

Independent Living Fund

Northern Ireland Impact Evaluation

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Foreword

This Report reveals, empirically, for the first time, to politicians, professionals and the public generally, what recipients of the Independent Living Fund, their families and friends have known for years: that it is genuinely life enhancing, essentially life giving, clearly cost effective and exceptionally law abiding.

Independent living is all about freedom for disabled people. It means the freedom to choose and control your own life, the freedom to determine and decide what you do, when, where and how you do it, and with whom, the freedom to live a life worth living.

The pages that follow show just how much the Independent Living Fund contributes, uniquely, to making freedom real for its recipients, and, by extension, their families and friends. The evidence of their lived experiences detailed here is remarkable in itself and for its consistent praise of the Fund.

Just as remarkable is the tenfold plus social return on investment calculation, taken from the research findings. It offers a distinct insight into the financial benefits of the Fund for society as a whole.

Conclusively, it is clear throughout that the Independent Living Fund goes some way to fulfilling the Government's obligations under Article 19 of the United Nations Convention on the Rights of People with Disabilities and, as such, is a prime example of best practice.

For all this, my heartfelt thanks goes to Emma O'Neill and Finbarr Fitzpatrick, for producing such a comprehensive, complete and influential piece of work, and to everyone else for contributing so willingly to this Report, especially those who bared their souls and told their very personal and private stories so that others might benefit.

Please, allow me to commend it to you, with praise, pleasure and pride.

David McDonald Chairperson Independent Living Fund Scotland Northern Ireland Stakeholder Group

Acknowledgments

We would like to express our sincere gratitude to the Independent Living Fund Scotland (ILFS) recipients and award managers who contributed to the impact evaluation, without your input the project would not have been possible.

We would also like to thank the ILFS Northern Ireland Stakeholder Group, ILFS and the Department of Health for their on-going support.



Executive Summary

There are 448 people receiving the Independent Living Fund Scotland (ILFS) in Northern Ireland (NI), with funding for 2019/20 financial year totalling £6.85 million. The fund was originally set up in 1988 as a dedicated financial resource for people with disabilities whose needs had previously meant their only options were residential care settings or a very restricted life. The fund tops up resources provided by local Health and Social Care Trusts (HSC Trusts) for individuals with the highest levels of assessed social care needs. ILFS recipients or their appointed award managers receive a cash payment that they use to either purchase services and/or employ their own staff to meet their assistance needs.

The fund aims to make a positive difference to recipients' lives in the following areas:

- Having choice and control to manage support and lifestyle preferences.
- Keeping fit and well in body and mind to maintain mental and physical health.
- Keeping safe and well inside and outside of the home.
- Undertaking work, learning, training, hobbies and interests.
- Maintaining relationships with family, friends and the community.
- Supporting informal carers to continue to provide assistance.

In 2010, the UK Government closed the Independent Living Fund to new applicants after a series of reviews by the Department for Work and Pensions (DWP) indicated it was no longer financially sustainable. The original ILF UK closed in 2015, with funding for existing recipients transferred to authorities in England and to devolved administrations in the rest of the UK. Based on the feedback provided during public consultation, the NI Executive Government determined the best option to manage the fund going forward was to form a successor body that would continue to provide funding in its original form.

A similar approach adopted by the Scottish Government resulted in the establishment of ILF Scotland (ILFS), which then undertook responsibility to administer the funds to people in Scotland and NI. A key priority for ILF Scotland is to ensure disabled people are at the heart of everything they do, which led to the formation of Stakeholder

Groups who include recipients, award managers and other key stakeholders to advise, guide and bring their lived experiences to the forefront of the organisation.

In April 2019, the NI and Scotland Stakeholder Groups came together for the first time; recipients highlighted the vital contribution the fund makes to their lives and together with non-recipients of ILFS raised the prospect of the fund reopening to new applicants because they wanted other people to have the same opportunities to achieve independence. In response, the Department of Health (DoH) Permanent Secretary, Richard Pengelly committed to a scoping exercise in order to prepare a proposal for consideration when the NI Health Minister returned to office. At the following ILFS NI Stakeholder Group meeting, the group discussed the need to build an evidence base to demonstrate the impact of the ILFS funding that would assist the proposal development.

Evidencing Outcomes

We co-designed and developed the impact evaluation with the NI Stakeholder Group to evidence:

- Direct impact for recipients
- Indirect impact for family, informal carers and their community
- Extended financial impact and social value

CILNI collected data primarily through an impact survey sent to all 448 recipients and/ or award managers. In total, 120 (27%) surveys were returned (recipients n=105, award managers n=15). In addition, CILNI collected eleven personal stories of using the fund by six recipients and five award managers who were immediate family members. CILNI obtained quantitative data relating to the employment of Personal Assistants (PAs) from its Payroll Service and ILF Scotland and it completed informal interviews with five PAs employed via the fund. CILNI gathered further information from two HSC Trust SDS Implementation Officers. It then analysed qualitative data using Thematic Content Analysis (TCA) and monetised and valued using Social Return on Investment (SROI) methodology.



Direct Impact

CILNI evidenced the direct impact of the ILFS funding for recipients using survey and personal story data. Initial analysis of the survey data indicated the fund made a difference to recipients at home (n=110), in the community (n=95), to health and emotional wellbeing (n=106) and in the areas of employment (n=8) and education (n=15). However, thematic analysis of the survey and personal story responses highlighted significant overlap of these domains as outlined in Table 1. Recipients directly attribute these outcomes to the ILFS funding and consider life without the fund as comparable to death. Over a minimum of 10 years, the combined influence of emotional wellbeing, health maintenance, sustaining natural support and 'getting on with life' demonstrate a clear preventative effect because recipients are better positioned to manage and overcome challenges they encounter in daily life. Based on this data alone, the fund has clearly achieved its original aims to make a positive difference to their lives.

Outcome	Sub outcome
Emotional wellbeing	Reduced isolation Feeling safe Optimism and motivation Choice and control
Health maintenance	Medical/health appointments Exercise and being active
Sustaining natural support	Informal carers Relationships
'getting on with life'	Employment and education Future planning
Prevention	Learning to be independent Sustaining natural support Early intervention

Table: Recipient Impact

Indirect Impact

CILNI was able to evidence indirect impact of the fund on family and informal carers where family members typically provide naturally occurring support systems surrounding recipients. Analysis of survey and personal story data indicated they too attributed input from the ILFS to their emotional wellbeing through improved mood and feeling better able to cope with their caring role. Aging parents of recipients outlined having the fund in place meant they could plan when they would be less able to provide informal assistance. As with the recipient data, the collective impact of these outcomes over time demonstrates the preventative effect of the ILFS funding because it has reduced the likelihood of a breakdown in the natural support surrounding the recipient and sustained the natural context of the relationships between family members.

PAs – Recipients and award managers preferred to choose PAs to meet their support needs. The evidence gathered suggests that ILFS funding indirectly affected PAs because it not only created employment opportunities within the community but was also the preferred option for PAs in comparison to other types of caring career options. They describe a reciprocal relationship with their employer, better rates of pay, and professional development opportunities. They also highlighted the personal fulfilment and motivation they felt within their role.

HSC Trusts – The impact evaluation has provided some evidence that suggests another indirect impact of the ILFS funding is how it facilitated a learning process for HSC Trusts, particularly in relation to the implementation of SDS. While it was only possible to collect limited data, the information provided demonstrates a positive influence on the broader social care context in NI.

Independent Living Movement (ILM) – The ILM strongly advocates that resources should be provided in ways that enable people to have choice and control over their support and lifestyle choices. The impact evaluation demonstrates why this model of resource provision works. Even in the presence of the highest level of assessed support needs and associated risk factors, people can achieve independence and sustain this over an extended period. Assistance has reduced some of the practical barriers disabled people face on a daily basis and in line with the ILM, people are living their lives with choice and control and are present and active in their communities. Notably, some of the recipients in this evaluation use their funding to actively campaign for the rights of people with a disability.



Extended Impact

The social value generated by ILFS for a range of stakeholders demonstrates extended impact and value for money. The ILFS, through its £6.85 million allocation to Northern Ireland recipients in 2019 generated a social value of £1: £10.89. This is based on a Total Present Value of £74,569,097 created against the input of £6,850,000.

The calculations applied financial proxies to twenty-one outcomes for five material stakeholder groups evidenced through the primary and secondary research. Value accrued per stakeholder is segmented below:

Stakeholder	Social value £	%
ILFS Recipients	£57,279,460	77%
Health & Social Care Trusts (HSCTs)	£15,029,490	20%
Personal Assistants	£1,509,353	2%
Family/Carers	£691,969	0.9%
Northern Ireland Civic Society	£58,825	0.1%
Total	£74,569,097	100%

Discussion

Based on the findings of the impact evaluation, the ILFS has achieved considerably more than its initial intentions, which strongly support the NI Executive Government decision to retain the fund in its original form. The direct, indirect and extended impact of the fund emphasises the importance of the current scoping exercise when examining if and how the fund could reopen to new applicants. Additionally, with no known publicly available literature to suggest the fund was set up as a preventative measure, ILF Scotland may wish to consider how it can further evaluate and utilise this as an invaluable learning resource for the broader social care and independent living contexts.

