

ILF Scotland Stakeholder Engagement Feedback Report – New Fund



11 August 2016

Executive Summary

Between June and August 2016, ILF Scotland undertook a number of stakeholder engagement events, across Scotland, to obtain direct feedback on possible uses of a new independent living fund for Scottish recipients. 11 events were held and the views of 278 people were captured. During the events, over 3500 individual comments were captured and 98.5% of those providing feedback stated that they felt they had been listened to.

There was an overall consensus that some form of combination between support during life events/transitions and single one-off grants would be preferred.

The majority view was that the eligibility criteria should be person centred and based on needs, not age. Using the level of DLA/PIP payment as a core part of the eligibility criteria produced mixed responses, i.e. some supported this as a necessity, whereas most others did not wish high rate DLA to be used to determine someone's eligibility.

There was considerable concern that people with mental health issues or those with learning disabilities would be ineligible for the new fund if the criteria reflected that of the current fund, in which a recipient only qualifies for ILF if they are in receipt of higher rate DLA.

Discussions on introducing a maximum and minimum level and duration of award, as part of potential stipulations of the new fund concluded that whilst there may be a need for both of these, any decision should be based on individual needs and circumstances. Any award had to be based on outcomes and provide additionality.

A large majority advised that an ILF award should not be linked to Local Authority input, with a corresponding view that Local Authorities should not take into account any ILF award (or the possibility of receiving one). Some concerns were also expressed about current benefits being cut if an ILF award were made.

There was clear support for individuals being allowed to re-apply in the future if their needs changed, but this had to be balanced against the

demands on the fund.

Promoting activities to address social inclusion and increase community participation also attracted much support. This led to calls for a fund which could support all the costs of inclusion and participation.

During the engagement events, there was an overwhelming recognition of the importance of fairness, with the view that whatever criteria were decided upon, the new fund had to be equitable across all of Scotland and not be subject to local variations in provision. The challenges this presented in relation to eligibility criteria due to differing Local Authority Social Work practice were recognised.

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This report is presented in three sections.

Section 1 describes the approach and its effectiveness.

Section 2 summarises the key outcomes and concerns.

Section 3 is a summary of the responses to the presented questions.

The detailed responses and information are contained in the annexes.

Section 1

Introduction

The purpose of the engagement events was to seek direct feedback from disabled people, disabled people's organisations, carers and wider stakeholders on how best to use the additional funding and how this could be used to benefit the most in the fairest and most equitable manner.

Fundamental to the engagement process was a respect for human rights and a commitment to co-production – the new fund would be developed by listening to the views of disabled people and presenting their views to the working group.

The working group would then use this feedback to further develop their thinking and assist them in making a recommendation to the Minister on how best to use the additional funding.

ILF Scotland, as the fund assessment and delivery organisation, was tasked with organising the engagement events and capturing the feedback on the presented themes and questions. Between June and August 2016, 11 events were held across Scotland and approximately 275 people were able to provide their comments, concerns and observations about the new fund. 98.5% of respondents stated that they had felt listened to and engaged with.

Overall, more than 3,500 comments were received and this report has summarised the key themes, captured the emotional responses and extracted new or innovative thinking on how best to use the new fund. It does not offer any recommendations, but by presenting the emerging themes and issues, it aims to offer a sense of how disabled people, in Scotland, feel the new fund should be used.

Engagement Approach

The Scottish Government and the Working Group were tasked with developing a set of affordable and sustainable options for how the new fund could be used, which would then be presented and discussed at a number of engagement events. Subsequently, two themes and 19 questions were developed by Scottish Government and these were presented and discussed at 11 events across Scotland between June and August 2016.

Information about the events, and how people could register to attend, was circulated on social media, through the submission of a press release, and via Working Group members. In addition, ILF Scotland also made information available on their website.

The event locations were chosen to be as wide and as encompassing as possible and in areas where there were known to be high numbers of current recipients.

Three events were requested by specific groups and were delivered in Glasgow, Scottish Borders and in Hamilton. A further event for local authority ILF Leads was held in Stirling and feedback from this is provided as an addendum to this report.

The breakdown of event locations and numbers attending is provided in Annex B. An assessment rating of the suitability of each venue is also provided for future reference.

Invited Groups

43 direct invitations were made to Disabled Peoples' Organisations with a further request for them to publicise the events further using their networks and communication channels.

Details of the event and event materials were placed on the ILF Scotland website and a press release was issued.

Local Authority social workers and managers were informed directly of events in their areas and a further specialist event for ILF leads was organised.

Invitations were made directly to current recipients in the area local to where the event was being held. Additionally the Equality Network (LGBTi) and MeCOPP (minority ethnic) were directly invited and notified of all events.

Evidence set and statistical validity

There is not a clear percentage response to the questions raised as the nature of the events were conversational not voting. The aim was to capture the discussions and to present the major significant themes following collation across all events.

Whilst one single comment may not have statistical significance, its value or relevance could have major importance and identify an issue that had not previously been considered.

11 events were delivered and the collective voices of approximately 275 disabled people and their organisations were heard, from the Western Isles to the Borders. In total, over 3,500 direct comments were captured and are available upon request.

Those who attended each event completed an evaluation and the responses are at Annex D. 98% of respondents rated the event as 'Excellent' or 'Good' and 98.5% agreed that they had been listened to.

Web and postal surveys

For those who were unable to attend the events, resources were made available online via the ILF Scotland website (www.ilf.scot) in order for them to provide feedback on the new fund proposals. A response date was set for the end of July to coincide with the timeframe for the main events. One completed return was received from the Western Isles using this approach. Three groups sought ILF Scotland support to facilitate additional events.

One further attendee took the information from the event he attended back to his own group and provided additional feedback from 9 of their members.

Equalities statement

Each event was made as accessible as possible and this was achieved through a sub-group from the working group advising on accessibility. This covered location issues, transportation, dignity and respect, presentational styles, lunch and personal breaks, aids to facilitate effective communication, Easy Read information resources and translation services. Large print and Braille resources were available upon request (although none were requested) and the Easy Read versions of the information packs were uploaded to the ILF Scotland website.

Personal assistants were also available at the larger events and ILF staff were available at all times to assist individuals as required.

Section 2

Key themes and issues from events

The following points represent both common responses and key issues raised from the collated responses from all events. They are presented as a neutral record of the engagement process and do not aim to provide answers as such.

- That the consultation felt authentic, genuine, and not a paper exercise.
- The large majority of participants were positive about a new funding being made available, although many commented that £5 million was not nearly enough.
- The fund should aim to minimise bureaucracy
- Awards should not be linked to Local Authority funding, and Local Authority funding should not be influenced by ILF Scotland funding.
- Although there was general resistance to Local Authority involvement with ILF Scotland, it was recognised by some that collaboration and partnership would be essential to the success of the new fund.
- All awards should be in addition to current funding from other statutory sources and not used as a replacement.
- There is variation in outcomes for individuals with similar assessment of needs but living in different local authority areas.
- With variation in LA input, obtaining ILF Scotland support becomes a postcode lottery for similarly assessed needs (if LA input not above threshold for ILF support).
- There were suggestions that due to challenges with, and variations within local provision, social care support for independent living could be taken away from local authorities and given to a new national body.
- Carers largely reported negatively on recent developments in social care, and expressed anxiety about the future.

- There was strong support amongst carers for the fund to provide emergency support in order to provide peace of mind.
- Given the very significant levels of unmet and under-met need, the access criteria for the new fund should be widened away from current ILF criteria.
- Ensure eligibility is based on need and is person centred.
- Ensure those with mental health or learning disabilities are not excluded.
- People should be able to re-apply – “Life is a long time and things change”.
- Awards MUST provide additionality.
- Business start-up support seen by many as offering interesting and meaningful possibilities.
- Tackling the barriers to community participation arising from the ‘crisis’ in social care for disabled people, and the increasing social isolation being experienced by many, should be a priority.
- Support around bereavement, especially of a parent/carer, seen as a major life event to add to Theme A.
- Group applications were largely welcomed, especially to create activities or respite services which might not be available locally.
- Transportation and additional personal costs to attend activities were often raised as concerns.
- around what services are currently available in Scotland.
- There appears to be common pressure points across Scotland with transitioning between services being identified as unclear and confusing for many.
- There is a real need to share information amongst all stakeholders.

