is also important that quieter voices can be heard. Co-production, as repeatedly evidenced in this report, takes time and effort. There is a risk that some of the Trust's legacy maybe undermined if other organisations adopt practices without also investing in the time and relationships required.

## 5.6 Reflections from the community researchers

Here we include two pieces of writing from the community researchers reflecting on the work of the Life Changes Trust and its place now in the wider policy and practice landscape. The members of the team have all taken long journeys alongside the work of the Trust. They share experiences as beneficiaries, awardees, and activists as well as community researchers. As such they provide unique insights into the Life Changes Trust's impact and legacy.

## Reflections from the community researchers who are people living with dementia and unpaid carers

**Mike Cheung, Natasha Hamilton, Myra Lamont, Martin Robertson, Annette Tait**

Our recent experiences as community researchers on the evaluation of the Life Changes Trust has given us an insight into what has been achieved to improve dementia services over the past ten years. The question that arises however is one of sustainability – *are these improvements sustainable in a changing environment, and have dementia services been sufficiently developed to be embedded in existing health and social care priorities and going forward in a National Care Service?*

From 2010 - 2021 the Scottish Government prioritised dementia, and led the way nationally and internationally with three Dementia Strategies. Each strategy period was for three years. The first strategy made the greatest impact, with funding to support early diagnosis and new initiatives. It also included policy projects, developed by Alzheimer Scotland, such as the Five Pillar model of post-diagnostic support, leading onto the Eight Pillar model of Community Integrated Support, and then progressing on to the Advanced Model of Care. At the same time, post-diagnostic support and Self-Directed support were being piloted and subsequently implemented. This was to bring about transformational change and improvement, for people living with dementia, and for unpaid carers. The Scottish Government Strategy working groups were made up of key individuals from statutory, third sector, voluntary agencies, and importantly people living with dementia and unpaid carers, all of whom made valuable contributions to dementia policy, across Scotland.

During the end term of the first Dementia Strategy, and during a period of extensive activity and changing attitudes to dementia, the National Lottery awarded £50 million to improve the lives of two diverse groups, young people with care experience and people living with dementia and unpaid dementia carers. From this funding, the Life Changes Trust was formed in 2013 and governed by a Board of Trustees. The dementia funding stream took some time to get established, recognised and accepted in the dementia landscape. The Trust got on with the task in hand, engaging widely with local communities, organisations and people living with dementia and carers, listening to what individuals had to say, working with willing partners, building trust and showing a willingness to support communities and individuals.



This was a different approach to the Scottish Government which engaged directly with statutory and third sector parties, along with able individuals who were living with dementia and unpaid carers, through consultation events and organisations like Scottish Dementia Working Group and National Dementia Carers Action Network, both groups supported by Alzheimer Scotland. The findings from these consultations helped inform national strategies, for example the National Dementia Strategy, which recommended different models of dementia care which Health Improvement Scotland were financed to pilot. In contrast, the Life Changes Trust focussed on keeping services local, building Dementia Friendly Communities based on local priorities, working with community groups and encouraging partnerships to apply for funding. It, thereafter, supported successful bids to build their projects, based on five aims for their beneficiaries.

1. I live in a place that suits me and my needs.
2. I am able to be as independent as possible.
3. I get the help I need when I need it.
4. I feel safe, listened to, valued and respected.
5. I am empowered to do the things that are important to me.

The Life Changes Trust had Human Rights at the forefront of all its work. This emphasis on Human Rights and successful models of practice, which evolved locally, such as Dementia Friendly Communities, fits very well with the models of practice proposed in the Scottish Government dementia strategies.