The social value generated by ILFS for a range of stakeholders demonstrates good value for money. ILFS recipients accrue the greatest value but the £15,029,490 value for Health & Social Care Trusts is noteworthy given the current pressures on their budgets. The biggest contributor to this figure for HSCTs is the savings accrued through reduced admissions to residential care facilities. In excess of 90% of recipients who responded to the questionnaire felt that in the absence of ILFS funding they would have had to move into residential care.

The SROI findings therefore augment the evidence base for the impact of the fund in two key areas namely, the outcomes achieved for recipients and external stakeholders and value for money.





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Abbreviation table

Centre for Independent Living Northern Ireland	CILNI
Department for Work and Pensions	DWP
Department of Health	DoH
Direct Payment	DP
Health and Social Care Board	HSC Board
Health and Social Care Trust	HSC Trust
Independent Living Fund Scotland	ILFS
Independent Living Movement	ILM
Member of the Legislative Assembly	MLA
Northern Ireland	NI
Personal Assistant	PA
Personal Budget	РВ
Self Directed Support	SDS
Social Return on Investment	SROI
Thematic Content Analysis	ТСА
United Kingdom	UK



1.0 Introduction **1.1 Independent Living Movement**

Independent living is a philosophy, a way of life and is represented by a worldwide movement of people with disabilities, working together for the same equal rights and opportunities as non-disabled people.¹ While there are varying definitions of independent living, many people living with a disability describe it as:

'having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means the right to practical assistance and support to participate in society and live an ordinary life'.²

Underpinned by the Social Model of Disability, the Independent Living Movement (ILM) highlights the systemic barriers, attitudes and exclusions by society (directly and indirectly) that act as a causative factor in disabling people. While physical, sensory, intellectual/learning, or psychological variations may result in individual functional limitations; these do not have to lead to disability because society should take account of and include people regardless of their individual differences.³ The global ILM has been fighting for disabled people's rights since the 1960s and gained significant traction, especially with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁴, where Article 19 entrenches the right to live independently and to be included in the community.⁵

From the early 1970s in the United Kingdom (UK), people with disabilities and their representative organisations have campaigned for, and won, important changes to policy and legislation that meant for the first time they could aspire to the same 'ordinary lives' as non-disabled people. Importantly they highlighted the need for resources to be provided in ways to enable people to have choice and control over their own support needs.⁶

⁴ European Network on Independent Living. Independent Living Heroes: Past, Present and Future, 2017. Available at: https://enil.eu/wp-content/uploads/2017/10/Independent-Living-Heroes-%E2%80%93-Past-Present-and-Future.pdf One of those achievements was the Independent Living Fund (ILF), set up in 1988 as a direct result of opposition to changes in the benefit system⁷. Using eligibility criteria, the ILF topped up funding available from local authorities across the UK. This was in recognition that those with the highest levels of support needs required assistance that local authorities did not provide. The ILF funding made a major difference to individuals whose needs had previously meant their only options were residential care settings, or a very restricted life for them and their families.⁸

1.2 History of the Independent Living Fund

Set up as a national resource, the ILF UK was dedicated to the financial support of disabled people, enabling them to choose to live in the community rather than residential care. Recipients typically used funding received from the ILF to employ a personal assistant (PA) or a carer. Although government-funded via the Department for Work and Pensions (DWP), the ILF was a non-departmental public body that operated as an independent and discretional trust fund managed by a board of trustees.⁹

The original fund closed to new applicants in 1993, with the implementation of the Independent Living (1993) Fund for all new applications from 1993 to 2007, with the applied eligibility criteria:

- Resident in the UK for at least 26 weeks per year.
- Receive social services support worth at least £340 per week.
- Receive or be entitled to the highest rate care component of Disability Living Allowance.
- Have less than £23,250 in savings or capital (including savings and capital of their partner).
- Live independently in the community rather than in residential care.

The amount of funding a person receives is based on an individual needs assessment that details how much care they need, how much it will cost and any personal contribution a person is expected to pay towards their care.



¹ Centre for Independent Living Northern Ireland. Available at: https://cilni.org

² What is Independent Living? Independent living in Scotland. Available at: http://www.ilis.co.uk/independent-living

³ Swansea Association of Independent Living. The Social Model of Disability. Available at: https://sail-swansea.org.uk/the-social-model-of-disability/

⁵ United Nations Convention on the Rights of Persons with Disabilities. Article 19 – Living independently and being included in the community. 2006. Available at: https://www. un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html

⁶ Campaigns in Action. Disabled People's Struggle for Equality. June 2018. Available at: https://dpac.uk.net/wp-content/uploads/2016/09/ILF_Report_Draft6.pdf?1ae85c

⁷ National Health Service. A Disability History Timeline. 2013. Available at: https://www.merseycare.nhs.uk/media/1749/disability-timeline-2013.pdf

⁸ Inclusion London. One year on: Evaluating the impact of the independent Living Fund. Available at: https://dpac.uk.net/wp-content/uploads/2016/09/ILF_Report_Draft6.pdf?1ae85c

⁹ The closure of the Independent Living Fund (ILF), House of Commons briefing paper. Number 07787, 28 February 2017. Available at: https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7787

If a person applied before April 1993, the maximum payment is £815 per week.

If a person applied after April 1993, the maximum payment is £475 per week.¹⁰

In 2008, the funding for the ILF was changed from a demand-led to a cash-limited basis due to the increasing number of applications to the fund; eligibility criteria were also changed to focus support on the applicants with the greatest needs. Further changes to the eligibility criteria were implemented in 2010 due to budgetary decisions taken by the previous UK Government. However, a defined increase in applications put the ILF budget under significant additional pressure and concerns emerged for the need to protect existing recipients. As a result, the trustees took the decision to permanently close the fund to new applicants.¹¹

Following a series of consultations and reviews in 2012, the UK Government announced that the ILF UK would permanently close, with funding for existing recipients transferred to local authorities in England and to the devolved administrations in the rest of the UK. on 30 June 2015. During this time, many disabled people raised significant concerns, including a number of legal challenges to protect the fund and the difference it made to their independence. However, the High Court and Court of Appeal upheld the DWP position that it was no longer a financially sustainable model in light of significant changes to social care policy and provision since the inception of the fund.¹²

After public consultation, the NI Executive Government announced that recipients from NI who previously received funding from the ILF UK would continue to receive funds through ILF Scotland (ILFS) when it was established on 1 July 2015. The Health Minister, Mr Simon Hamilton indicated *'my decision to implement these new arrangements is underpinned by the outcome of my Department's public consultation on how ILF users in NI would be best supported after the closure of the ILF UK. It was clear that the majority of respondents preferred Option 2: Form a successor body.*¹³

Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/184151/closure-of-independent-living-fund-eia.pdf ¹² Independent Living Fund Post Closure Review. Department for Work and Pensions. January 2017.

Available at: https://www.gov.uk/government/publications/independent-living-fund-post-closure-review

¹³ Northern Ireland Assembly, Written Ministerial Statement,

NEW ARRANGEMENTS FOR THE FUTURE SUPPORT OF INDEPENDENT LIVING FUND USERS IN NORTHERN IRELAND, 19 May 2015.

Available at: http://www.niassembly.gov.uk/assembly-business/official-report/written-ministerial-statements-2011-2016/department-of-health-social-services-and-public-safety--new-arrangements-for-the-future-support-of-independent-living-fund-users-in-northern-ireland/

Since then ILF Scotland has continued to provide funding for people in NI, with funds administered by the same staff who administer funds for people in Scotland.¹⁴ Currently there are 448 recipients in NI¹⁵, with funding for 2018/19 financial year totalling £6.85 million.¹⁶ When ILF Scotland was set up it committed to having disabled people at the heart of everything they do. In both NI and Scotland, Stakeholder Groups were established to provide advice, direction and lived experience to help inform how the organisation should operate. Disabled recipients chair the Stakeholder Groups, which have over 30 members including recipients, award managers and other key individuals who have a primary stake in the organisation.

¹⁴ Thttps://ilf.scot/northern-ireland/



 ¹⁰ The Independent Living Fund. NI Assembly briefing paper. Number NIAR 192–13, 11 March 2013. Available at: http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2013/social_dev/4413.pdf
¹¹ Closure of Independent Living Fund (ILF) and integration into mainstream care and support system. Department for Work and Pensions. 18 December 2010.

 $^{^{\}rm 15}\,$ Data obtained from ILF Scotland. 15 November 2019.

¹⁶ Data obtained from ILF Scotland. 11 November 2019.

1.3 The role of ILFS for NI recipients

To demonstrate the role of the ILFS for people in NI, Figure 1 outlines a recipient model of independent living. Each layer of the model interacts with the other to achieve independent living and will naturally change or evolve over time.

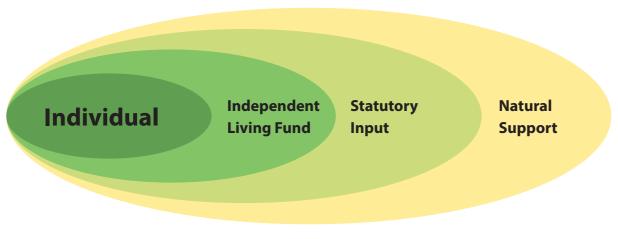


Figure 1. ILFS Recipient Independent Living Model

Individual: The individual is at the core of the model, represented by their personal traits and characteristics. These include physical and emotional health, support/ assistance needs and individual lifestyle preferences and choices.