Key Concerns

The conversational style of the discussions often meant that individuals voiced their concerns and worries about existing provision, as well as

how a future fund might be used to address them. Their views are captured here to balance the positivity around how a new fund might operate:

- ILF should not become the fund to go to if there were gaps in provision elsewhere; across all events respondents wanted the clear distinction that an ILF award was to provide additionality to what should be in place from statutory services.
- It became clear that there is variable provision of different types of social supports across Scotland which can be further compounded by geographical location as well as demographics. The Western Isles, Dumfries and Aberdeen identified specific rural and remoteness issues resulting in a lack of local support providers. In these areas, transportation, access to activities and social isolation were key concerns. The Western Isles mentioned a lack of support for younger disabled adults and a reluctance to move them into older person's care homes (where there were specialist services) away from family and community.
- Social isolation, community participation and living independently "outside of the 4 walls" were the key areas that most people wanted further support in. Additionally, there was considerable support and concern for carers, particularly unpaid parents or family members, to be supported and protected as a key long term enabling component of independent living.
- When asked to prioritise one area where the new fund could focus, the most common response was simply "more support" This reflects the commonly held view that disabled people were under-supported across Scotland, and that their right to independent living was being compromised as a result.

Additional Concerns

Several concerns were raised during the events about understanding the full level of unmet need across Scotland. There was widespread recognition of significant numbers of people having disability related needs but not being eligible for support due to Local Authority criteria.

Linked to this unmet need were concerns about the proposed level of funding being made available to the new fund. Several questions were asked about priority groupings for the new fund, with some specific reference to the people who would have been eligible for ILF support under the criteria in place at the point of closure to new applicants in 2010.

This was further narrowed to those that have now become 65 or older in this window as potentially high priority but missing out twice (depending on the new criteria).

Several events had participants who have sons/daughters with mental health problems and/or learning disabilities. They raised their concerns that their children have support needs but do not meet the current high rate DLA threshold which would make them eligible under current criteria. They wanted the new fund to recognise the support needs of people with mental health and learning disabilities and not be discriminatory against them due to not meeting High Rate DLA/PIP.

Innovative and creative themes

A common issue raised at many events was the lack of awareness of information about what services were available to them? It was felt that it was difficult to determine what should be available as a statutory right and what support services were available locally.

A recommendation to ILF Scotland was the creation of a central knowledge/information resource hub of what people are entitled to and what support is available by area; ILF Scotland would then be a part of this.

Across all events it was clear that overcoming social isolation and increasing community participation were major factors (and concerns) in enabling independent living. Potentially there was a role for technology to play in connecting people and developing online communities. Skype, iPads and smart technologies were mentioned as tools to achieve this.

“Going to T in the Park”; this was mentioned in the context of transition and being able to participate in activities which might be considered a “rite of passage”.

Several different groups raised the concept of pooled applications for group activities; people doing what they want locally and possibly creating activities where there was little or no local provision. The point was also made that if there was an application from a group, that an individual from that group should also be able to apply for their own specific needs.

Living in rural areas and on the islands came in for special mention. This was due to the overall lack of specialist services and provision in these remote areas. One cited example was of lack of specialist support for younger adults wanting to remain close to their families and communities and not wanting to move into an older person’s care home to receive it.

The idea was to create personalised and shared housing for up to 4 people to enable disabled people to live independently yet still being able to access specialist support (as a multiplier effect i.e. one specialist being able to support 4 simultaneously).

Respite, short breaks and support for carers featured strongly across all events and some unusual ideas to support them included group minibus purchase, caravans, log cabins and greenhouses.

There were also a small number of calls to recognise the emotional and psychological needs of people above the practical nature of QSS; dealing with any change could cause challenges and emotional support during times of difficult transitions were seen as important (bereavement mentioned several times).

The local authority threshold sum as a qualifying condition came in for mixed comment. There was a common view that reaching the threshold sum was very dependent on Local Authority policy, and that an individual may reach the sum if they lived in Local Authority A, but not if they lived in Local Authority B. This could compromise an individual's ability to access a national provision due to a local constraint. This contributed to calls from several events to remove support for independent living for disabled people from local authorities and create a new national body responsible for providing this support.

Emotional responses

This section is offered by way of conveying a sense of the feelings and emotions expressed by those attending the events.

Many respondents found it difficult to express their thoughts around eligibility criteria as they fully appreciated the potential impact on others. Those that did voice specific ideas around eligibility made it clear if it would be helpful to them or, more frequently, disadvantage them or their family member. There was a very strong sense of fairness and equity and using criteria which would support as many people as possible yet recognition that not everyone could be helped.

Age criteria and receipt of High Rate DLA/PIP came in for emotive debate; especially in the face of perceived age and mental health/learning disabilities discrimination. Whilst it might not have been deliberate use of the term, it was felt that many people and groups with substantial support needs were missing out on support as they did not meet the "blunt" eligibility criteria of 16-64 High Rate DLA.

There was also much discussion around those that “had missed out” by the fund closing in 2010. Would they go to the front of the queue this time round and what would happen to those now older than 65 who would have been eligible previously (i.e. will retrospective awards be allowed for those now 65-70 who didn’t receive the award 2010 – 2016)?

People expressed concern at not being able to access the new fund if they were downgraded as a result of a PIP re-assessment. There were several comments about the re-assessment process being “horrendous” and “de-humanising” and for any new ILF assessment to be as simple and straightforward as possible. Use of a single shared assessment was cited by a small number of people in an attempt to avoid unnecessary intrusion into people’s lives.

There was unanimous agreement that an ILF award should be fully portable and nationally consistent, and there were calls for the creation of a national information database on standard services and costs. There was comment about trusting the professionals (local authority social workers) to do their job properly and allowing ILF Scotland case officers to use their discretionary abilities and national sense of appropriateness to determine the correct level of award.

There was clear majority agreement across events that even if a local authority acts as the point of referral to ILF Scotland, that award payments should not be linked. There was very strong sentiment about local authorities not taking into account someone’s ILF award when deciding the local authority resource allocation.

There were very few comments regarding personal contributions to an individual award so any comment here would be speculation. The question was not asked and there was only one direct comment suggesting that a contribution should be made.

Section 3

Summary Feedback by Questions to Themes

This section aims to present a summary of the collated comments obtained. With some questions, conflicting or opposite responses are present and this represented the nature of the discussion.

Theme A Summary – A time-limited award for a specific life event

Theme A attracted much support and key areas of life events expressed as requiring support during transition were moving out of the family home (to live independently), becoming a parent, losing a parent (also as a primary carer) and sudden onset/rapid deterioration in health/circumstances.

Of note, there was much mention and agreement for emotional and psychological support as well as practical support during times of difficult or sudden transitions – bereavement and becoming a parent being the main examples.

There was further agreement for support to move into employment and leaving employment. However, the question of duplication of services was raised and how this would be different to what should be in place through Business Gateway, Access to Work and workplace provisions under the Disability Discrimination Act?

The main concern with Theme A was that it “felt very similar” to what SDS should be doing already. This was further supported by the idea that an ILF award should not be the gap payment to make up for what other agencies had a statutory duty to provide.

Q1 What do you think of the list of life events that a time-limited ILF award might support?

The offered list was met with approval but it was identified that those transitions or life events were largely foreseeable and thus able to be planned for by statutory services.

Q2 Is there anything missing from the list of life events?

