

Note of Meeting

Northern Ireland Stakeholder Group Meeting

Tuesday 19 September 2023, 11.30 am to 3.30pm

The Mount Conference Centre and via Zoom

Permanent Members Present (in alphabetical order)

Caroline Wheeler

David McDonald, Chairperson

Frances McHugh (via Zoom)

Niqi Rainey

Robert Dallas

Affiliate Members Present (in alphabetical order)

Amanda Paul

Bryan Myles

ILF Scotland Representatives in Attendance (in alphabetical order)

Elizabeth McGarrity

Harvey Tilley (via Zoom)

Lee House

Linda Scott

Peter Scoot (Via Zoom)

Robert White

Sandra Sweeney

Department of Health Representatives in Attendance

Colin Dunlop

Other Attendees (in alphabetical order)

Danny Donnelly (MLA)

Finbarr Fitzpatrick (Bisimprovement)

Jack Armstrong (Policy & Research Officer for Danny Donnelly)

Mervyn Bothwell (NISCC)

Permanent Members Apologies (in alphabetical order)

Collette Jones

Kieran McCarthy (Vice Chairperson)

Michaela Hollywood

List of Actions:

- Lee to use alternative to doodle poll to arrange future meetings. (Complete)
- Lee to re-send links from Michaela to Stakeholder Group on PA support and the future landing programme. (Complete)
- Assessors from Northern Ireland to source possible Recipients to be interviewed by Finbarr as part of the social return on investment evaluation work.
- Lee to send the presentation out on PA support and training from Mervyn Bothwell. (Complete)

1. Welcome, Introductions, Apologies and Housekeeping

David welcomed everyone to the meeting and advised those present of the guests scheduled to attend at various points during the meeting. Lee advised of the fire exits.

2. Minutes of Previous Meeting

David asked that more detail of who was contributing and speaking at the meeting be added to the minutes.

The previous meeting's minutes were approved and will be uploaded to the website. ILF Communications Team to action.

Actions points from previous meeting:

- Colin and Linda to discuss uplifting the PA rate by 12% in advance of April 2023 and backdating to 1 April 2022. (Complete)
- Lee to share links from Michaela to the communication team on PA support and future landing programme. (Complete)

3. Matters Arising

Niqi asked if the Charter for Involvement meetings were going ahead. Linda advised this is on the agenda for the meeting.

4. Re-Opening of the 2015 Fund in Northern Ireland

David congratulated Scotland on the announcement that their Fund would be re-opening in April 2024.

Colin advised the Stakeholder Group that the position of the Department of Health remained the same as previously discussed i.e. no Minister and no Executive. Colin has spoken with Jack Blaik and will be finalising a submission to provide information to the Department of Health on the steps taken by the Scottish Government to have the Fund re-opened and about the likelihood of some pressure to re-open in Northern Ireland.

Caroline mentioned that disabled people in Northern Ireland would not be receiving equity of funding compared to Scotland. Robert and Niqi supported this statement and agreed with David's suggestion of writing to the Permanent Secretary. David advised the Group that they need to raise the re-opening of the Fund with all the main political parties in Northern Ireland and need to get re-opening included in the Programme for Government. The Group agreed that David would invite the Permanent Secretary to a meeting to discuss the re-opening of the Fund.

David explained that the recent Report on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities, which he had had the opportunity to discuss with the UN Committees Rapporteurs, had included reference to the Independent Living Fund and the need for its re-opening here. Robert asked David for more information on the UN Convention. David agreed to provide it at the next meeting. Also, its relevance to the Fund would be discussed later in this meeting and David agreed to include the UN Convention in his letter to the Permanent Secretary.

Peter advised the Group that feedback from Scottish Government indicated that the main influences on re-opening of the Fund included the reputation of ILF Scotland and confidence in its ability to deliver, and

the strength of lobbying from DPOs in terms of increasing campaign work and demand for ILF Scotland to re-open as part of the Shadow Geneva Report. David suggested that Group members might liaise with members of other organisations they know.

Robert White, Sandra Sweeney and Elizabeth McGarrity joined the meeting at 12.20pm.

Finbarr Fitzpatrick joined the meeting at 12.25pm via Zoom.