Natural Support: Surrounding the individual is the naturally occurring support that is available to them. The level of natural support available to an individual is unique to their circumstances, but is often provided by parents, siblings, children, extended family, spouse/ partner, friends, neighbours and others in the community.

Statutory Input: The third layer of the model consists of the statutory input provided by HSC Trusts. In NI, social care is delivered using Self Directed Support (SDS)¹⁷, which places emphasis on promoting independence and personalisation of care, through the provision of care in the right place at the right time.¹⁸ When a HSCT assess an individual as needing personal social services, they allocate them a Personal Budget (PB). The individual has four options to choose from to decide how they will use their budget to meet their support needs.

Option 1 - Direct Payment

A Direct Payment (DP) is a cash payment made to individuals or their representatives in lieu of services the HSCT would otherwise provide. People can then use this payment to fund the employment of Personal Assistants or purchase goods or services.¹⁹

Option 2 - Managed Budget

Individuals can opt to have their PB managed by a service provider of their choice. Their HSCT can arrange to make payments directly to the provider.

Option 3 - Trust Arranged Support

Individuals can choose their HSCT to make the appropriate arrangements to meet their assessed care and support needs. This typically includes domiciliary services, day care and residential settings.

Option 4 - Any combination of Options 1-3

The last option is any combination of options 1-3 that are tailored to provide support appropriate to needs. For example, a DP might be used to employ a PA for support in the community, while Trust Arranged support may work better for other needs.²⁰

Independent Living Fund: The final layer of the model and most distant from the recipient, represents the financial input received from ILFS. Similar to a DP, the award can be used to pay for personal care and domestic assistance and aims to make a positive difference in the following key areas:

- Having choice and control to manage support and lifestyle preferences.
- Keeping fit and well in body and mind to maintain mental and physical health.
- Keeping safe and well inside and outside of the home.
- Undertaking work, learning, training, hobbies and interests.
- Maintaining relationships with family, friends and the community.
- Supporting informal carers to continue to provide assistance.²¹



¹⁷ Self Directed Support. Health and Social Care Board. Available at: http://www.hscboard.hscni.net/sds/

¹⁸ Department of Health Social Services and Public Safety. (2011). Transforming Your Care; A Review of Health and Social Care in Northern Ireland. Belfast: DHSSPS Available at: http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

⁹ Direct Payments have been available in NI since 1996 through the provisions of the Community Care (Direct Payments) Act (1996) later amended to include all eligible service users through the provisions of the Carers and Direct Payment Act NI (2002).

²⁰ Self Directed Support. Health and Social Care Board. Available at: http://www.hscboard.hscni.net/sds/

²¹ Independent Living Fund Scotland. Your Responsibilities. www.independentlivingfund.scot

2.0 Aim

The aim of this project is to develop an evidence base that demonstrates the impact of ILFS funding for NI recipients. We place particular emphasis on how the funding facilitates independence for existing recipients, how they use their funding, and what impact this has in their daily lives. The project will also consider if and how ILFS funding indirectly benefits immediate family or primary carers and the wider community in which recipients live. Outcomes and impact for all material stakeholders (existing recipients, families, primary carers, social services and the wider community) will be thematically analysed, and then monetised and valued using Social Return on Investment (SROI) methodology.

3.0 Methodology

CILNI implemented the impact evaluation using the following six key work stages:

Stage 1: Project inception

CILNI developed the impact evaluation methodology and co-produced this in consultation with the ILFS NI Stakeholder Group to a) identify what the evaluation should consider, and b) how this could be achieved. This involved meeting with the ILFS NI Stakeholder Group, representatives from ILFS and the DoH.

Stage 2: Establishing scope and identifying stakeholders

During initial consultations, CILNI identified the need to demonstrate the direct impact of the fund for recipients', the indirect impact for informal carers, family and the community, and to consider the broader economic and social care context in NI.

Stage 3: Stakeholder engagement to map and evidence outcomes

This stage included

- Impact survey the administration of a co-designed impact survey exploring lived experiences of using the fund. CILNI sent an invitation to participate (Appendix 1) and survey (Appendix 2) to all 448 existing ILFS recipients. In total, 120 (27%) surveys were returned, completed by recipients (n=105), and award managers (n=15).
- Personal Stories in-depth personal accounts and descriptions of using ILFS. funding. CILNI completed eleven personal stories consisting of six recipients and five award managers, who were also immediate family members.
- Personal Assistants CILNI collected guantitative data relating to PAs from the CILNI Payroll Service and from ILF Scotland. CILNI completed informal interviews with five PAs employed via the fund. Four PAs were non-family members, and one was a sibling of the recipient.
- Meeting with Self Directed Support (SDS) Implementation Officers from local HSC Trusts.







Stage 4: Thematic Content Analysis

This stage involved analysing the qualitative data collected from the impact surveys and personal stories. We used Thematic Content Analysis (TCA) as a categorising strategy to develop a comprehensive, descriptive understanding of what impact the fund had, as outlined in Table 1.

Phase	Description of the process
1. Familiarisation with data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generate initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3 . Search for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4 . Review themes:	Checking the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5 . Define and name themes:	On-going analysis to refine the specifics of each theme and the overall story the anal- ysis tells, generating clear definitions and names for each theme.
6 . Finalise themes	The last opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature.

Table 1: Phases of TCA

Stage 5: Social Return on Investment (SROI) analysis

We completed SROI analysis on the outcomes evidenced during Stage 3 and Stage 4 that account for stakeholders' views of impact. It is an approach to understanding and managing the value of the social, economic and environmental outcomes created by an activity or an organisation. SROI is a framework to structure thinking and understanding, based on the following seven principles:

Principle	Details
1. Involve stakeholders	Understand the way in w change through a dialog
2. Understand what changes	Acknowledge and articul and stakeholders of the or which aspects of the orga the scope; and determine account in order that stak decisions.
3. Value what matters	Use financial proxies for in of those excluded from n markets.
4. Only include what is material	Articulate clearly how act evaluate this through the
5. Do not over-claim	Make comparisons of per appropriate benchmarks,
6. Be transparent	Demonstrate the basis or considered accurate and reported to and discusse
7. Verify the result	Ensure appropriate indep account.

Table 2: Principles of SROI





which the organisation creates gue with stakeholders.

ulate all the values, objectives organisation before agreeing ganisation are to be included in ne what must be included in the akeholders can make reasonable

indicators to include the values markets in same terms as used in

ctivities create change and ne evidence gathered.

erformance and impact using s, targets and external standards.

on which the findings may be d honest and that they will be ed with stakeholders.

pendent verification of the



To maximise validity and co-production, we shared findings and discussed with the ILFS NI Stakeholder Group, and individuals who contributed their personal stories. This stage involved co-developing a final report with the ILFS NI Stakeholder Group, in addition to a visual, impact card displaying the outcomes, impact and social value generated by the ILFS.

4.0 Evidencing outcomes

4.1 Survey findings

In total, we received 120 completed surveys. Initial analysis of responses indicated the fund made a difference to recipients at home (n=110), in the community (n=95), to health and emotional wellbeing (n=106), and in the areas of employment (n=8) and education (n=15). However, thematic analysis of the survey responses highlighted significant overlap within these domains. The following sub sections outline the thematic findings from the perspective of recipients, and award managers.

4.1.1 Recipients

We received 105 surveys from recipients, the majority of whom lived with parents (n=64) or alone (n=19). The youngest respondent was 29 and the oldest was 84. Most had been using the fund for 10 to 15 years (n=64). Two respondents noted they had been using the fund since its inception in 1988.

Thematic analysis of the survey data produced four broad outcomes, underpinned by ten sub outcomes, as shown in Table 3. While they are detailed individually, they undoubtedly connect and resonate with each other.

Outcome	Sub
Emotional wellbeing	Redu Feeli Opti Choi
Health maintenance	Med Exer
Sustaining natural support	Infor Rela ⁻
'getting on with life'	Emp Futu

Table 3 Outcomes generated by recipients

22





b outcome

- luced isolation
- ling safe
- imism and motivation
- pice and control
- dical/health appointments rcise and being active
- ormal carers ationships
- ployment and education ure planning

Theme: **Emotional Wellbeing**

The first theme to emerge from the recipient survey data was the impact the fund had on recipients' overall emotional wellbeing. Having practical assistance that facilitated living at home, community life and in education, training or employment resulted in the improvement and sustainment of their emotional health.

Sub theme: Reduced isolation

Spending time with others was very important for recipients, for many living at home meant they could live with their family, partner/spouse or have regular contact with loved ones.

... I can spend time with my family... I would be socially isolated and lonely without this support...

Recipients had regular company from those who provided formal support, which reduced social isolation.

... my PAs keep me company...

This resulted in feelings of emotional connection and improved mood.

- ... knowing people are coming everyday having them to talk to and hear what's going on...
- ... I suffer from depression and without carers coming in I would be alone...

Maintaining relationships that extended outside the home also contributed to feelings of wellbeing.

... I see my neighbours and friends daily...

...maintaining contact with lifelong neighbours and friends...

Additionally, social isolation was reduced through increased participation in community and social events.

- ... being part of the community... feeling outside connections...
- ... ILF helps me to access social trips and events...

Sub theme: Feeling safe

Emotional wellbeing was enhanced through the sense of safety felt while living at home.