This attracted extensive and emotive discussion with major events such as bereavement, moving home, moving between locations, skills to deal with change, and any activities which supported an individual to be less socially isolated and engaged with their local community seen as missing. Reablement featured strongly in all discussions around this subject.

Support to move into employment (paid or voluntary) or setting up a business were seen as good ideas although there was some confusion about what other grants and benefits might be able to support this.

Getting married, becoming a parent, support during maternity and support during a gender transition were identified as other specific life events.

A key observation was that whilst the focus of discussion was on practical support measures, support for the psychological and emotional impact of dealing with a life event should also be considered.

Q3. Do you have views on maintaining the existing qualifying support services (QSS) definition (personal and domestic care)?

The key message was that any support from ILF Scotland should be used to achieve independent living outcomes in general and should not be task orientated like QSS.

Q4 Do you have views on ensuring that a time-limited ILF award is not used to fund outcomes that can be delivered by other agencies?

There was overall consensus that an ILF award should not fund outcomes which should be delivered by other agencies.

Any award should also be additional and enable the individual to achieve independent living outcomes (which are achievable and measurable). It should fund things which cannot be met elsewhere and be based on needs. Whilst there was recognition that Local Authorities may be “squeezed” by other pressures, most felt that ILF should not be the gap fund and Local Authorities should not be “let off the hook”. This discussion was at times balanced by the view that ILF Scotland could be used only to fund things which fall outwith a Local Authority’s own criteria.

Q5 What are your views on retaining the previous ILF eligibility criteria of supporting disabled people aged 16-64 who are on higher rate DLA or PIP?

Most respondent felt uncomfortable with this question. Whilst they recognised the need for criteria, they did not want to exclude or disadvantage others by their recommendations. However, there was overwhelming agreement that the age criteria should be changed to include those over 65. People still retain their disability after 65 and with life expectancies getting longer and pension ages increasing, the criteria should reflect this.

There was comment that there was already a good deal of awareness and support for disabled children so the lower age limit may still be valid. Additionally, there was comment that some people with mental health issues or learning difficulties could arguably have substantial support needs but not be in receipt of high rate DLA (and thus ineligible for an ILF award).

Overall, the general feedback was that eligibility should be based on needs (and the professional judgement of healthcare and social work professionals) and any award based on achieving independent living outcomes.

Q6 What are your views on having a minimum and maximum ILF award sum?

There was mixed feeling about maximum and minimum award levels but strong agreement that there should be a maximum to ensure the fund can reach as many people as possible. However, any adopted levels should be for guidance, rather than absolute, and professionals must be trusted in their judgement.

The main feeling was that it should be flexible and ILF be allowed the discretion to adjust according to the needs of the individual. There was a feeling that there should not be a minimum award as a little amount can make a lot of difference but some felt that any minimum amount should be for more than it cost to administer.

There were many comments about people becoming confident with managing money through experience with Direct Payments, and instead of having a time limited weekly transitional amount, consideration could be given to an upfront lump sum which the award manager could then plan out over the period of the transition (more at the start then tapering off as circumstances stabilised). There were two comments that if some people are given a weekly amount, they will use that amount for as long as they have it indicating that the system could create dependency.

Q7 What are your views having a minimum and maximum duration of award (the length of time an individual would receive ILF support)?

There was strong consensus that this should be based on individual needs and circumstances and not be time limited. It would need to be in full partnership with the local authority with the ILF component focusing on independent living outcomes.

Fundamental to the principle of a time limited award was the need for an exit plan and clear handover arrangements for support afterwards.

Short term payments over known periods such as school holidays could help many people as the support needs become higher during these periods. There was much support for the idea of an upfront sum which could be planned out for as long as it was needed, rather than capped after a point in time.

A further idea was proposed for an interim award for the period it would take the local authority or care provider to put in place their care assessment and support package. Theoretically this should be for 28 days.

Two concerns were raised about the time limited nature of this theme:

- Transitional events do not always go as planned – what happens if something goes wrong or if there is a significant change in circumstances during the agreed time window of award?
- A hospital discharge should be a well-planned and managed transition – if the award runs out too soon or the agreed post discharge support package is not sufficient, there is a high risk of re-admission.

Q8 Do you have any views on whether ILF support should be linked to local authority input?

A large majority stated no.

However, there was much recognition of the work LA social work teams do and that there should be a holistic assessment of needs including both “life and limb” support and independent living outcomes “away from the 4 walls”. There was a desire to cut down on the number of assessments and possible use of a single shared assessment.

A clear outcome from the engagement process across all events was that there were local variations in provision and service and that the

independent discretionary nature of ILF Scotland was valued as it brought a degree of national level consistency of overall award.

Although not a linkage as such, there were many comments about using an NHS diagnosis as the basis of support needs and the possibility of using the NHS to flag possible award recipients as well as via LA social work teams.

There were also significant groups which might not be in receipt of a local authority input and these could be disadvantaged if the LA input was the sole criteria – mental health and learning difficulties were specifically mentioned.

Theme B Summary– A single grant to support independent living

Theme B attracted much energetic and vibrant discussion ranging from alternative therapies to business start-ups. It was felt that there was some overlap with Theme A as many of the things discussed as a one off support or service would also be essential to have during a major life event or transition.

The overriding consensus for this theme was that the award should be used to support Reablement and be additional to SDS. This would mean different things to different people so a single “approved list” would not be appropriate; it should be based on the needs of the individual, helping to achieve their independent living outcomes.

“Having something to do during the day helps me face the nights.”

Two significant uses of this theme were identified by many people – the need to overcome social isolation and to overcome barriers to participation in the local community. One participant commented that “Having something to do during the day helps me face the nights.”

The view was that the Local Authority was able to provide the “life and limb” support to ensure an individual was safe in their own home but that more was needed to help people get out and about and to be involved in their communities.

Barriers to this included difficulties obtaining transportation, transportation costs and the costs of a personal assistant to attend the event/activity.

Q9 What do you think of the list of areas that could be supported by single grant ILF awards?

Adaptations, equipment and business start-ups all came in for favourable responses. Many people posed the question whether other funds or services should be providing this (Scottish Welfare Fund, Access to Work, NHS, Local Authorities)?

Across all events, there was much enthusiastic and lively discussion on wider possible uses (see Q10). The overall consensus was that however it was used, it should be for additionality and things which helped connect people to their communities and reduce social isolation.

Lack of transportation, access to transport, finding the deposit for a personal vehicle and personal assistant costs were mentioned specifically as barriers to achieving participation.

There were several innovative comments and ideas about the use of technologies supporting communications and developing online communities for those less able to get to events and activities; Skype and iPads were mentioned and the use of touch screen technology was seen as a possible way forward.

Q10 Is there anything missing from the list of areas that could be supported?

This question resulted in a very large set of ideas and the collated set should be referred to (Annex A Q9 and Q10).

A significant observation made by those attending the Dumfries event was that location is everything. Whilst it was good to be able to discuss possibilities of what a one-off grant could be used for, pragmatically it might not be able to source or obtain those services locally.

If services had to be sourced from elsewhere, any grant might have to take into account the additional costs of accessing it.

Many additional items were added to the list and ranged from aromatherapy to college courses, to caravans and greenhouses. It was clear that the additional items mentioned were about enabling the individual to participate and enjoy activities and socialisation outside of the home or to develop skills to assist Reablement. Any grant should be able to make a difference to the individual and contribute towards achieving their outcomes and not just be based on eligibility.

Some items were mentioned for use in the home and these included mobility aids, hoists and beds that had a higher quality (and cost) than could be provided through the NHS/LA. There were several calls for increased communications technologies and the use of tablets and touch screen displays to connect with others (creating an online community was mentioned). Although not specifically aimed at ILF Scotland, there were calls for a centralised website to help disabled people and their carers to navigate their rights and identify what support they should be able to access and where to find it.

Q11 Do you have any views on ensuring that ILF grants do not duplicate other services?