*It has been interesting to see that the themes of respect, support and empowerment have been clear in all the LCT projects I have reviewed as a Community Researcher. These are the same values I have experienced with the LCT since I became involved with them. These skills should be embedded in future work going forward and therefore form part of the LCT legacy. (AT)*

After substantial investment and growth in services for people living with dementia, both by the Government and Life Changes Trust, COVID-19 struck and at a time the Life Changes Trust was coming to the end of its life. The pandemic was a big blow for people living with dementia and unpaid carers, who felt isolated and abandoned during national lockdowns, as services had to shut down and people living with dementia were identified as high risk, because of age and disability. Unpaid carers of those living with dementia in a care home, and those living with dementia in a care home have been really impacted by COVID-19 due to enforced separation. This has really highlighted the need for more work around all five of the principles listed above, as they are no longer an option for care home residents and unpaid carers.

Sadly, there is an argument to be had that the rights and opportunities of those living with dementia in a care home and unpaid carers are vastly different to those living in the community, despite the needs being the same.

TIDE, who have funding from Life Changes Trust, have worked hard with unpaid carers and the Government to try and bridge this gap and highlight the importance of keeping these connections. TIDE has certainly had a big impact in the campaigning around this area. It would be great to see some legacy work around those living with dementia in a care home alongside unpaid carers. Your caring role doesn't stop just because your loved one lives in a care home.

The impact on individuals has been detrimental, as dementia is a progressive neurological degenerative condition. Unpaid carers have carried excessive burdens during this time, the majority of whom were left unsupported, despite Local Authorities having responsibilities to offer Adult Carer Support Plans. (Carers Scotland Act 2016, Carers Charter 2018).

*The LCT supported me to become involved in peer-to-peer work, organising conferences by carers for carers, attending conferences to share my experience and provided peer funding to develop peer-to-peer resources. Not only did this help me it helped other carers who had no support other than from peers. The legacy of the LCT for unpaid carers is only the beginning, a lot more work and campaigning needs to be done with Local Authorities and local Carer Centres to raise the profile of unpaid carers of people living with dementia. (AT)*

We now move into a period of uncertainty: NHS services are changing and under pressure, the development of a National Care Service, the end of the Life Changes Trust and many more changes to the delivery of services by the voluntary sector who provided dementia services. Funding streams depleted and services redesigning with fewer staff, raises big concerns especially as continued funding is not guaranteed as services shut down.

*This is being done in the here and now with Scottish Government recovery plan commitments to improve services for people living with dementia and unpaid carers. I fear it is over ambitious at a time when services have been reduced or redesigned to meet changing demands due to COVID, in addition some projects are at the end of funding. Who will be accountable to fulfil these commitments? (MR)*  
*I also fail to understand why health and social care record systems are incompatible and records unable to be shared, causing real frustration for people with dementia. (MR)*

The Life Changes Trust has been planning an early closure and has been proactive in forward planning, developing legacy partners centrally and locally, to continue the work of the Trust. The Life Changes Trust has been of enormous value to Scotland and its people. In addition, they developed many resources built on practice and by peers as evidence of good practice, and these resources will need to be reviewed and up-dated regularly. But, the question about sustainability is still concerning - *is this enough to continue the exceptional work that has taken place for people with dementia and unpaid carers over the past ten years?*

On a positive note the Trust has empowered individuals to work on dementia both through organisations and by themselves.

*I truly believe that the main legacy has been the empowerment of individuals, such as myself, and many others. This cannot be quantified financially, which makes it difficult, but the legacy can be seen in the peer-to-peer groups being set up, the fact that both Civil Servants and Ministers are willing to listen to us either as individuals or through organisations different to the ones used in the past. The Trust has also produced a report regarding The Social Credit of projects; this entails extrapolating the amount saved per Pound spent. The results were all positive, and would be for virtually all projects. This report allows campaigners et al to show potential funders, in particular local Health and Social Care Partnerships, that money spent now will be money saved in the future, and not in the far future. It literally shows that "it doesn't always have to pay to be grippy". (MR)*

Going forward, the Government is maintaining its commitment to keep dementia as a priority in its COVID-19 National Recovery Plan and is currently consulting with the legacy partner of the Trust, Age Scotland and other relevant parties.