... gives me security of knowing I am safe and in my own environment helps my emotional health...

...allows me to have a personal assistant who provides a safe environment and attends to all of my physical needs...

Having assistance when outside the home meant that recipients felt safe to be active in their community.

...my support worker helps me to take part in community events and looks after me when I'm out and about...

Sub theme: Choice and control

Using the fund improved emotional wellbeing through the choice and control it facilitated in recipients' lives. This was evident through both living at home and the ways in which individuals' decided to live their lives.

... I don't want to live in an institution ILF means I can live in my own home... ... I plan my day week and year with the fund and what I'm going to do...

Sub theme: Optimism and motivation

Many recipients described how much they enjoyed living at home and the happiness they felt there.

... the pleasure of being at home...

... I enjoy being supported in my own home...

As a result, they experienced greater optimism and a positive outlook in their daily lives.

... I wake up happy and ready for my daily activities...

... I feel even with my disability, the support I get means I have a life and not only an existence. It really lifts me up and stimulated to give me purpose...

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Theme: **Health Maintenance**

Having additional assistance benefited the health of recipients by supporting them to maintain their health needs.

Sub theme: Medication and health related appointments

Recipients described how their support ensured they were able to manage their health related medical needs.

- ... my staff make sure I get to all my appointments and pick up prescriptions...
- ... I can attend medical appointments with this assistance...

Sub theme: Exercise

Some recipients highlighted how they used the fund to keep physically healthy.

- ... staying fit and active...
- ... my PAs keep me fit...

With assistance, other recipients could attend classes and leisure centres or be active outdoors to maintain their health.

- ... going swimming which enables me to keep reasonably fit...
- ... I go to yoga and swimming once a week with my carers...
- ... getting out and about and being outside in the fresh air...

Theme: Sustaining natural support

We also evidenced the positive effect the fund had on the natural support networks surrounding individuals.

Sub theme: Supporting family

As many recipients lived with parents or other family members who were also informal carers, having assistance meant they could have regular breaks to rest.

... my parents get a break from looking after me... ... my sister gets time for herself...

Sub theme: Maintaining relationships

Formal assistance also resulted in less perceived dependence on support from informal carers, and maintained relationships with loved ones outside of their caring role.

...less stressed than having to depend on my parents...

... the fund means living in my own home with my wife and family. It means having quality time with them rather than worrying about taking care of me. It means a lot to me...







Theme: 'getting on with life'

Many recipients emphasised how having the funding from the ILFS meant they could live their lives and achieve desired goals.

Sub theme: Employment and education

Those in employment or education explained how they used the fund to assist them to go to work or gain qualifications.

...my staff help me get ready for work so I can contribute to society...

... I completed my degree last year...

... I did a HND ILF helped me go to college...

Sub theme: Future planning

Part of getting on with life was being able to plan ahead; having the fund in place meant recipients could make plans and work towards goals in the future.

... I've planned my holiday and my support comes too... I couldn't do that without the fund...

... I plan my day week and year with the fund and what I'm going to do...

Some recipients described their plans to pursue their education or return to work, even if that was not possible at the current moment.

... I hoping to go back to college and then work having ILF lets me plan ahead and set goals...

... ILF means I can finish my degree and I'm planning to do a Master's...

4.1.2 Award Manager survey findings

Fifteen award managers returned completed surveys, all of whom were family members and informal carers for the recipient. Thematic analysis of the award manager survey data produced one broad outcome, underpinned by three sub outcomes, as shown in Table 4.

Outcome	Sub
Emotional wellbeing	lmpr Copi Planı

Table 4: Outcomes generated by award managers

Theme: Emotional wellbeing

All of the award managers described how having the fund in place for either a child or sibling impacted their personal sense of wellbeing.

Sub theme: Improved mood

Improvements in mood were evident through a reduction in worry about the needs of recipients.

... it relieves me of worry as her mother...

... we know he's safe at home and secure...

By having assistance in place, one award manager described how reduced caring responsibilities resulted in improvements in her own mental health.

... I couldn't go back to life without ILF I had no time for me anymore and was very depressed...





b outcome

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Sub theme: Coping

In consideration of life without the ILFS, award managers indicated that they could not cope with their caring role.

... I don't know how we would cope with all the support he needs everyday...

Furthermore, they felt their loved one would no longer be able to live at home without the support from the fund, as they would not be in a position to provide informal care on a longer-term basis. Having the fund in place has meant they have been able to support their loved one on a longer-term basis.

...she'd not be able to stay at home anymore...I couldn't cope long term without ILF... ...without the help of ILF he'd have been in a home a long time ago...as a family we could not manage without ILF...

4.2 Personal story findings

Eleven individuals shared their personal stories of using the fund (recipients n=6, award managers n=5). Each illustrates how the outcomes in Section 4.1 interact with each other, and collectively over time. No two personal stories are the same, with a wide range of variation in individual characteristics including the nature of assistance needs, naturally occurring support, statutory input from HSC Trusts and the amount of funding received from ILF. However, all attribute the ILFS as an essential factor in promoting and sustaining independence in their lives, and share how important having the fund is to them.

4.2.1 Recipients

Six recipients provided their personal stories of using the fund (Appendix 3). Thematic analysis of their personal story data revealed identical findings to the survey data. However, the in-depth narratives extended the understanding of how the fund has impacted recipients over the lifetime of the award. This resulted in the inclusion of an additional outcome for recipients as shown in Table 5.

Outcome	Sub
Prevention	Learı Susta Early

Table 5: Outcomes generated by recipient personal stories

Theme: Prevention

A clear preventative effect emerged from the data, which demonstrated how the combined impact of emotional wellbeing, health maintenance, sustaining natural support and 'getting on with life' prevented an overall decline in outcomes for recipients.

Sub theme: Learning to be independent

This was evident through the concept of learning to be independent, which was attributed to the ILFS funding. This facilitated a learning process in both the context of an individual's specific condition and how they could achieve their own independence.

...it has taken time since my accident...how I used the fund then has changed as I've learned to be independent learning what I can and can't do how I can do it... ...I learned to become more and more independent on my own since I left school...ILF did

... I learned to become more and more independent of that it made it happen made it possible...

One recipient describes how her journey of independence began with the ILFS. This initiated a learning process that lead her to change the statutory input she received to a Direct Payment, resulting in enhanced choice and control of assistance needs.

... I started with Trust then got ILF then I changed to a Direct Payment...back then I was only beginning to understand how to be in control independent...now I manage all of it myself...I can decide to do what I want to do...

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b outcome

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Sub theme: Resilience

Recipients demonstrated how the fund acted as a buffer or protective measure against the challenges they encounter on a daily basis.

... I've had to be in bed for the past nine months with pressure sores the pain is unreal really bad but ILF has meant I'm still here in my home and connected to the outside to my family friends...

... yes getting personal care and the serious part of looking after me is important but I'll tell you what getting out and about and socialising and having something to look forward to that's independence...it keeps me going...

Being more resilient promoted motivation and optimism to keep progressing and moving forward with their lives.

... it's a load of cogs that work together... the ILF is a cog that keeps me striving along... ... without the input from my PA I more than likely would deteriorate both physically and emotionally slowly withdrawing more and more from the world the ILF has helped open up to me... ... it's allowed me to think large... ILF allows me to think what is possible...

Sub theme: Early intervention

Four of the recipients who contributed their personal story explained they accessed the ILFS at an early stage. They describe the assistance from the fund as core to improving their health and emotional wellbeing.

... it really has been day and night! I really was reduced to a shell, the help provided by the ILF has played a major role in basically rebuilding both my health and emotional wellbeing...

... before I got ILF I was in bed for nine years and couldn't do anything for myself... then I was able to sit in a chair and now my wheelchair I had ILF my staff to help me progress build myself up to where I'm now...

The early intervention of the fund similarly prevented a decline in health that could have resulted in not being able to live at home.

...I was in hospital for about a year after my accident then six months after I got ILF...if I hadn't got ILF I would still be in hospital not at home...

... I had the fund in place as soon as I left school otherwise I would be isolated and institutionalised in bed...

4.2.2 Award Manager personal story findings

Five award managers provided their personal stories of using the fund (Appendix 4). Thematic analysis of their personal story data echoed the findings from their survey data; however, it further extended the interpretation and understanding of the indirect impact of the fund. This led to the addition of one more broad outcome, underpinned by three sub outcomes, as described in Table 6.

Outcome	Sub
Prevention	Copiı Relat Planr

Table 6: Outcomes generated by award manager personal stories

Theme: Prevention

Award managers clearly outlined how the fund had prevented a decline in the natural support surrounding the recipient.

Sub theme: Coping

Award managers described how having the fund in place meant they as informal carers were better able to cope with their role.

... I can sleep at night now a full nights' sleep was rare before having the fund...

... it's still hard caring at times but ILF makes it easier for us...

... I dread to think what life would be like... we're older now and it's harder to manage... without the fund life would be very hard for all of us...

Two award managers explained how assistance for their loved one meant they could continue to work which helped them manage psychologically.

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outcome

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... without ILF me and my husband couldn't work so if he'd stayed in the day centre I would have to give up my job which is important not only financially but more psychologically than anything...

... if we didn't have ILF I would have to give up my work to look after him...working helps me manage so things would change dramatically it wouldn't be good...

Sub theme: Relationships

Emphasis was placed on how the fund facilitated and maintained positive relationships with loved ones.