There was strong agreement that an ILF grant should not duplicate existing services or provision and should provide additionality which enhanced an individual's life.

“Local authorities help get people out of bed – ILF gives people a reason to get out of bed!”

Any grant should be on alternatives which make a real difference and are measurable in terms of achieving outcomes.

There was recognition and agreement that “tandem working and shared responsibility” is key to achieving a good support package for the individual. Several questions were asked if it might be possible to integrate charity provision into the support package or use charity funding if there was a gap somewhere (“Turn 2 Us” was mentioned).

One idea was of a checklist of all the things which should be provided by other agencies and a guide as to how ILF awards could be spent to provide additionality.

Pooling funds and matching funds also came in for discussion during this question. Whilst there was clear agreement for no duplication, it was felt that if an individual had access to even a small sum from one agency/organisation, that this might be the starting point to obtain matched funding from others.

Q12 What are your views on retaining the previous ILF eligibility criteria of supporting disabled people aged 16-64 who are on higher rate DLA or PIP?

There were similar responses to Q5 in answering this question and it caused concern for many. However, the age criteria were felt by most to be unfair given the increases in retirement age and longer living. Many comments were made that the disability does not go away when someone becomes 65 and that increasing age makes living with that disability harder.

High Rate DLA was recognised as a means of identifying those with complex support needs but it as a single tool could miss those with mental health or learning difficulties who may equally have substantial and complex support needs.

There was further comment that High Rate DLA does not transfer directly to high level PIP and if an individual is downgraded they might then be ineligible for an ILF award.

Overall the feeling was that eligibility should be based on needs and use human rights as the baseline for criteria. Potentially anyone with a diagnosis could be eligible.

During discussions around eligibility, the question was raised around understanding the level of needs across Scotland? How many people were currently eligible under the existing criteria and how many people had missed out during the closed period 2010 – 2016?

There was strong feeling that any criteria should be guidelines rather than absolutes and that the professional judgement of local authorities and ILF Scotland could be used well within a flexible framework. A suggestion was made to base this around a professional referral system rather than an individual being automatically eligible due to being in receipt of another benefit or assessment.

Q13 What are your views on having a minimum and maximum single grant award?

There were mixed views on this although a consistent response was that any award should be based on identified needs. A further common message was that there should be no minimum level for two reasons:

- A small amount can often be made to go a long way
- Having any level award will have meant that one agency has identified a level of need and this could be used as entry criteria to other organisations/charities to match or pool funding (i.e. being used as a gateway award).

Most people agreed that the fund was too small and that some level of maximum cap was essential so as to be used as widely as possible.

No limits were suggested but some thought that any minimum award should be for more than the cost to administer it.

There were a small number of requests (<10) for a national database of what costs are reasonable/standard costs of services and support.

There was some support for a tiered award with a simpler assessment route to obtain lower level awards or services.

Q14 What are your views on allowing reapplications to a single grant award scheme?

“Life is a long time and lots can happen”

There was unanimous support for this but with reservations about the frequency of re-application. However, if conditions or circumstances changed for the individual then they should be able to re-apply.

The point was made about understanding levels of demand and oversubscription with the subsequent need to assess the level of uptake of the fund before considering re-applications.

Q15 Do you have views on allowing group applications to a single grant award scheme?

In principle this met with wide agreement but with reservations about protecting an individual application. The feeling was that a group award could be used to access or develop resources to reduce social isolation and increase participation where there was no or little existing provision locally.

It was seen as a method of bringing a much needed resource to a wider group of people and potentially creating a sense of community spirit.

However it would need to be well defined and linked to achieving outcomes. “The Wheel Inn” was cited as a good example of this working in practice.

There were issues around leaving the group if any one individual did not derive the intended outcomes from the group activity or, if they felt uncomfortable with the reality of the group activity. Not only would the individual then miss out but would the group suffer from the loss of a member and no longer be able to sustain it?

There were definite statements that organisations should not be able to apply as they had access to other funding mechanisms and this would compromise the amount of available funding for individuals.

Final summative questions

Q16 Do you have a preference between Themes A and B?

The overall consensus was for a hybrid of both Theme A and B.

It was felt that both themes offered value but that they would need to ensure equity and fairness across Scotland. A combination of themes was the preferred response.

The general feedback across all events was that Theme A would be highly relevant in the following situations:

- Moving out of the family home into independent accommodation.
- Sudden onset or rapid deterioration in health or circumstances.
- Bereavement, especially of a parent/carer.
- Transitioning between locations.
- Transitioning between services, especially child to adult.

Theme B was consistently relevant to everyone and in theory was broad enough to support a wide range of needs.

Q17 What do you think is the most important area that ILF should support?

- More support.
- “Funding for joy!”
- Overall anything which enhanced quality of life and helped to overcome social isolation and support participation in the community. “Everything in Theme B should be allowed!”

Q18 Is there anything missing that is not covered by the options presented?

- Provision for disabled adults and older people in residential care settings.
- Support for individuals to live in shared accommodation.

- Advice and social support.
- Befriending services.
- Support and training for carers.
- Wider training and awareness for service providers in better meeting the support needs of people with disabilities.

Q19 Do you have any other thoughts or comments on the options presented?

- The level of unmet needs across Scotland needs to be recognised and addressed.
- Can more funds be made available?
- Need to rethink the application process to make it simpler.
- Ensure that eligibility is based on the actual needs and outcomes rather than on a single pre-qualifying benefit, with the option of focusing eligibility on a diagnosis.

Summary

The 11 engagement events across Scotland obtained the views and comments from 278 disabled people, their organisations, carers and interested stakeholders. Over 3500 comments were captured and the overall consensus was for a mixture of both themes and a broadening of the eligibility criteria away from age and not on a set level of disability benefit. The findings are not absolute but aim to offer a broad spectrum of group and individual observations on how best to use the new fund.

The clear observation is that an ILF award must work alongside the support available from local authorities but not be a replacement for it.

It should be equitable and fair, based on needs and achieve independent living outcomes which are in addition to statutory provision.

Any maximum amounts should be flexible and allow both local authority and ILF Scotland to holistically assess the needs of the individual and re-applications should be allowed if the fund has the ability to service it.

The evaluation of the events indicated that people felt that they were listened to, that the discussions were useful and that they had been well organised. Finally, it is observed that by presenting the many responses to the questions posed, that this report may raise more questions than the new fund on its own is able to address.

Annex A – Detailed Feedback to questions

The most consistent and voiced responses to the presented questions to the engagement events across Scotland during June and July 2016 are presented below. A further spreadsheet is available which details all captured individual comments. Responses to each question are presented “as is” and no analysis or conclusions are offered.

Section 1 - A time-limited ILF award to support independent living for a specific life event

Purpose - To offer a weekly based ILF award that supports independent living for disabled people who need help to deal with a specific life event or life transition

Q1 What do you think of the list of life events that a time-limited ILF award might support?

- Need to define transition events to make it clear they are not short breaks or respite.
- Where should the Local Authority step in and where would ILF start?
- Death of a parent or carer would be significant.
- Moving home to own independent home cited by many.
- Concern that many life events are sudden and traumatic and not able to plan for but need rapid intervention and support.
- As it is a transition event, any extra funding should not impact on regular funding mechanisms.
- Reablement seen as very important by many.
- Problem with additionality - who defines this and where does ILF fit?
- Support for both child-adult transition and adult -older person but further recognition that impact of disability increases as people get older.

- Support for new carers/carers networks.
- Noticeable drop in services from child to adult.
- Becoming parents for the first time.
- Must not be a substitute for filling gaps elsewhere.
- Life events can happen at any age.
- Overcoming social isolation.
- Should be flexible on circumstances and needs.
- Personalisation of services.
- Developing skills to be more independent.
- Emergency cover fund for support during difficult times.
- Psychological and emotional support as well as practical support.
- Support getting into employment and education.
- Sudden onset or deterioration of circumstances (and need to know that support is there).
- Specialist employment coaches.
- Befriending services.
- Attending community leisure events and activities.
- Visiting families during illness or if they are far away and isolated.
- Move away from round the clock support to a package that enables independent living.
- Focus on individual cases and not a restrictive list of events. Split levels between low needs and high support needs.
- Transition support is important, especially for children moving from school to college.