Over the years of Dementia Strategy and the Life Changes Trust, evidence of dementia practice models and resources have been developed, that are successful and sustainable with appropriate funding. Building on these models of dementia care should be a priority in a National Care Service in Scotland. Strong leadership, networking and commitment will be required to keep dementia high on the agenda as health and social care is going through reform during a pandemic and subsequent recovery, while at the same time developing a National Care Service.

Government, local government, statutory, third sector and voluntary organisations all need to put their differences aside and work together to rebuild dementia care and services, post COVID-19.

## Reflections from a community researcher with care experience on recruitment and legacy

**Allan Othieno**

I think the Life Changes Trust has made at least some progress on all five of its principles for advancing the interests of young people with care experience, and on the fifth point in particular: *I am empowered to do the things that are important to me.*

The WAC Ensemble is a project close to my heart. And I think the WAC Ensemble project alone has massively empowered young people to pursue things that are important to them. Obviously, for the WAC members, but also for the audiences who are inspired by the WAC's stories. Some of whom have gone on to make a first foray into the performing arts (and discovered that they are absolutely brilliant at it!). But also for less theatrically oriented young people - who have seen how other people like them can stand up and just shine. Sometimes when you see the light in other people it coaxes from you the obligation to let your own light shine. Which can manifest itself in any field/occupation/hobby so long as there is passion.

I have seen first-hand this emboldening and empowering effect. Which will outlast the Trust itself. And so will the WAC Ensemble that the Trust started. So that is an honourable mention.

Unfortunately, this can be contrasted with a problem within the care experienced community. A problem that we struggled with in recruiting young people as co-researchers. It is my opinion that coming from the background of care experience comes with difficult problems that are woven deeply into day-to-day life in such a way that it can be difficult to engage in long term projects. Some examples:

- The stigma surrounding care-kids can nurture a fear of being "discovered". This can be profound and last an entire childhood. It should then be no surprise that such children grow up to be adults with a well-developed habit of wariness about the notion of outing yourself. Even anonymously. To be part of the co-researcher team you would have to stand up and declare "I have care experience". Not knowing who exactly you are declaring it to and what might come of it.

- The reason one has care experience in the first place. This may include a complicated family structure. The ongoing relationships therein can be difficult and demanding. Or the complete lack of such a relationship can also be challenging. This continues long after care experience itself.

Childhood trauma, and harder-to-define psychological issues, that are born from hardship during key developmental stages, are not easily compartmentalised and can make any long-term commitment **seem** daunting, unpleasant, or impossible. Regardless of how accessible and accommodating the research team is, how it **seems** - that is the critical element in recruitment. Here, I am eager to proclaim emphatically that the Stirling Uni Team went above and beyond, and were incredibly welcoming and supportive in every way imaginable.

But the life-long difficulties that follow from care experience can run deep. So, it is my recommendation that future projects with young people with care experience also budget for a facilitator with therapeutic/counselling background. Someone to be available to the care experienced people for support and 1-1 sessions. Not a full course of cognitive behavioural therapy or anything like that. But someone to call whose role is explicitly to offer psychological support should it be required. The model I have in mind is the one used by Scottish Youth Theatre and their partnership with Pure Potential Scotland. Framed correctly, this could be an effective way to retain young people on projects longer term. (And for what it's worth I think this could be an effective/helpful policy more generally. Lots of people could benefit from a little therapy).

To end on a positive note – it is my view that the Life Changes Trust has been a shining example of how a major organisation can make huge and impactful progress, using a human, compassionate, and sensible ethos. I believe that the demonstrated success of this empathetic approach has been enlightening to many similar organisations across Scotland; and has been encouraging to other organisations who already have a similar view. Through the research we have done, I now think that significant meaningful progress has been made in the national attitude towards young people with care experience. Both from service providers and in general. And that the Trust has played a meaningful part in pushing forward that progress.



