

Co-Production Working Group Meeting 2

Tuesday 7 November 2023 – 10.30am to 12.30pm Online via Microsoft Teams

In Attendance:

Peter Scott, ILF Scotland (Co-Chair) Iain MacAllister, Scottish Government (Co-Chair) Calum Macaulay, Glasgow Centre for Inclusive Living Jim Elder-Woodward, ILF Scotland Advisory Group Sam Smith, CCPS Lyn Pornaro, Disability Equality Scotland Fran Holligan, COSLA Catherine McGoldrick COSLA Tressa Burke, Glasgow Disability Alliance Pauline Nolan, Inclusion Scotland Gaby Nolan, Lothian Centre for Inclusive Living Donald Macleod, Self-Directed Support Scotland Cameron Smith, Scottish Commission for Learning Disability Donna Murray, Social Work Scotland Jenny Miller, PAMIS Andy Miller, Scottish Commission for Learning Disability

Present:

Robert Peterson, Scottish Government

 ILF Scotland, Denholm House, Almondvale Business Park, Almondvale Way, Livingston, EH54 6GA

 Tel: 0300 200 2022
 Email: enquiries@ilf.scot
 Web: www.ilf.scot

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 Registered office: Denholm House, Almond vale Business Park, Almondvale Way, Livingston, EH54 6GA

Steven Hanlon, Scottish Government Lauren Glen, Scottish Government Jack Blaik, Scottish Government Amelia Andrzejowska, Scottish Government Linda Scott, ILF Scotland Erika Mather, ILF Scotland Marriane Scobie, Glasgow Disability Alliance, deputy for Tressa part of meeting

Apologies Received:

Jan Savage Scottish Human Rights Commission Fiona Collie, Carers Scotland Andy Higgins, ILF Scotland Advisory Group

Item 1: Welcome and Introductions

The Chair thanked all for attending second meeting of the Co-Production Working Group and asked those attending for the first time to introduce themselves.

Item 2: Declarations of Interest

The Chair provided a brief explanation of the rule that if there is a risk of conflict, it should be disclosed to group members before the statement is made and/or voting on final decision. None raised at this time.

Item 3: Minutes of Previous Meeting

Minutes approved.

Item 4: Matters Arising and Actions

The Chair ran through actions from the first meeting of this group. All had been completed or to be addressed during this meeting.

It was noted that future meetings to be held virtually by default unless specified and agreed differently in advance.

Reassurance given that if attendance not possible then ILF Scotland is happy to pick up issues to discuss on individual basis.

Amendments to ToR and Co-Production definition accepted and it was noted that the discussion was helpful to firm up and finalise the ToR.

Item 5: Co-Production Check In

Co-production check in added as a standing agenda item to engage with the group by asking about the process so far etc.

The Chair acknowledged that this is just the beginning of the co-production process, but the opportunity is here to tell us if anything can be done better in relation to adhering to principles of co-production.

Easy Ready was circulated and thanks extended to Disability Equality Scotland for their support with it and comments shared indicated that group members found the Easy Read useful.

The challenging timescale and rapid Information flow was acknowledged. The upcoming Festive period offers a break and an opportunity to review the pace when we restart in January.

Item 6: Link to DLA (Paper 4 for discussion)

A brief introduction of the topic and paper 4 was provided.

Group members discussion included:

- In response to a question about level of cost (staff / admin) necessary to retain DLA element, it was noted that although there is no direct fee attached, it is time consuming and creates administrative burden for both ILF Scotland and applicants.
- The potential consequences of losing social security benefits and its impact on ILF award was debated. Some risks were outlined: if person loses DLA/PIP/ADP after the review there is often impact on other benefits/ other social support e.g., blue badge.
- Currently operating in the landscape of 3 different benefits delivered DWP and SSS and there are differences between criteria for DLA / PIP / ADP. If entitlement to DLA/PIP is rejected after the review, currently ILF award is not suspended until the outcome of the appeal. However, according to the policy in cases when appeal is not successful the recipient will lose ILF award.
- It was recognised that some people choose not to apply for benefits. A design using receipt of benefits as a criterion may discriminate against people who decide not to apply for social security but would otherwise be eligible for ILF.
- It was suggested that, if possible, we should avoid linking to benefits but retain the link with social care assessment. There was an awareness among the group that social care assessment is not flawless and various challenges were discussed.
- General comments provided on social security system being perceived as hostile and not user friendly; language was given as an example how challenging it is to navigate the system which leads to unintended discrimination.

 Equity point raised regarding current ILF recipients. However, discussion on existing policies is not within the scope of this group. Reassurance given that this point will be addressed and ILF Scotland hopes that policies could be harmonised for existing ILF recipients.

Conclusion: Recommendation agreed to make no link to DLA or equivalent benefits as an access principle in the re-opened fund.

Item 7: Award Management (Paper 5 for discussion)

Short introduction of paper 5 provided.