Q2 Is there anything missing from the list of life events?

- Reablement is a common theme.
- Moving house and from family home to own home.
- Moving between local authority areas and support during this.
- Home adaptations.
- Transgender transition support.
- Prepayment cards.

- Emergency care and support.
- Transportation cited by almost everyone as a significant issue.
- Legal costs planning for wills/guardianship.
- Maintenance and equipment support costs (during and post transition).
- Community based activities which are not day centre based.
- Many people are not confident in their use of the internet or current technology so online support could be offered.
- Social engagement and interaction cited by many.
- Short breaks mentioned by many.
- Support during maternity.
- Support after bereavement (especially emotional and physical and if the carer was the one that passed away).
- Driving lessons.
- Transition into employment/volunteering/education/redundancy.
- Grants to set up new community based groups.
- Communications support for young people outside of course/study time.
- Mobile emergency care service.
- Support for those with less complex disabilities.
- Support for employers (buddy systems).
- Mentoring change.
- Summer holiday support when schools close.
- Skills dealing with change.
- Adults under 65 with disabilities living in residential care are an overlooked group. In rural and island settings, it can be the case that younger adults with disabilities are placed in older person's care homes due to lack of specialist provision. This makes it harder to personalise care for adults in non-specialist settings.
- Adults with disabilities moving into and living in residential care should have the same rights to the proposed ILF and those in the community. Transition to support shared or group accommodation for both younger and older persons. In rural and island settings it can be the case that younger people with disabilities are placed in

older person's care homes.

- Greater challenge to support those that move into non specialist care homes to remain close to the families and communities.
- Adults moving into care homes should have the same rights to the proposed fund as those in the community.
- Transition to support shared or group accommodation for both younger and older persons.

Q3 Do you have views on maintaining the existing qualifying support services (QSS) definition (personal and domestic care)?

- Do not duplicate LA.
- LA should fund basic care needs.
- ILF should be used more creatively for enablement and social inclusion.
- New fund should not cover QSS.
- QSS criteria would not fit with a time limited award (i.e. needs would still be the same after the time period).
- Ensure portability and consistency across all LAs.
- Grant should be useable outside of 9-5pm hours.
- QSS is a bit too restrictive.
- Should be determined by the disabled person.
- It should be used in the way SDS should be used.
- See the person and not the disability.
- Address loneliness and isolation.
- Give an amount to an individual and let them decide how best to use it.
- Needs to go beyond QSS.
- This should be about living life.
- Separate QSS vs Additionality.
- Age range to go beyond retirement.
- Has to be a maximum to ensure fund is fairly shared.
- LA should provide the starting point (with ILF providing a key component of the total support package).

- Accessible to all.
- Socialisation.
- New Fund should not affect current recipients.
- Need to reflect support to live in the community.
- Enabling recipient choices.
- Interface with medical staff when entering hospital.
- Creativity with packages.
- ILF used when pricing LA award - this should not happen.
- Equine therapy, sailing, driving, hydrotherapy, swimming, skiing.
"Things to get out and do things!"
- Can ILF be used for lower levels of eligibility?

Q4 Do you have views on ensuring that a time-limited ILF award is not used to fund outcomes that can be delivered by other agencies?

- Agreed that ILF should not be used to fund what others should be.
- Possible use as short term brokerage to enable a permanent package to be put in place.
- Fund should be about additionality and tailored to individual and their situation.
- Flexible end date to meet individual needs.
- Potential for flexibility.
- Must be used to fund things that cannot be met elsewhere.
- Create a central knowledge hub of what people are entitled to.
- Ensure Additionality is monitored and measured
- Must ensure dignity, respect and inclusivity.
- £5m is not enough.
- Do not duplicate services already out there.
- Outcomes based assessments clearly identifying the life event/transition.
- Ensure ILF funding is about choice.
- Recognition that LAs may be squeezed by other pressures
- Need to take into consideration the timescales for assessing needs.

- Could there be a shared database of information/service mapping to check which services were already funded by other agencies to ensure the new fund was additional?

Q5 What are your views on retaining the previous ILF eligibility criteria of supporting disabled people aged 16-64 who are on higher rate DLA or PIP?

- General consensus that age criteria will leave many people out.
- Criteria need to be flexible to act as a safety net for those who are not getting support.
- Should be based on diagnosis and not high rate DLA/PIP.
- Over 65s disadvantaged as do not get as large a care package from LA [offset against attendance allowance?].
- Fairer not to have age criteria. Should not restrict to high rate DLA/PIP.
- Criteria should be different to local community.
- Ensure if people change from high rate DLA they do not lose their ILF award immediately.
- Criteria makes things impersonal - focus on the individual.
- Should not be dictated by other agencies/DWP.
- Already lots of support for disabled children.
- If no criteria then fund will be spread too thin - this is a difficult decision.
- Using an LA threshold disadvantages those who do not have a LA input.
- Can't help everyone.
- Would LA recognise the time limited period for the ILF award and work in partnership during that period?
- Is an age limit discriminatory?
- Least restrictive criteria as possible.
- Life expectancies are longer and pension ages are increasing.
- Recipients should not be eligible if they have significant personal reserves in the bank. PIP horrendous process.
- Transitional events can be wide ranging and unpredictable. £340 a

week too blunt a tool to use for eligibility.

- What about those not on high rate DLA but with substantial support needs?
- People still retain their disability after the age of 65.
- What happens to disabled people who do not receive DLA/PIP and only receive ESA?

Q6 What are your views on having a minimum and maximum ILF award sum?

- Should depend on individual needs.
- Flexible.
- ILF should have discretion to adjust.
- Must be worthwhile to administer.
- No minimum - people can make a little go a long way to making a difference in their lives.
- A maximum amount needs to be in place to ensure as many people can receive.
- Can ILF pull in other funding streams?
- Does this take into account location?
- No maximum award.
- No means testing.
- No minimum limit.
- A fair contribution is ok.
- Factor in inflation and cost of living. 3-12 months ok.
- The relationship between time and amount is very important.
- Is 1 hour a suitable minimum?
- Move away from hours of support to how much money might be available (which would then be planned out to last).
- A weekly award would be used regardless to make sure it is used (and not taken away!).
- Guidance rather than absolute.
- A minimum award could trigger access to other sources of funding.

- Need to trust the assessors to make good assessments and then decide on required amounts.
- Additionality is key.
- If there was a minimum or maximum award this should be related to what the life event was and provisional costings must be done to reflect this before proposing.

Q7 What are your views having a minimum and maximum duration of award (the length of time an individual would receive ILF support)?

- Strong consensus that this should be based on the individual needs and circumstances.
- Should not be time limited.
- Need to focus on what outcomes are trying to be achieved and focus on how best to achieve them.
- Fund needs to be in partnership with LA/Health Authority.
- Timescales would need to be clear especially if LA is taking over support afterwards.
- Must reduce/remove anxiety around the review process.
- Time limits should be SMART.
- Must include an exit plan for what happens after the time limit/funded period.
- One year could be a fair limit - could someone then re-apply?
- How does Community Empowerment Legislation fit in (could it complement ILF?).
- Ideal would be to focus on achieving a successful outcome(s).
- Short term payments could help many people (school holidays cited several times).
- People are becoming more SDS minded so managing a bigger payment upfront and taking control of how the money is spent is becoming more commonplace.
- Hospital discharges are a difficult scenario - practicalities of timescales and support available at home post discharge all take time.
- How fast can support be put in place?