Jack Armstrong joined the meeting in person at 12.25pm

5. Social Return on Investment Valuation

Finbarr gave a brief update on the research progress so far, explaining that the evaluation 4 years ago will be updated, taking into account the cost-of-living crisis and the COVID-19 pandemic. Finbarr has completed 3 interviews with Recipients and has a further 2 planned in the coming weeks. He reported that so far, the reported personal experiences have been uplifting with Recipients showing resilience through Covid. Linda asked the Stakeholder Group to get in touch with Finbarr if they would be willing to be interviewed to support the research.

Finbarr explained that themes coming through the research so far include:

- Impact on health re COVID-19
- PA retention
- Flexibility on furlough
- Enhanced impact of ILF Scotland

Finbarr advised that the report will be completed by late October 2023.

6. Policy Update – Suspensions

Linda advised that currently, funding may be suspended for a variety of reasons and in certain circumstances, permanently closed. The proposed change in policy would mean that an award would generally remain in suspension and could be re-started providing applicants remained eligible.

For example, if a Recipient spent time in hospital and then a longer period in a residential home but returned to the community after a year or two, ILF Scotland would be able to re-start the award, providing the person remained eligible. In addition, the policy provides ILF Scotland with the discretion to continue to pay awards beyond 28 days where Recipients in hospital require support from their PA or support provider, up to a maximum of six months. Niqi asked Linda what would happen after 6 months. Linda advised that this will be looked at on a case-by-case basis.

Both sponsor teams have agreed the proposals in the revised draft, and it is now out for consultation with the Stakeholder and Advisory Groups.

David suggested that the policy should be clearer about who contacts ILF Scotland to advise of hospital stays and noted some additional comments. Linda asked for members to submit any comments to her.

Caroline raised the issue of self-employed PAs and private providers not working to a Direct Payment rate of £15 per hour but charging a 'private' rate to Recipients of £18 per hour. Linda will discuss with Robert White. Niqi asked how strict ILF were at applying the Threshold Sum and Linda said that it had relaxed somewhat during COVID-19, but assessors are ensuring this is adhered to by the Trusts. Caroline raised an issue about Direct Payments and the cost of daycare.

7. Supporting Award Managers / Third Party Payroll

Linda advised that Colin is still waiting on information and will update the Group as soon as he has this. This item to remain on the agenda for the next meeting.

Caroline commented on the time, effort, and money the admin impact has on her time with Lee. She estimated that in one week she could spend 20 hours or more on administrative tasks relating to the PAs that care for Lee.

Colin Dunlop left the meeting at 2pm

8. UN Convention on the Rights of Persons with Disabilities

David introduced Jack Armstrong. Jack explained he is the policy and research officer for Danny Donnelly and that they are looking at proposals for a Private Members Bill, getting prepared for when there is a new Assembly in place. They are particularly keen to ensure the incorporation of the United Nations Convention on the Rights of Persons with Disabilities into domestic law. They are hoping that the incoming Minister will pick this up and include in the next Programme for Government.

David stated that this submission must be about much more than just accessibility for disabled people and should also consider the right to independent living. David raised issues about travel accessibility, complex assistance and additional funding needed for severely disabled people. Niqui said there is a great loss to society in not doing this i.e. not facilitating inclusion and participation. Caroline commented that severely disabled peoples' and their loved ones' voices are not being heard and

that the Government doesn't recognise the contribution of unpaid carers and that social care would fold without this. David reminded the Group about article 19 of the Convention and the need to use this to push for ILF re-opening and highlighted the aging population of carers and their worries about their loved ones into the future. Robert emphasised that future proofing is important because carers worry about who will look after their loved ones when they are unable to.

Bryan asked how the bill was being promoted and if all political parties were supporting this submission and Jack commented that this is part of an Alliance Manifesto. Jack commented that they are currently focusing on the content, but promotion will be important, and they will build the case for the public through the group that Danny sits on and through formal consultation.

Danny Donnelly, MLA for East Antrim, joined the meeting at 3.16pm, introduced himself to the Stakeholder Group and asked for feedback on what should be incorporated in his submission to the UN Convention on the Rights of Persons with Disabilities.

David provided Danny with an update on the history of the Fund and noted that ILF re-opening wasn't include in the Manifesto. He referenced re-opening in Scotland next year and Article 19s central relevance to the Independent Living Fund and how vital it is to enable our most severely disabled people to get out and about and be heard. Amanda spoke about how she relies on unpaid care because paid care just 'gets her up'. Caroline noted there are 360 thousand unpaid carers in Northern Ireland and that unpaid carers needed time to themselves. She said that ILF is empowering and gives disabled people and their families a quality of life. Getting the bill passes and ILF re-opened is what is needed as well as quick assessments. David commented that

the emphasis must be on disabled peoples' rights. Danny agreed that it's about dignity as equal citizens. Niqi said it's about the right to be independent and have choice and control in their own lives – we take that for granted but disabled people should have this too and it is so much cheaper to have people at home than in care. Caroline noted the positive impact that having disabled people as part of the community has. Niqi made the point that all ILF's funding is used directly on supporting disabled people.