... it gives me that opportunity to go on holiday with my daughter and bring assistance and it's all about my daughter...she means the world to me...it contributes to our togetherness...

... when my mum died things between us just got worse and worse so when he got the fund and came back here to his home I could go back to being his sister again and doing the nice things so it's been brilliant for both of us...

One award manager explained how the assistance for her son helped to manage his complex needs, which contributed to better relationships with other members of his family.

... as parents we are his main carers... it's been tough looking after him as his needs are have been very complex...the fund kept our marriage together for longer so we were there for him...

Sub theme: Planning for the future

Award managers who were aging parents of recipients emphasised how the fund allowed them to think about the future and how they could best use the fund to plan ahead.

... we're planning for his future with the fund knowing we have it he has it means we can think about what happens when we're not here...

... we know we have the fund for our son and can make plans now and for his future...

... when my wife died she lost her mum but we had to sit down and say right what will we do now...we said we'd plan ahead and we use ILF to do that...

4.3 Personal Assistant (PA) data

Data collected from the CILNI Payroll Service, ILF Scotland and survey respondents indicated employing a PA was the preferred method of using the fund. We held informal interviews with five PAs, all of whom had been employed for more than five years, to consider the impact of the fund for them. The recipient knew two prior to their recruitment through working for a local HSC Trust or domiciliary service and two were unknown prior to appointment. The remaining PA was a family member who had been an informal carer for many years prior to their formal role. In this case, it provided an alternative career pathway following redundancy from their job. We conducted the interviews under the following key themed areas.

4.3.1 Pathway to employment

For some the PA role represented a change in career as they previously worked in community development or youth-based roles. For the new entrants to the care profession, there was a period of adjustment but with the experience gained, they now see this as their long-term career path. For others who came from another domiciliary or residential setting, it represented a transition to a working environment where they felt respected, valued and received training to facilitate on-going personal and professional development. This has engendered a professional respect and trust, which has provided continuity of employment and support for the PA and ILFS recipient respectively.

4.3.2 Training & Development

All of the contributors indicated that they received on-going training relating to the assistance needs of the ILFS recipient. This included:

- Manual handling and personal care techniques, provided by both the employer and HSC Trust Occupational Therapists.
- Additional training provided by the employer including supporting physical and emotional wellbeing.



4.3.3 Employee Benefits

For those that previously worked in the domiciliary sector, they identified pay and employment conditions were better in their current role. They described greater flexibility with their employer in relation to taking annual leave and working around individual and family circumstances. All have learned new skills and reported feeling greater motivation in their employment due to the variation in activities and close relationship with their clients. Some viewed their roles as part of a specialist career pathway; working as a PA represented opportunities for personal fulfilment, achievement and progression.

Additionally, PAs described how part of their role was to create opportunities for the recipient, such as finding out about new activities in the community and providing support to create new experiences. This in turn created opportunities for PAs to learn new skills and develop their knowledge of the best ways to support their client, which further extended into their employment roles with other employers.

4.3.4 Impact on ILFS Recipient

All of the PAs indicated that the one to one support provided within their role was more responsive to their client's needs. They felt their client had progressed with PA support, and their emotional and physical well-being had stabilised or improved. All identified that the continuity in relation to personnel overtime had made a positive difference.

4.4 HSC Trust information

We gathered information on how the ILFS influenced the broader social care context in NI through discussions with two SDS Implementation Officers. They both highlighted how the fund contributes to the overall personal budget and resources for recipients and how it complements the current social care / SDS model of choice, control and flexibility.

"...when it comes to flexibility ILF is the trailblazer..."

Interestingly, they also explained how during the development and implementation of SDS across HSC Trusts, they had identified how ILFS was already achieving the ambitions of SDS; the ILFS model had provided them with opportunities to extend their understanding, learning and training provisions to HSC Trust staff.

5.0 Social Return on Invest Analysis

Social Return on Investment (SROI) is a principles-based method for measuring extrafinancial value (such as social value not currently reflected or involved in conventional financial accounts). It can be used by any entity to evaluate impact on stakeholders, identify ways to improve performance, and enhance the performance of investments.

The SROI method as it has been standardised by the Social Value UK, provides a consistent quantitative approach to understanding and managing the impacts of a project, business, organisation, fund or policy. It accounts for stakeholders' views of impact and puts financial 'proxy' values on all those impacts identified by stakeholders, which do not typically have market values.

Measuring the social and economic impact of public funded services has become increasingly important as commissioners and service providers seek to cut costs and do more with less. Although it is easy to say that a service or an organisation's corporate social responsibility strategy does good work and has a broad reach, this can be difficult to demonstrate in a meaningful way. Measuring social impact, using tools such as SROI, is a way of understanding impact and communicating it to stakeholders.

In evaluating the social impact of projects and services, the value being saved or created can be viewed in terms of how immediate these are to selected services. Some impacts will likely confer tangible savings for beneficiaries over a short timeframe whilst others will be far less immediate. This has been collated using a Stakeholder Map, which explores the stakeholders of the ILFS, and the proposed outcomes and impact derived for each stakeholder, which are illustrated in Table 7:





akeholder	Outcomes - What we think will change for them	Impact - Longer term effect of the Outcome
ecipients	Improved mental and physical health, increased confidence and self -esteem, improved employability, improved relationships, Reduced isolation, feeling safe, Optimism and motivation, Choice and control in shaping their care package, Capacity to contribute to and participate in society.	Improved Emotional Well-Being. Health Maintenance. Sustaining Natural Supports. Independent Living – Learning to be independent.
amily & rimary Carers	Improved relationships. Reduced stress. Better off financially. Feeling valued.	Reduced pressure on parents. Planning for the Future.
Northern reland Civic Society.	Increased participation by ILFS recipients Increased volunteering	Growth of the Independent Living Movement in Northern Ireland.
entre for dependent ving	Enhanced insights into ILFS policy Revenue generation &	Increased influence in the sector
orthern Pland.	enhanced sustainability.	
omiciliary/ ocial care ervice providers.	Increased customer base	On-going sustainability of services

Table 7: Social Return on Invest Analysis

Northern Ireland Impact Evaluation



Impact -. Longer term effect of the Outcome

	Delivery of HSCT purpose
	- To improve health
	and wellbeing and
	reduce health and social
l	inequalities.
	Achieving HSCT vision -
	To continuously improve
	health and social care
	delivery and foster
	innovation in pursuit of this
	goal. We will seek to achieve
	the right balance between
	providing more health and
	social care in, or closer to,
	people's homes ²² .
	Effective Early Intervention.
	Increased pool of
	experienced carers with
	expertise in supporting
	Independent Living.
	Long-term sustainable
	employment.
(Impact – Longer term effect
	of the Outcome.
	ILFS recipients gaining
	employment and sustaining
	economic activity for longer.
	Upskilling of a traditionally
	low skill sector.

5.1 Calculation Results

The social value generated by ILFS for a range of stakeholders demonstrates extended impact and value for money. The Independent Living Fund based through its £6.85 million allocation to Northern Ireland recipients in 2019 generated a social value of £1: £10.89. This is based on a Total Present Value of £74,569,097 created against the input of £6,850,000.

The calculations applied financial proxies to twenty-one outcomes for five material stakeholder groups evidenced through the primary and secondary research. Value accrued per stakeholder is segmented in Table 8.

Stakeholder	Social value £	%
ILFS Recipients	£57,279,460	77%
Health & Social Care Trusts (HSCTs)	£15,029,490	20%
Personal Assistants	£1,509,353	2%
Family/Carers	£691,969	0.9%
Northern Ireland Civic Society	£58,825	0.1%
Total	£74,569,097	100%

Table 8: Social Value by Stakeholder

The financial proxies have been chosen to best represent the value to the stakeholders. Where it has not been possible to identify a value representing the change for the stakeholder directly, other values have been considered, which include changes for other relevant stakeholders.



Figure 2: Calculating SROI

The SROI ratio is calculated over 5 years to reflect the longer-term impacts that the service has on stakeholders. A discount value of 3.5% was applied over the 5-year period. This is in line with the Government's Green Book, which requires that public money be discounted at a rate of 3.5% per annum²³.

Outcomes in this context are the changes that occur over time through the interventions and services funded by ILFS. They can be measured at a variety of levels: individual, organisational and community and can be considered intentional or unintentional. Whilst deemed material to the stakeholder map in Table 1, outcomes relating to the wider Northern Ireland Economy, CILNI domiciliary and social care providers were not included in the calculations due to their negligible impact on the final SROI calculations. A full breakdown of the outcomes valued per stakeholder group is offered in Table 9.