- Revolving door problem of ineffective home support post discharge leading to readmissions.
- Preference to have an upfront lump sum and plan how best to use it (likely to need more initially then taper off as things stabilise).
- Things can go wrong during a transitional event and unforeseen circumstances may require urgent re-assessment and further funds.
- A minimum and maximum duration of award would need to depend on what was best for the individual and their circumstances.

Q8 Do you have any views on whether ILF support should be linked to local authority input?

- Very strong consensus that ILF awards should not be linked to LA input as this leads to inconsistencies at national level due to local funding differences (postcode lottery).
- Assessment should not be linked to LA input as this is a red herring.
- Should be determined by benefit or linked to NHS database.
- LA should have overview of all funding streams supporting the individual.
- Issues of statutory duties placed on LAs.
- Single shared assessment between LA and ILF.
- Desire to cut down on number of individual assessments.
- Issue of not having a dedicated care manager.
- Whose needs are being met - organisations or individuals?
- Check that outcomes have been met.
- Cannot afford to break link with social work.
- Keep LA input but treat ILF as separate additional fund
- Application process should be via individual and not LA.
- Different LA provision across the country makes it essential for ILF to be separate so as to be consistent and equitable.
- Keep it equal for all.
- Should include people with variable and mental health.

- Will ILF get more than £5m?
- Strong views that the applications process should not be done by/controlled through the LA.
- A link with the LA, in combination with the higher rate PiP/DLA criteria, best guarantees that the limited funding available is directed at those with highest levels of need.

Section 2 - A single grant ILF award to support independent living

Purpose - The purpose of this theme is to offer a single 'one-off' grant award payment to support independent living.

Q9 What do you think of the list of areas that could be supported by single grant ILF awards?

- Some things should be provided by LA/NHS.
- Emergency and temporary care and support whilst overall package is being developed.
- Adaptations.
- Training.
- Transportation (deposit for a car cited several times).
- Training for people about disabilities (taxi drivers securing wheelchairs example).
- Supporting people moving into employment or voluntary opportunities.
- Technology - devices and specialist communication aids.
- Skype and iPads for social contact.
- iPads mentioned to keep the children occupied and provide the parent with some respite.
- Driving courses.
- Funerals.
- Business start-ups seen as good idea but additionality needs to be matched against available funds through Access to Work.
- Where does Scottish Enterprise fit in to the business start-up ideas?
- Alternative therapies (i.e. hydrotherapy, physiotherapy).

- Shouldn't the LA be funding home adaptations?
- Life experiences such as music/sports/ festivals/social events).
- Cost of taking PA to events.
- Support for award managers.
- Support for respite and short breaks. "Immediate Funds" to offset the time the LA will take to get to a decision and allocate requested funds.
- Additionality on the level of input of LA.
- Ensure the basics are established before additionality.
- Huge amount of opportunities for DP to have their own business.
- How would it be checked to confirm the money has been used appropriately?
- Communication aids - young people especially.
- Assistance dogs.
- Leisure and social purposes.
- Transport costs.
- Additional services make up the quality of life.
- A bit of money now can help the long term fiscal health of recipient [not mentioned but there is also a debt prevention benefit here].
- Connecting people into their community.
- Equipment gaps.
- Touch screen technologies.
- One comment was that there should not be a single grant.
- Specialist beds (adapted, stronger).
- Gym membership.
- Leisure and cultural activities (i.e. play guitar, learn a new skill, self-confidence, social life).
- Coaching for people to move into employment/voluntary opportunities.
- Specialist computer technologies and software.
- Gardening
- Maintenance for specialist equipment.
- Extra day care over an agreed period?
- Would a personal contribution be required?

- Same entry criteria for all.
- Additionality over what the LA is able to provide.
- Frequency/amount should focus on the outcomes to be achieved.
- Could it pay for insurance (car) for another named driver to be able to drive another persons' car?
- Location is crucial.
- Emergencies never happen in core hours!
- Decisions should focus on individuals and additionality.
- Spending to save.
- Groups ok to apply.

Q10 Is there anything missing from the list of areas that could be supported?

- Moving house costs.
- Costs to support live in carers.
- Attending courses/conferences.
- Specialist furniture and equipments.
- Transport.
- Flexible grants that can make a difference to the individual.
- Linking national databases to signpost organisations to other organisations.
- Consideration given to the geographical situation (including availability of available support services).
- Sports participation [assumption is that this is different to attending sporting events].
- Support during discharge from care.
- Integration back into society.
- Emergency/crisis care.
- More support to lead own life.
- Being an equal citizen; no dehumanisation.
- Upward Mobility.
- Horse riding.
- Treatment that the NHS won't cover.

- Transport issues in rural areas.
- Help maintain property/handyman services.
- Setting up home working.
- Meeting a cost gap in better equipment (wheelchairs cited).
- Setting up community centres.
- Transport costs for medical visits and accessing training.
- Carer breaks (to support individual becoming more confident).
- Flexibility to look beyond the normal.
- Avoid duplication.
- Cooking classes.
- Befriending services.
- Centralised website to help disabled people to navigate their rights.
- Treatment vs. fun things!
- Is it first come first served?
- What happens when the £5m runs out?
- Do you go onto a waiting list?
- Is "lifetime" award fair to all?
- Crisis response fund (contingency fund in place and some form of pre-approval in place so individuals can access it directly in times of emergency).
- Upfront money for a deposit for a car (weekly costs can be met but struggle with deposits).
- Hobby classes.
- Exercise tutors.
- PA support for college attendance.
- Cameras.
- Equal citizenship and participation.
- Much is already agreed through SDS so must ensure additionality.
- Help for carers to get them out.
- A greenhouse.
- Insurance to put other drivers onto insurance.
- Disabled taxi service (business start up idea).
- Log cabin at the bottom of the garden (respite and breaks).

- Group activities.
- Specialist technologies and access to the internet. Some support for overnight care.

Q11 Do you have any views on ensuring that ILF grants do not duplicate other services?

- Should be additional and not duplicate.
- Need to demonstrate impact and measure outcomes.
- Should be for alternatives which make a difference.
- LA criteria might make people ineligible for certain types of funding.
- Should be a checklist of things which should be provided by other agencies.
- Some categories of equipment will not be funded through NHS/LA so these could maybe go on an approved list?
- Must ensure ILF does not provide anything unsafe or not approved.
- Criteria should be based on individual situation and needs.
- Scottish Welfare Fund may do many things so must avoid duplication.
- Family holidays (as opposed to respite).
- Ask "have you applied for other funding?"
- Additionality is essential.
- Max LA input and max ILF input.
- Don't let LAs off the hook.
- Key is tandem working and shared responsibility.
- Should be a one-off grant and no re-application [this appeared once].
- Theme A met with unanimous agreement in Aberdeen.
- Create an information group.
- Will there be a continuous re-assessment process?
- Could there be negotiation with other agencies that have rejected support requests? "Turn to Us" links?

- "LAs help people get out of bed - ILF gives people a reason to get out of bed!"
- Should a reduction in LA funding be matched with a reduction in ILF funding?
- How can ILF target the appropriate audience without working with the LA?
- Pooling funds and matching funds seen as good ideas (with some reservations expressed).
- One small award may lead to another small award.
- ILF must not be the go to organisation if others have gaps
- Scrap ILF and merge it with SDS.

Q12 What are your views on retaining the previous ILF eligibility criteria of supporting disabled people aged 16-64 who are on higher rate DLA or PIP?

- Similar responses to Q5.
- Concern over too simple a single criteria (i.e. high rate DLA) which may miss many people with a substantial need.
- Can't assume higher care provision across all LAs due to inconsistencies.
- Must ensure a safety net for those not assessed as high rate DLA/PIP.
- Let people use their diagnosis and base award on need.
- High rate DLA does not transfer directly to high level PIP and people are being downgraded so may not get the support they need.
- Concern about people with needs but who are not on a defined benefit.
- Age should not be limited to 64. Higher rate DLA very punitive.
- Problem is for people for whom DLA/PIP has stopped.
- No upper age limit.
- Can another marker be used?
- Age brackets shouldn't be used as it doesn't take into account changes in society in the last 20 years.