9. Joint Stakeholder Meeting Update

Members commented on how disappointed they were that the joint event in October had to be rescheduled and that this had caused some stress and inconvenience. Linda apologised, referenced the letter Harvey had sent out explaining why it had to be postponed and confirmed that she will set up a planning meeting soon.

10. Review Visit Update

Liz advised the Group that there are currently two assessors for Northern Ireland. Sandra Sweeney will now be supporting in a management capacity. She spoke about the current challenges in all Trust areas relating to difficulties in the provision of day care, getting information for care schedules, and, for Recipients, the challenge of retaining PAs. Caroline raised the issue on the need for higher wages for PAs because they can work elsewhere for more money and less responsibility. She thinks the rate needs to be £15 per hour to sustain people in employment and raised how difficult it is to get PAs trained and then they can't retain them – Trusts won't train one PA but it is not feasible for employers to wait on group training.

Finbarr Fitzpatrick left Zoom at 1pm

11. PA Training Programme

Mervyn Bothwell from the Northern Ireland Social Care Council (NISCC) joined the meeting in person at 1pm

Mervyn shared a presentation that focused on free learning for PAs and advised about access to the app and where more details can be found.

Niqi asked if there was a cost to register with the Northern Ireland Social Care Council and asked if it would be possible to have a separate section for PAs. Mervyn confirmed it costs £30 to register.

Caroline commented on the lack of basic training for PAs and that there was a need to provide a foundation of learning for them. Mervyn responded that safe practice modules are being introduced next year for social care workers and they would have to complete these within the first six months of employment. He realised, however, that, life is quite different in respect of PAs e.g. family members as PAs.

Lee to share the presentation and video with the Stakeholder Group.

Frances McHugh left the meeting at 1.20pm

Peter Scott and Harvey Tilley left the meeting at 1.33pm

12. Charter for Involvement

Linda advised the Group that Emma is currently off sick, and the meetings would be rescheduled when she returns, hopefully in October. Linda suggested only one or two meetings will be required, focusing on what has been achieved and prioritizing what is still to be completed.

Part of the discussion will also focus on Recipient feedback, the mechanisms of which ILF Scotland is currently revising. It was stopped because of Covid-19 and hasn't been re-started yet. There is also a clear link between the Charter and ILF Scotland's Equalities statements, which need to be renewed in April 24.

13. Terms of Reference and Membership

David advised the Stakeholder Group that he would like to restructure membership. He suggested that Amanda, as well as being a member in her own right, would represent another Group she is the Chairperson of, The Omnibus Partnership, consisting of disabled people working to strengthen their rights, with many of them potentially eligible for a re-opened Fund.

He would also like to invite Michael Lorimer, Chairperson of the Independent Monitoring Mechanism for Northern Ireland, which is the body officially charged with keeping an eye on the implementation of the United Nations Convention on the Rights of Persons with Disabilities here, to join as an Affiliate Member.

David suggested that the Stakeholder Group become a DPO. Everyone agreed to these suggestions because of the potential for additional reach and Frances asked for all Group members to lobby other groups as well as their MLAs. Peter notes in the comments at the meeting that he wished to consider further the Group becoming a DPO.

David asked that the Terms of Reference be reviewed at the next meeting. There is a need to look at the quorum and those members not attending. Linda to draft a letter for David advising those members who have not attended for the last year that the Group intends to remove

them from the list of members but give people an opportunity to respond. All agreed to this.

David asked members to give some consideration to changing the name to Advisory Group, like Scotland. To be included on the agenda for the next meeting.

Robert White and Sandra Sweeney re-joined meeting at 3.09pm

14. Any Other Business

Bryan informed the Group that his organisation is hosting an event at the Stormont Hotel on 7 November and all Stakeholder Group Members and ILF Scotland staff are welcome to attend.

15. Proposed Next Meeting & Arrangements

Next meeting - Tuesday 5 December at the Mount Conference Centre where a Christmas lunch will be provided. The meeting will also be held on Zoom for those unable to attend.