²³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/220541/green_book_complete.pdf

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centre for • • • • Independent • • • living • • n.i. • • • •

Stakeholder	lmpact Value	% of impact
Recipient	£57,279,460	77%
Improved Health & Well-Being	£24,775,772	
Reduced Social Isolation	£3,039,860	
Enhanced Safety & Security	£8,730,679	
Increased Choice & Control	£11,305,639	
Increased Physical Activity	£2,118,670	
Improved Family Relationships	£3,790,396	
Increased Engagement with Local Community	£2,033,668	
Enhanced Contribution to Society	£1,189,726	
Gaining Skills & Qualifications	£158,828	
Gaining or Sustaining Employment	£136,222	
Health & Social Care Trusts	£15,029,490	20%
Enhanced capacity to deliver purpose & vision	£5,329,579	
Reduction in people going into residential care	£9,604,416	
Reduced Crisis Interventions	£95,495	
Personal Assistants	£1,509,353	2%
Better Off Financially	£358,661	
Access to Quality Training Opportunities	£991,305	
Reduced Stress at Work	£34,816	
Improved Family Cohesion	£124,571	
Family/Carers	£691,969	0.9%
Reduction in Stress & Anxiety of Parents	£354,787	
Family Members Feel More Valued	£52,561	
Carers are Better Off Financially	284,621	
Northern Ireland Civic Society	£58,825	0.1%
Stronger Independent Living Movement	£58,825	
Total	£74,569,097	100%

Table 9: ILFS Stakeholder Outcomes Value

5.2 Financial Proxies used

Financial Proxies and sources used for the calculations included

- Financial Proxy; Relief from depression/anxiety (£36,766) http://www.hact.org.uk/value-calculator
- Financial Proxy; Sustaining full-time employment (£14,433) http://www.hact.org.uk/value-calculator
- Financial Proxy; Value of Social networks and involvement £4,511 http://www.hact.org.uk/value-calculator
- The value of increased frequency of interaction with friends, relatives & neighbours-£7,750 (Putting a Price Tag on Friends, Relatives, and Neighbours (Institute of Education, University of London April 2007) £15,500 adjusted for inflation)
- Financial Proxy; Feeling safe at home £12,274 http://www.hact.org.uk/value-calculator
- Financial Proxy; Feeling in Control of Life £15,894 http://www.hact.org.uk/value-calculator
- The average cost of residential home fees in Northern Ireland came in at £516 per week during 2016-2017, according to Which? Elderly Care. (See note 4.) Meanwhile, the average cost of a nursing care home came in at £670 per week. https://www.caresourcer.com/caresupport/financing-care/care-homesnorthern-ireland-fees/
- Financial Proxy: Regular Volunteering £3,274 http://www.hact.org.uk/value-calculator
- Financial Proxy: Cost of missed GP appointments £30 https://www.england.nhs.uk/2019/01/missed-gp-appointments-costing-nhsmillions/
- Financial Proxy: Positive Relationships with Family £6,784 http://www.hact.org.uk/value-calculator
- Financial Proxy: Feeling connected to my community £3,753 http://www.hact.org.uk/value-calculator

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- Lifetime value of having at least a Level 1 Qualification £6,000 https://www.gov. uk/government/uploads/system/uploads/attachment_data/file/32354/11-1282returns-intermediate-and-low-level-vocational-qualifications.pdf (using the midrange figure between £36k and £60k = £48k) and estimating a 5-year working period/part time nature of work over a 40-year working life)
- Cost of a hospital stay £340 per day https://www.belfasttelegraph.co.uk/news/ northern-ireland/delayed-hospital-discharges-costs-health-service-15m-eachmonth-35553371.html

5.3 Discounting

It is necessary to "discount" the values generated by each of the financial proxies used in order to reduce the risk of over claiming. The following considerations were accounted for in the discounting of the ILFS funding:

- Deadweight: Assesses how much of each of the outcomes would have happened anyway, without the services funded by the ILFS i.e. the extent that recipients would have accessed independent living support to enable them to remain in their own homes in the absence of the ILFS.
- Displacement: An assessment of how much of each of the outcomes displaced other activities or outcomes that would otherwise have occurred. Such as statutory services funded through Self Directed Support.
- Attribution: An assessment of how much of each of the outcomes was generated by the contributions of other organisations or people such as considering, the role of peers, family members and other supports accessed from community, voluntary or statutory services.
- Drop-off: In future years, beyond the initial year in question, the amount of each outcome that can be directly attributed to the project will be reduced as it becomes more influenced by other factors.

While there is a likelihood that through SDS some of the health and well-being outcomes may have been achieved, it is evident from current statutory funding levels and policy priorities that equivalent levels of funding to the ILFS allocation to support independent living in the community would not have been made available. Given this analysis, we attributed low levels of deadweight to the calculations and found that 1. Low levels of displacement (5-10%) of other services have been included in the calculations. There is no robust evidence base emerging that ILFS has displaced other domiciliary or home-based services rather the contrary in that it has strengthened existing care packages and added an independent living dimension.

2. Reduced isolation, improved family relationships and increased capacity to contribute to their local community and wider society are among the outcomes reported by participants through the questionnaire survey and personal stories. This indicates that in the absence of ILFS there would not have been sufficient community or voluntary services or inputs from family available to achieve similar outcomes for recipients. We have therefore apportioned high levels of attribution (70-80%) for ILFS to the achievement of recipient outcomes.

The SROI ratio is calculated over 5 years to reflect the longer-term impacts the service has on stakeholders and how this would be affected if the fund were no longer available. Given the complex needs of many recipients, the drop off in impact would be in the range of 20-50% in years 2-5.

5.4 Sensitivity Analysis

Given that the analysis contains estimations and assumptions, it is prudent to review where these decisions have had a significant effect on the overall SROI calculation and to consider, therefore, the assurance that can be placed on such figures.

However, as an evaluative analysis, the Study contains confirmed data regarding ILFS funded outputs. The research makes extrapolated assumptions on the numbers affected based on the data collated through the desktop review process and the mixed method consultations with participants, employers and stakeholders.

The sensitivity analysis explores the impact on the SROI ratio of changing some of the study's key assumptions. Discount rates thought to be significant were amended to clarify the impact of changing attribution, deadweight or displacement.

Outcome values generated from research methods were adjusted to determine the impact of changing values, given that consultation results were extrapolated over the full stakeholder group.

This sensitivity analysis did not significantly alter the final calculations, which are considered assured.





6.0 Discussion

The aim of the impact evaluation was to create an evidence base that could demonstrate what impact the ILFS has for recipients by considering how the funding facilitates independence, how funding is used and what impact this has in their daily lives. The project also sought to evidence how ILFS funding indirectly impacts immediate family or informal carers, and the wider community in which recipients live.

6.1 Direct Impact

Based on the data provided by recipients, the fund has clearly achieved its original aims to make a positive difference to their lives. Recipients in their own words, describe the fund as essential to their emotional wellbeing, health maintenance, exercise and being active, sustaining natural support, and 'getting on with life'. Collectively, over time, these impacts have had a powerful preventative effect and for some, the fund acted as an early intervention during critical transitions in their lives.

Interestingly, at an early stage of data collection, recipients introduced the concept of learning to be independent, describing independence as a process rather than an event. Having the fund for an extended period has facilitated their journey of independence by giving them time to explore, test and understand what independence means for them.

Recipients directly attribute these outcomes to the ILFS. With no known publicly available literature to suggest the fund was set up as a preventative measure, this impact alone demonstrates how the ILFS has achieved considerably more than its initial intentions. It cannot be underestimated what this means to recipients, who consider life without the fund as comparable to death.

6.2 Indirect Impact

The findings indicate the primary indirect impact of the fund related the naturally occurring support systems surrounding recipients, who were typically family members. Recipients identified that the assistance they used the fund to pay for meant informal carers could have regular breaks from their caring role. The award managers described how the assistance from the fund had a positive effect on their emotional wellbeing and importantly sustained the natural contexts of their relationships as parent and child, or sister and brother.

As PAs were the preferred choice to meet assistance needs amongst recipients and award managers, the evidence gathered suggests they were indirectly impacted by the fund because it not only created employment opportunities within the community, but was also the preferred option for PAs in comparison to other types of caring career options. They describe a reciprocal relationship with their employer, better rates of pay, and professional development opportunities. They also highlighted the personal fulfilment and motivation they felt within their role.

The impact evaluation has provided some evidence that suggests another indirect impact of the ILFS is how it facilitated a learning process for HSC Trusts, particularly in relation to the implementation of SDS. While it was only possible to collect limited data, the information provided demonstrates a positive influence on the broader social care context in NI.

Furthermore, evidence emerged which suggests that ILFS funding has indirectly impacted the ILM as a whole. The ILM has strongly advocated for resources to be provided in ways that enable people to have choice and control over their support and lifestyle choices; the evaluation demonstrates why this model of resource provision works. Even in the presence of the highest level of assessed support needs, independence can be achieved and sustained over an extended period. Assistance has reduced some of the practical barriers disabled people face on a daily basis, and in line with the ILM, people are living their lives with choice and control, are present and active in their communities, with some of the recipients in this evaluation using their funding to actively campaign for the rights of people with a disability.







6.3 Extended impact

The social value generated by ILFS for a range of stakeholders demonstrates extended impact and value for money. While ILFS recipients accrue the greatest value, the £15,029,490 value for Health & Social Care Trusts is particularly noteworthy given current pressures on budgets.

The biggest contributor to this figure for HSCT's is the savings accrued through reduced admissions to residential care facilities. In excess of 90% of recipients who responded to the questionnaire felt that in the absence of ILFS funding they would have had to move into residential care, providing further evidence of the preventative effect.

The SROI findings augment the evidence base for the impact of ILFS in two key areas namely, the outcomes achieved for recipients and external stakeholders and value for money.