Points raised in the discussion included:

- Views expressed that Third Party Award Management must be an option maintained within a re-opened fund but focus first on support to manage the award by recipients themselves; also, a need was identified to develop programme of stakeholder communications to ensure that disabled people, their families and unpaid carers have the necessary information on Award Management responsibilities.
- It was indicated that this policy is essential for certain recipients people who do not have capacity.
- Examples of misuse of funds were raised where family was appointed to manage support. Although risk is always there ILF is aware of only a small number of occasions when things went wrong.
- ILF Scotland default position is that person manages their own award so they have full control. The practice is that during reviews the disabled person makes what decisions they can/choose to, but Award Manager takes the administrative tasks and actions. The question is how to make it better and even more accessible to people who lack capacity.

- Discussion of the support available to family members acting as award managers.
- Conflict of interest discussed in relation to situations when family members, carers, guardians – are acting as paid PAs. It can be a real concern and has been increasing due to the pandemic and social care recruitment challenges.
- It was emphasised that a Human Rights framework refers to supported decision making principles. The need to draw from United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was pointed out and the need to aspire to the commitments included there. At ILF Scotland, assessors endeavour to ensure that reviews are aligned with human rights principles.
- Request was made that SW will not be allowed to become Award Managers as there is too much conflict of interest. Current policy states that the use of SW is a last resort. SW typically no longer have the capacity to take on this role. It was agreed to SW should not normally be award managers.
- It was acknowledged that the topic is challenging for yes/no answer but the need of the support for recipients to make decisions was recognised as the most important principle and decided to ensure that note on supported decision making is incorporated within the policy as a principle.

Conclusion: Recommendation agreed to keep Award Management Policy and ensure a focus on supported decision making.

Item 8: Age

Short introduction of the paper 6 provided

An age analysis table was presented with the data from December 2021 collected from 14 local authorities on care packages. The figures are estimates only and data is not validated and not fully representative of the whole population of Scotland. It is being used for Illustrative purposes only, to

examine potential expansion of access to older people. There are complex interrelations between population age and care packages offered and the table offers merely an indication of the trend to give some context while making the decision on age as access principle.

Group discussion included:

- Some comments were shared in relation to the age table, and it was noted that the data presented was collected after pandemic, which significantly affected care packages.
- It was suggested that it may be simpler to keep age limits to working age (16 to state pension age at time of application). However, the risk of unwarranted age discrimination was raised.
- Many agreed that discrimination against older people is prevalent in the system and DPOs are aware of many discriminatory practices. Suggestion was made that removing ourselves from the "working age" language would be welcomed, especially given that age is a protected characteristic.
- It was voiced that some felt uncomfortable with the eligibility being linked with the working age whereas others preferred to discuss this in line with other potential eligibility criteria.
- The question was asked if level of demand can be treated as an additional element. It was noted the ILF membership across the UK was always less than the population that would have been eligible, with significant variation across the UK.
- It was put forward that the fund should focus on addressing what are peoples' highest unmet needs rather than making it dependant on how old they are.
- Views were expressed by some group members that under 16 should be eligible too; reasons included that it would support parents and carers to ease pressure and allow them to use the time to work or self-development; additionally, others viewed support to children as our duty to set young people up to achieve and be part of community.
- Some conversation about general meaning and potential impact of threshold sum took place. It was mentioned that the recommended threshold at £600 in IRASC was mostly for illustrative reasons.
- It appeared that most of group members supported the idea of removing age barrier for re-opened ILF and it was decided that it will be subject to discussion at the next meetings alongside other potential access principles.

Action: To provide information in the set of papers for 22 November on implications of not having age limits in the reopened fund.

Item 9: Wider Engagement (Paper 7 for agreement)

A short introduction to the engagement plan presented.

Noted that during the public consultations for the purpose of Transition Fund, the locations with the highest attendance were Edinburgh, Glasgow, and Dundee.

Important for ILF Scotland to start talking publicly about the re-opening.

Alongside Minutes being published on the website, there is a need to organise and promote the engagement events, provide regular updates on the coproduction group progress on the website and social media.

Group inputs included:

- Proposal made that carers organisations and carers centres be included in the marketing and wider engagement plan.
- It was suggested that a north of Scotland location to be added, potentially Inverness. Stirling was also suggested as a potential location.
- The question was asked what support can be offered to people to participate. Perhaps looking at the distribution of the existing recipients may indicate where the events should happen. However, it was voiced that it is not the most important where the events are but what will happen during these events, and we should try to avoid long panel speeches and make sure that there is an active engagement from attendees. Reassurance given the Transition Fund consultation had very positive feedback but also ILF will be seeking further advise on active engagement.
- Concerns raised re risk that most of the accessible venues are already booked up in December due to Christmas functions; some offers of support made to identify suitable places.

Action: Group members to provide suggestions to in relation to the attendees list via email to Erika.

Action: To incorporate comments from the group members to the engagement plan and start activities in relation to the scheduling of the events. Update on engagement plan to be included on the agenda for 22 November.

Item 10: AOB

Question asked about the possibility of recording the meetings. Issues in relation to adhering to SG Data Protection procedures were voiced and situation being complicated due to presence of external stakeholders.

Item 11: Next Meeting Arrangements

The next meeting is scheduled for 3pm on 22 November via Teams.