- Must be careful not to discriminate.
- The application is the pivot - based on need - anyone with a disability but permanent disability.
- Should use human rights indicators as criteria.
- Have different thresholds for the new fund.
- Getting the balance right - no individual who doesn't have high DLA could still benefit from a small amount of fund
- May need to have the possibility of people/voluntary organisations applying on behalf of individuals.
- If PIP is removed - emergency funding with specific criteria.
- Needs to be flexible.
- Discrimination against younger people who did not qualify before the closing of ILF [2010].
- ILF should be scrapped/SDS should be scrapped (taken off LA and combine together).
- Have we identified the number of people who are in need of ILF who never received it using the existing criteria?
- LA may see this as extra and reduce their amount of support.
- Should complement LA support but not replace it.
- Mental health and learning difficulties cited as having substantial support needs but do not qualify for high rate DLA.
- Would opening the criteria lead to a flood?
- Think about eligibility v referrals - trust the LA for their professional judgement.
- Eligibility should be guidance.
- Not QSS but flexible and out reaching.
- Consideration of lowering the age limit to 14/15.
- Do not restrict to HR DLA/PIP.
- Could it be based on proof of diagnosis?
- Those with disabilities but not on HR DLA/PIP would be excluded and only receive ESA.

Q13 What are your views on having a minimum and maximum single grant award?

- Should have a maximum but no minimum.
- Must be linked to individual need
- If no contribution to be made then there should be no minimum.
- Have a flexible maximum allowing a higher value to be made by a decisions panel.
- If funding streams are exhausted elsewhere then use ILF.
- Consider a joint funding stream.
- The £5m promised last year should also form part of the New Fund.
- If there was more money in the pot this would be easier to fund.
- Admin costs would be a problem if ILF were available to everyone - it would open it up to reach more people instead of waiting on LAs to reach everyone.
- Application proportionate to award.
- Should have a database of what costs are reasonable in order to determine a maximum award.
- Database kept on standard costs.
- Equipment - funding should also consider maintenance as well as purchase.
- Different application process for small awards [no amount stated].
- Would a maximum amount breach human rights?
- Split fund levels of criteria i.e. those which the LA would not fund.
- Minimum should at least cover admin costs to make award.
- Set a maximum over a given period.
- A set maximum would support it being used more widely.
- Is there a defined "priority" group e.g. 16-24 year olds as this may balance out the bottle neck of the people who have been eligible but waiting since 2010?
- No- identify the needs.
- Consider preventative spends as well. Small amounts of money can make a big difference so no minimum.

- Theme B and a grant system would be less bureaucratic than Theme A and that max/min amounts should reflect this.

Q14 What are your views on allowing reapplications to a single grant award scheme?

- Yes, but there should be a time limit for re-applications.
- Must be able to re-apply if conditions change.
- If someone re-applies, have a strict limit on the amount that are re-applying for.
- Education for those who do not know what is available.
- DWP flyer goes out with DLA letter (at age 16) to let people know about ILF.
- People could become greedy if allowed to re-apply [single comment].
- Would be in favour of a time limit on re-application.
- Potentially means-tested - e.g. if they need another piece of equipment they should be able to re-apply.
- Validity in limiting number of re-applications to ensure as many people as possible can benefit.
- What about an individual ceiling amount that an individual can apply "up to" rather than number of times?
- Should be based on individual needs and outcomes being achieved i.e. if something is working for an individual then maybe it should continue.
- Short breaks - Glasgow set up schemes with service providers - would welcome a one off payment to assist with cost.
- Complex needs - paying for additional care.
- Holiday breaks for those who don't have carer/live on their own [assumption that this would be a regular request i.e. reapplication].
- LAs don't cover respite for those who don't have carer.
- Judge each application on merit.
- It should not be seen as a single one-off grant as peoples' needs change over time.
- What happens at the end when the carrot is taken away?

- Possibly a fixed amount in any one time frame i.e. 3 years. Life is a very long time.
- Reapplications should only be considered after the demand under the new scheme has been assessed and reviewed. If the new scheme is oversubscribed, reapplications should potentially not be considered. If the new scheme is undersubscribed, consideration should then be given to changing the criteria to widen access, including considering allowing reapplications.

Q15 Do you have views on allowing group applications to a single grant award scheme?

- Yes, but the application should be based on outcomes.
- A group of individuals trying to achieve something should be allowed to apply but not an organisation.
- Potential conflict with other funding sources i.e. Postcode lottery.
- "The Wheel Inn" is a good example of this working.
- This could bring isolated individuals together.
- Possible help to get something off the ground /prepare applications for other funding streams.
- Creates opportunities for clubs particularly in rural areas.
- Yes - e.g. training as employers in a group situation.
- Yes, but not if it then means an individual cannot apply for themselves for their individual needs.
- Great for social activities and holidays.
- Group vehicle/minibus.
- "Community spirit".
- Means a wider group can benefit.
- Could an amount be set aside for group applications?
- Top-ups for projects funded elsewhere.
- Would allow a group to purchase a static caravan for example on a time share basis to provide respite/time away throughout the year.
- Should be outcomes focused.
- Even a small award can make a big difference.
- Definitely - those who want social activity but not individually.

- Start up funding for community groups.
- Support groups - pay for travel etc.
- Seen as a good idea but some practical issues.
- How is impact of grant going to be measured? Is it being used to maximise outcomes?
- Forming a club. Caveat - must undertake fundraising to become sustainable
- May cause problems if someone wants to leave
- Individual funds could be grouped together for transport, equipment etc.
- Consider individual contributions to a shared pot.
- This may be beneficial to many communities.
- It could be more cost effective for ILF Scotland to deliver.

Section 3 – Summative questions

Q16 Do you have a preference between Themes A and B?

The overriding consensus that a mixture of both themes would be preferred (n = 278). Only one event voted for a single theme which was Theme B (n=17; A=0, B= 15).

One group made the observation that both schemes have equal merit if they provide additionality and are delivered equitably across Scotland. Only one respondent (n=278) advocated for the continuation of the current lifetime/longer award.

Q17 What do you think is the most important area that ILF should support?

- "Funding for joy!"
- Social inclusion.
- Transport and mobility.
- Accessibility to stay in own home.
- Inclusion in the community.

- Anything that supports good health and well-being and quality of life.
- Social activities and help to get out and about.
- Everything listed in Theme B should be allowed in the new fund.
- Should not be age restricted.
- Choice, flexibility and rights.
- Preventative work.
- New fund must have additionality and not duplicate services.
- Disabled people must be listened to and have control.
- New Fund must ensure that disabled people are part of the community and friendships are developed and maintained.
- Needs of the person must be the focus with discretion and flexibility.
- Must ensure independence and choice.
- Help to set up work experience programmes.
- Start up business.
- Holidays.
- Technology.
- Use fund to meet unmet needs.
- Enablement.
- Independent living.
- Online community development.
- Respite
- Access to community and education.
- Should support mental health issues.
- Personalised and shared housing for up to 4 people in order for more disabled people to live independently.
- Purpose built accommodation.
- Adaptations, equipments and technology.
- Emergency care and support.
- Palliative care.
- Improving communication for all
- More support for social inclusion and a peer network.
- More PAs for those with learning difficulties.

- Flats for carers.
- Digital inclusion and more access to technology.
- BSL training and a deaf village model for Scotland.
- Assistance devices which are not available on the NHS [none specifically mentioned].
- More accessible transport.
- Inflation issues.
- Look at changing the financial assessment.
- Eligibility is crucial.
- Transitions are the most important area to fund.

Q18 Is there anything missing that is not covered by the options presented?