6.4 Limitations

Limitations of the impact evaluation relate to the sample size. While 27% of the NI ILFS recipient/award manager population contributed to the project, without data from all 448 recipients/award managers, it is not possible to conclude everyone has had the same experience as detailed in the findings. This is also reflected in the SROI findings where we have made conservative assumptions based on the sample size and aggregation across the total ILFS recipient/award manager population. However, it is worth considering the high level of positive outcomes reported, and the complete absence of less than favourable findings typically anticipated in any form of evaluation.

6.5 Points for consideration

Based on the findings of the impact evaluation, the ILFS has achieved considerably more than its initial intentions, which strongly support the NI Executive Government decision to retain the fund in its original form. The direct, indirect and extended impact of the fund emphasises the importance of the current scoping exercise to examine if and how the fund could reopen to new applicants. Additionally, with no known publicly available literature to suggest the fund was set up as a preventative measure, ILFS may wish to consider how this can be further evaluated and utilised as an invaluable learning resource for the broader social care and independent living contexts.

7.0 Appendices







Appendix 1 Invitation to participate



You can also view our Privacy Notice on our website at https://www.cilni.org/privacy-policy/

If you do have any questions about this letter, please do not hesitate to contact us on 0300 200 2022 or via the enquiries@iff.scot email address.

Thank you.

Yours faithfully

Stalte

Peter Scott Chief Executive Officer



Appendix 2 - Impact survey

Thank you for agreeing to take part in this project and for completing our survey. We would like to reassure you that completing the survey will in no way affect your ILFS award, and you can withdraw from the project at any stage without having to give a reason.

The following questions are designed to explore your experiences of using the funding as either an ILFS recipient, or on behalf of the person whose award you manage. There are no right or wrong answers and you can continue your answers on a separate sheet of paper if necessary.

Please complete and return by 8th December 2019

1.0 About you (please tick)

Are you: Male Female

How old are you? _____ years

Who do you live with?

Parents Partner / Spouse Other family Friends

Paid support worker Alone

What best describes your health condition or disability? Please tick all that apply.

Physical Visual Hearing Learning

Speech / Communication 🗌 Mental / Emotional 🗌

If you would prefer to describe your health condition or disability, please do so below:

2.0 About your ILFS Award

How long have you received your ILFS award? ______ years

How do you use your ILFS Award? Please tick all that apply.

To employ a Personal Assistant (s) 🗌 Use an agen

Other: Please comment

3.0 About Independent Living

3.1 What does Independent Living mean to you?

3.2 How does your ILFS award contribute to yo Please describe in your own words

3.3 What difference does it make to your life in Please describe in your own words

At home:



ili that apply.
ncy or service provider \Box
Please describe in your own words.
our independence?
the following areas?

In your community:

Your health and emotional wellbeing:

Education, training and employment:

What would life be like if you did not receive an ILFS Award? Please describe in your own words.

Thank you for completing our survey and sharing your experiences of using an ILFS award.

If you would like to take part in the Personal Story section of our project, please leave your contact details below and someone will be in touch to arrange to meet with you.

Name:

Address:

Postcode:

Telephone:

Email:

Appendix 3 - Recipient personal stories

PS01

Sean is a 48 year old man who lives alone. In 2007, he was involved in a life changing accident, which resulted in tetraplegia, a form of paralysis. He accessed the ILFS six months after he was discharged from hospital in 2008 and has remained in his own home since then. He enjoys spending time with his family and friends and has a keen interest in sports, computers and films. He uses the fund to employ one PA who is also a childhood friend and receives assistance from his HSC Trust domiciliary services.

Independence is:

... having assistance to stay at home... being here... it's the small things that seem small but matter very much...

ILFS contributes to my independence:

... I've did a few courses ECDL Stages 1, 2 and 3... ILF funding meant I had a carer back then when I was there... I've been bed bound since March 2019 so using computers is very important to me... I can do things online... it's my independence...

... I was a very active person I played hurling, soccer, golf and interested in everything... when the accident happened it was very hard not to get to those things... with ILF it has helped me massively with this to get to games it's been great...

... it has taken time since my accident... how I used the fund then has changed as I've learned to be independent learning what I can and can't do how I can do it...

... it's taken a strain off the family... it gives relief to my mum or my sister...

If there was no ILFS:

... I would be in hospital not at home... life would be impossible absolutely impossible... it's actually scary to think about it... it's as important as having food to survive...

... it's a load of cogs that work together... the ILF is a cog that keeps me striving along... without it your day wouldn't start...







PS02

Bill is 40 years old and lives with his parents. He has a condition that impacts his speech and uses a wheelchair to assist with mobility. His award from ILFS was in place for his discharge from hospital at nineteen and he also uses a Direct Payment to employ a small team of PAs. Bill enjoys computer technology, socialising and spending time with his family.

Independence is:

... unfortunately I am quite dependant on others but when I am facilitated to do something independently it means so much. When something is difficult/impossible to do it is all too easy to not even bother trying and over time that attitude only gets worse...

ILFS contributes to my independence:

... it really has been day and night! When I first took ill I really was reduced to a shell, the help provided by the ILF has played a major role in basically rebuilding both my health and emotional wellbeing...

... support provided by the ILF helps me take part in and play a larger role in family life it has also greatly reduced the load on my parents...

... with my ILF funded PA I am able to participate in many different social activities (shopping, concerts, meals with friends etc.). Apart from keeping the mind and body more active, this has helped me maintain friendships and even develop new ones...

... at one stage I took a short web design course I completed the course but it had quite a negative effect on me physically I became tight/shaky. At least with the ILF I know that option is there...

If there was no ILFS:

... not really something I want to think about! I believe I would be a different person, without the input from my PA I more than likely would deteriorate both physically and emotionally slowly withdrawing more and more from the world the ILFS has helped open up to me...

... the strain on my parents caring for me 24/7 could and probably would become too much. I can see myself having to leave my home and move into a nursing home...

... it would be a life but it wouldn't be living...

PS05

Pam is 37 years old and lives with her parents. As a young teenager, she became unwell with ME and was bedbound at home for nine years. As a result of her condition, Pam is blind and has severe muscle weakness with paralysis. She recently completed a degree, receiving first class honours and is currently pursuing postgraduate education. She loves music, dancing, shopping, socialising and family time. Pam has used the ILFS funding for 10 years and together with a Direct Payment employs a team of ten PAs.

Independence is:

... I can do my own thing when I want to... your own decisions in your own life...

... not having to answer to anyone...

... yes getting personal care and the serious part of looking after me is important but I'll tell you what getting out and about and socialising and having something to look forward that's independence...it keeps me going...

ILFS contributes to my independence:

... before I got ILF I was in bed for nine years and couldn't do anything for myself... then I was able to sit in a chair and now my wheelchair I had ILF my staff to help me progress build myself up to where I'm now...

... yes there are still things I can't do but ILF lets me push the boundaries I can work the carers around me...l can do what I want in my day...

...ILF helped me complete my degree...my PAs read my notes to me...I'm doing a Master's next year I can plan to do that with ILF because I know I have it there to support me...

... there's laughter in the house... I'm happier so Mum's happier...

... I started with the Trust and then got ILF then I changed to a Direct Payment...back then I was only beginning to understand how to be in control independent...now I manage all of it myself...I can decide to do what I want to do...

If there was no ILFS:

... that thought scares the life out of me... I know I would fall into a depressive state...

... the alternative is being in a home... I'd just be sitting there... I'd have no life...





PS09

Eddie is 38 and lives with friends. He is originally from Germany and has lived in NI since 2003. Following a serious accident in 2004, he has spinal injuries including paralysis and reduced mobility. He has used the ILFS for 13 years and receives a Direct Payment from his local HSC Trust that he uses to employ three PAs. Prior to his accident, Eddie was studying to become a Sports Coach at university, which he later completed. He is an avid sports fan and loves socialising and travelling.

Independence is:

...deciding what I want to do on a daily basis...living a normal life and being part of my community...

... if you want freedom you have to work for it... I work for my independence I work the fund for my independence...

ILFS contributes to my independence:

... it makes life easier... after my accident it helped me retain my routine it gave me my life back... when I got the fund at the start it was like okay now I can live my life... I was no longer tied down...

...everyone needs something to get them up in the morning...having ILF gives me something to get up for every morning...it makes me feel better...

...with Trust help it was in and out rushing to be done and gone...it made me feel very uncomfortable and worse about my condition...you feel like a product...now I employ my PAs to help me live my life...

... it's hard to accept your disability so to be out and about and you have something to look forward to it makes you a part of the social lifestyle you had before...

...they (PAs) drove me to university they looked out for me and took me home...l couldn't do that on my own...they put the smile back on my face...

... I have already made arrangements to go on holiday and have been before and take my PAs...with Trust carers I wouldn't be able to do that...

... the difficulties will always be there but I now see a way through it...

If there was no ILFS:

... I would rather be dead if I didn't have ILF being in an institution... it wouldn't be worth getting out of bed in the morning...

...it would be like going back in time...I can't think of it now what it was like back then in that time...I've got used now to fresh air...there wouldn't be anything to look forward to... having my life back means everything to me...

PS10

Stephen is 66 and lives alone. He has a progressive physical condition that has resulted in severe weakening and breakdown of his muscles. Currently he employs three full-time and four part-time PAs and arranges his assistance using a combination of HSC Trust domiciliary services, a Direct Payment and has used the ILFS funding for twenty years. Stephen holds a Master's degree and has a keen interest in human rights and the policies and practices of bodies that affect the lives of disabled people. An active member of the Independent Living Movement in NI; when not working he enjoys reading, music, going to the pub, cinema, theatre, dining out with friends and just being out and about in the open air.

Independence is:

... to have just as much choice and control over my life as any non-disabled person...

ILFS contributes to my independence:

...the Independent Living Fund gives me a life a worth living...it gives me control over my life...

...my PAs can do more for me than domiciliary care workers can.....there's no you can only do this you can only do that the way it is with care company staff... with my PAs it's very flexible around what I'm doing...it's allowed me to do broader stuff that I wouldn't otherwise be able to do...

...it's vital to me...it's given me the flexibility to do the things I want to do but I've also learned a lot over the time I'm using it...





... I've done a lot of campaigning fighting for things for people like me that wouldn't couldn't have happened without ILF...

... it's allowed me to think large... ILF allows me to think what is possible... I did a master's degree and ILF definitely helped I couldn't have done it without ILF...it enabled me to succeed...

... ILF is much more fluid and flexible in the way it's managed and they allow people to be people and live their lives...

... the most recent report from my consultant refers to the fact that given my particular condition I am in remarkably good nick...in no short measure much of this is directly due to the Award...

If there was no ILFS:

... I would be dead... that's physical and psychological...

... I wouldn't get the right support that I need for my condition agency care workers wouldn't support me in the way I need they have their own rules and ideas about how I am supported...

PS11

Marie is 29 years old and lives with her parents. She was born with a condition that affects her muscle strength and has a hearing impairment. Marie is one of the youngest ILFS recipients in NI and alongside using a Direct Payment, she manages a team of twelve PAs, which includes two family members. She has an undergraduate degree, recently completed her Master's degree and is considering further education. Currently Marie works in policy and campaigns; when not studying or working, she likes to watch sports and films, travelling and socialising with family and friends.

Independence is:

...ability to do what I want when I want... live on my own schedule...

... expression of self-identity...

ILFS contributes to my independence:

... I've independence from family members...my PAs give me the ability to integrate with community activities...

... I went to university... without ILF I would not be as qualified or in employment...

... I learned to become more and more independent on my own as I grew up when I left school...ILF did that it made it happen made it possible...

... it gives me freedom to be who you are it's essential for mental and emotional wellbeing...

If there was no ILFS:

... involvement in community and society would be impossible without ILF...

... I would be isolated and institutionalised in bed... I would only exist...





Appendix 4 - Award Manager personal stories

PS03

John is 84 and manages the ILFS award on behalf of his daughter Susan, who is 69. Susan was born with learning difficulties and has regular seizures; she has always lived with her parents but sadly, her mum passed away over 10 years ago. Alongside using the fund, she attends a local day centre for three days per week. They have been using the fund for over 20 years and currently employ two PAs who are extended family members. Susan likes to spend time with her friends at the day centre, shopping, socialising and going on holiday with her dad. John is retired but enjoys gardening, sports and travel.

Independence is:

...having a life...

ILFS contributes to my independence:

... it gives me that opportunity to go on holiday with my daughter and bring assistance and it's all about my daughter... that's independence...

...when she's out with the carers shopping and socialising she's learning new skills...she's enjoying herself...

...she's here at home and she has all her things here so it's good...I think it's a brilliant thing...she means the world to me...it contributes to our togetherness...

...when my wife died she lost her mum but we had to sit down and say right what will we do now...we said we'd plan ahead and we use ILF to do that...

If there was no ILFS:

Independent Living Fund

... respite wouldn't work we tried that before... I would be too worried about her and she didn't like it...

PS04

Anna is mum to Katie who is 42 years old. As a young child, doctors discovered that the right side of her brain was not functioning as it should which resulted in learning, physical and sensory difficulties. Anna manages the fund on behalf of Katie, which she has received for 17 years. They use the fund to employ two PAs who are extended family members, receives assistance from HSC Trust domiciliary services and Katie attends her local day centre five days per week. She loves going for drives in the car, feeding birds, meeting friends and dining out.

Independence is:

... it means my daughter can live at home where she feels safe and loved...

ILFS contributes to my independence:

... having the ILF fund is brilliant because I can get the girls (PAs) up whenever I need them... they take her away out in the car... they sit with her when we go out... they're brilliant with her...

...they do the things she wants to do...the relationship she has with the girls is very special...we feel content when she's away out with them and they're very very good to her...

... she loves getting out with the girls loves it... she really looks forward to getting out and is so happy when she comes home...

If there was no ILFS:

... I dread to think what life would be like... we're older now and it's harder to manage... without the fund life would be very hard for all of us...

... if she was in a home it would be terrible for her and for us... really terrible... I hate to think about what that would be like if we didn't have the fund to keep her here... it would break my heart it really would... having the fund means so much...











PS05

Sheena manages an ILFS award on behalf of her son Martin, who is 47. Martin was born with Deletion 36 Syndrome that impacts learning, speech/communication and his physical and mental/emotional health. They have used the fund for 20 years to employ PAs, alongside a Direct Payment and HSC Trust domiciliary services. Martin attends his local day centre one day per week and likes to dine out, go to the leisure centre and be active outdoors.

Independence is:

... it gives him his freedom... independence from his parents...

ILFS contributes to my independence:

... being out and about, swimming, eating out, complimentary therapies, clubs... his needs are met first and foremost and that's what it's all about...it's his needs and making his life as pleasant as possible for him...

... before we got ILF my son was in a day centre full time... it was a horrible place... when he came home he needed time on his own in another room and was very withdrawn...the difference now because we have things in place it was so noticeable when he was out of the day centre but other people noticed too...they couldn't get over how good he was doing...

If there was no ILFS:

... without ILF me and my husband couldn't work so if he'd stayed in the day centre I would have to give up my job which is important not only financially but more psychologically than anything...

... I just couldn't cope with it... he would not have survived so it's been a life saver for him and for me...

PS06

Siobhan manages an ILFS award on behalf of her son Joe, who is 35. Joe

previously lived with his parents and siblings but recently moved into his own home in the community. He was born with complex health needs including, physical, learning, visual, hearing, speech and communication challenges. They have used the fund for 13 years, alongside a Direct Payment and HSC Trust services. Joe enjoys living in his own home and likes to spend time with family, friends, travelling and shopping.

Independence is:

... its quality of life...

... he has more control over his life not just his disability...

ILFS contributes to my independence:

... it keeps him alive...

... he's been able to move into his own home... it has helped him progress into independent living in our community...

... as parents we are his main carers... it's been tough looking after him as his needs are have been very complex...the fund kept our marriage together for longer so we were there for him...

... before the ILF my own health deteriorated I had a nervous breakdown... I'm better now getting better...

... before he had no quality only 5 days day care it was the only choice he was given until the social worker said there was ILF...now his life has expanded he does everything shopping travel his health care needs and appointments...

... I can sleep at night now a full nights' sleep was rare before having the fund...

... it's still hard caring at times but ILF makes it easier for us...

... we're planning for his future with the fund knowing we have it he has it means we can think about what happens when we're not here...

If there was no ILFS:

... he would have no life anymore... I don't know how I'd cope my health would deteriorate...

... day care isn't suitable... he needs more to have his own life but we couldn't do it on our own...





PS07

Janet is sister to Manus who is 53 years old; he lives in his childhood family home with another childhood friend. Manus was born with learning difficulties, autism and mental health needs so Janet manages his ILFS award on his behalf. He has received the ILFS for 12 years, and alongside a Direct Payment, they use the fund to pay for the services of a local agency that provide a team of support staff to assist Manus to live independently. He enjoys drawing, clothes shopping and spending time with family and friends. Both Janet and Manus took part in their personal story of using the fund.

Independence is:

... independence from my family and makes me feel like an adult...

... being able to stay in my family home...

ILFS contributes to my independence:

... when my mum died things between us just got worse and worse so when he got the fund and came back here to his home I could go back to being his sister again and doing the nice things so it's been brilliant for both of us...

... when everything was set up this became a model home that the Trust used to come to and show others how it can be done because it works so well...

... I look forward to seeing them (support staff) coming in... I have fun with them they're kind to me...

... as his sister I'm very happy with it all he has an awful lot going on and his medication has a major effect on him with all his health problems they're on top of it there's no nonchalance with them...

... what he has here now is on a power with what he had when we all lived together as a family growing up...the stimulation is almost the same as when we looked after him...his life has been able to continue...

... he's totally content here and that means so much to the two of us... ILF works so well... it's miraculous I never thought it could be so good it's not like care it's more than that...

If there was no ILFS:

... he would most likely be in a residential home for special needs... he wouldn't get the individual attention and care he receives at home...

... I can't imagine where his emotional feelings would be if he had to move from home...

... if we didn't have ILF I would have to give up my work to look after him...working helps me manage so things would change dramatically it wouldn't be good...

Appendix 5 - SROI Impact Map

Can be viewed as a separate document.

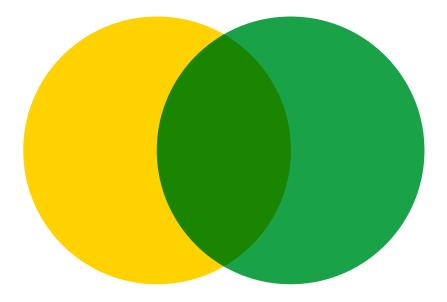


IF Living Fund









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