- Telecare seen as important but with major concerns in reduction in physical support services.
- Must be able to demonstrate the impact of the £5m e.g. case studies, surveys, phone interviews.
- Split funding between Theme A and B.
- Additional costs that are there for PAs which are not currently covered.
- 0% interest bank to cover emergencies and crisis situations.
- People could be "pre-cleared" so that payments can be made quickly.
- Standardise PA rates.
- Flexibility.
- A mechanism to generate further income [not clear if this is for ILF or the individual].
- Funding the additional person at events and activities.
- Support for holidays.
- Training for carers.
- Adjusting to new disability or decline in condition/health.
- Training for professionals and those in services (i.e. health and taxi drivers).

- Equipment for those who find it hard to speak and read.
- What will the assessment process look like?
- Community capacity advice and support with local area coordination.
- PA training.
- Support in upkeep for assistance dogs.
- Consideration of higher costs in rural areas.
- Is there going to be a charge?
- Recycling scheme for wheelchairs and equipment/technology.
- Advice and social support.
- Filling the gaps.
- Additionality is extremely crucial.
- More cars/taxis to accommodate wheelchairs.
- Quality of life.
- Disabled adults in residential care settings are relatively forgotten population.
- By definition, living in a shared, often non-specialist settings, they have less personalised care than disabled adults living at home in the community.
- Adults with disabilities living in residential care should also be able to benefit from the new scheme.
- The current scheme is not delivered equitably with disabled people's access to ILF funding being partly dependent on which local authority they live in.
- ILF should seek to ensure that the new scheme is fair and equitable for disabled adults wherever they live across Scotland.

Q19 Do you have any other thoughts or comments on the options presented?

- There should be a yearly event to update on ILF and its progress.
- LAs have said that if specialist equipment is provided by another organisation then they should also make the adaptation for its proper use.

- Will existing users be able to access the New Fund?
- Training to ensure good carers are available and well trained.
- One off grants available for additional help during specific periods e.g. when a carer falls ill etc.
- No review of grants - need good feedback channels.
- Rethink application channels.
- Referring agencies (LA, NHS) could recommend awards below minimum amount. If applying for below minimum, (this assumes a lower tier) then no visit is required and a simplified process is followed.
- Light touch monitoring and accounting of funds.
- Don't lose focus on additionality.
- The New Fund should be similar to a trust fund and should be open to all disabled people to apply and should not be restricted to a specific criteria i.e. benefit level.
- It may be a good idea to use a % of the new fund for this purpose.
- Help to meet individual needs not system needs.
- People with the most significant needs already get support - can ILF support those who are not eligible for help from the LA?
- More money for ILF to be re-opened fully as it is for current users and this would make a more long term difference to more people.
- Can the fund be opened to people in residential care for extra things i.e. equipment?
- Ensure criteria are focused on actual needs and outcomes, with the option of focusing eligibility on diagnosis rather than on rate of DLA/PIP.
- ILF has an amazing opportunity to focus on quality of life.
- Give people what they want, not just what they need.
- When will the fund be opened?
- More money should be made available for ILF by Scottish Government.
- Manage expectations.
- Could the fund be used to enable disabled people who wish to buy a therapist dog?

- Independent living support should not be provided by the LA.
- Support for the parent to be a parent and not a carer.
- Funeral costs.
- Alternative therapies.
- Support for disabled people leaving work/going into retirement.
- More money please!
- Self-assessment?
- Ensure ILF links with other organisations to find out what is currently out there.
- Ensuring all future information is available in accessible formats.
- How does ILF Scotland reach out to other cultures and communities living in Scotland?
- Support for pregnant ladies and new mothers.
- Disability champion for rural areas.
- Could the fund be linked creatively with other funds elsewhere to be more cost effective?
- Adults with disabilities in remote and island communities often have less access to specialist services.
- Fuel and transport poverty and higher costs of living in rural and island communities.
- What would the assessment process look like? Could it be streamlined for emergency situations?
- Will it be possible to spend £5m evenly or proportionally across Scotland?
- Could people be given the option to apply to the fund and use that money to top up and be in addition to what they receive from the LA?
- The new fund should be about the opportunity to live and not just exist.

Annex B Breakdown of events by location and number

Date	Location	No.	Venue	Event Venue Rating
20 th June	Dumfries	9	Easterbrook Hall	Excellent- 63%; Good - 37%
28 th June	Glasgow	50	Glasgow City Hotel	Excellent – 53%; Good – 47%
30 th June	Aberdeen	22	Double Tree, Hilton	Excellent – 78%; Good – 22%
4 th July	Stirling	27	Stirling Court Hotel	Excellent – 33%; Good – 67%
6 th July	Inverness	17	Eden Court Conference Centre	Excellent- 80%; Good – 20%
11 th July	Edinburgh	40	Novotel, Edinburgh Park	Excellent- 54%; Good – 41%; Fair – 5%
12 th July	Dundee	22	Dundee University	Excellent – 81%; Good – 19%
14 th July	Borders	27	SBSEC	Excellent – 23%; Good – 77%
26 th July	Hamilton	17	Lifestyles Centre	100% (1 return)
9 th Aug	ILF Leads/ SWS	17	Raploch Centre, Stirling	Excellent – 46%; Good – 54%
10 th Aug	GCIL	30	GCIL, Glasgow	Excellent – 59%; Good – 41%

	Number	Disabled Persons	Disabled Person's Organisations	Parents and Carers	Local Authority/ Social Workers
Dumfries	9	1	6	2	0
Glasgow	50	13	14	22	1
Aberdeen	22	2	6	11	3
Stirling	27	11	3	7	6
Inverness	17	3	1	12	1
Edinburgh	40	12	11	13	4
Dundee	22	1	14	4	3
Borders	27	20 (3)	3 (from 20)	2	5
Hamilton	17	2	0	13	2
ILF Leads	17	0	0	0	17
GCIL	30	12	0	18	0
Totals	278	77	58	121	42

Annex C Comments and Quotes

- “Local authority support helps me get out of bed; ILF Scotland support gives me a reason to get out of bed!”
- “Funding for joy!”
- “Open constructive discussion” – Dumfries
- “Found it very helpful and listened to as a parent of a disabled young person” – Glasgow
- “Thought the planning and facilitation of the event was excellent. Really encouraged by the openness of the ILF Scotland team to views and ideas. Very engaging event.” – Glasgow
- “Felt listened to as well as being involved in the process. Was great to see that you are engaging with the people who are affected by ILF, rather than the decision being made top down.” - Aberdeen
- “Superbly facilitated, very well organised.” – Aberdeen
- “I really enjoyed the friendly convivial atmosphere. Everyone was great and I did feel everyone's opinions were shared equally and valued. We were all listened to.” – Inverness
- “We would like to see ILF ensure that they are not duplicating SDS/LA budgets and responsibilities. Supporting preventative work e.g. transitions. Supporting by condition/diagnosis not age or benefit eligibility. Support planning not assessment. Not having to choose either A or B but combination + Option C.” – Dundee
- “Good debates and discussions, interesting however the reality of the complexities of how the fund will be distributed and not sure how the questions and/or concerns that it will reach the people (or some of) who may benefit the most.” – Edinburgh
- “Discussion was lively and at a good pace. Lots of information was provided and gave a good overview of current thoughts and development of the fund” - Borders

Annex D Evaluation Feedback

Evaluation forms were received from 165 people from a total group of 278. This represents a 60% response rate.

	n = 165	Excellent	Good	Fair	Poor
Q1	How do you think today's event was?	105	57	3	0
Q2	Did you get a chance to share your views?	157	1	0	0
Q3	Did you think the discussions were useful?	157	1	0	0
Q4	Do you feel like you were listened to today?	155	2	0	0
Q5	How well informed are you about what happens next?	74	79	9	4
Q6	The speakers were clear and easy to understand?	122	38	1	0
Q7	The information on the day was clear and easy to understand?	91	70	2	0
Q8	The venue suited my needs?	99	64	1	0