**ED&I Webinar : strengthening research equity in NI**

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Laura Collins, Family Carer

*Reflections and Considerations of PPI as a PIER Member*

In the opening pages of her 2023 book, entitled ‘Unpaid Care Policies in the UK’, senior research fellow Liz Lloyd states, “Unpaid care, made care in the community, a possibility”.

Just nine words that say it all.

“Unpaid care made care in the community, a possibility”.

If only, I had known this truth, on the day that I unwittingly said goodbye to £1 million pounds. The day, I turned down lifelong residential care for my very disabled 4-year-old son.

The day, I gave up a nursing career to ensure he would be loved at home, and have some quality of life. The day I gave up a future work pension.

I did not know then, that 40 years later, I would be in the exact same position, still providing 24/7 support, but now as a senior citizen.

So transfer of the institutional ‘care burden’ across the UK, was accomplished successfully in the 90s, but the transfer of the support funding for future family carers was not.

Sustainability of community care since then has sadly been achieved, on the backs of compassionate citizens, at great individual personal cost.

So I was on my own…searching for what would help me, to support my son’s developmental journey…and this urgent need, meant I looked to the latest research, spoke with others in the same boat, and used all our knowledge to engage with any consultation process...long before we had any involvement legislation.

My son would reach the age of 30 years, before we had the first Autism Pathway in NI. I worked for 3 years in partnership with commissioners to develop this - bringing lived and learned experiences together, with the latest international research. This was a rare opportunity where carers had a **mandated** voice in decision-making and service redesign.

Co-commissioning with those with extensive lived experience, remains an aspiration. This is due to three common barriers that usually limit carer engagement in PPI and research:

1. Poor communication of value of research and benefits of involvement

2. Mistrust of public bodies - many do not deliver services well

3. The constraints of caring - some are housebound, as caring 24/7. Many like me, have no respite services. Is there an automatic offer of telephone or online opportunities, or the offer of replacement care cover being funded, in order to attend in-person mtgs?

Plus Carers also fit into other excluded groups, facing even more barriers. A new paper from Cunningham et al (JCE), states: “Disability is not just underreported , it is ignored in trials.” One carer in four is actually disabled.

How do we now address this growing intersection of disadvantages?

We do have UK-wide standards for public involvement, as well as our own NI ones. We do have unpaid carers listed as a Section 75 inequalities grouping, but this does not provide the protections it portends to.

Therefore, how do we ensure equality impact assessments, are in the forefront of our minds, in any new research topic considerations?

How do we show active inclusion, across the whole research lifecycle?

The new health equity agenda being explored today, can be a useful tool to address historic sidestepping, of entrenched inequalities. It can complement, the integrated care system’s shift left agenda, of earlier prevention and ongoing wellbeing support.

So, as budgets tighten, and the social care sector provision shrinks, investment needs to be prioritised… for unpaid carers’ support and research,… for those who have always provided over 90% of adult social care …for free.

We do now eventually seem to be on the systems radar - we are being seen for our contribution and the impact that caring brings. A new DH ‘Emerging Inequalities Audit’ has identified that caring is now effectively a social determinant of health:

“No.34. Carers suffer from higher levels of ill health, including increased stress and mental health issues and increased social isolation

“No. 35. Older carers who provide care have poor health, in comparison to those of the same age who are not care givers.

These two points are part of the new public consultation, on the draft Equality Action Plan and the Draft Disability Action Plan.

Addition of new E.D.I. policies will strengthen current PPI practice, especially for the underserved carer community. Hopefully, this will usher in, a better way of being fair, where difference is celebrated, within a bias-free culture and an improved ‘engagement capable environment’ is grown.

I have always raised the case for lived experience involvement, but have only really been able to do so, at strategic levels, in an effective and informed way, due to the investment in me as a PIER member.

I jumped at the chance of being involved in research opportunities, when I joined the PIER network some15 yrs ago.

I do believe that THE PIER model is an example of best practice. It is a hidden gem in our PPI world, which does not blow its own trumpet.

Its purpose is to help the R&D Division with PPI in decision-making processes, raise awareness of the benefits of PPI in research, among researchers and the wider public.

It is a growing community of interest, with a strong values base, where servant leadership is at its heart.

Uniquely the membership is quite diverse - each person brings their own individual perspective. They do not represent any particular grouping. Members gift their time to learn more and support research where best they can.

I have valued the Division’s long-term financial commitment to enable our group to meet quarterly; delve into a wide range of research proposals and avail of training.

The dedicated capacity building programme has generated a depth of research insight, which has enabled over time, for 40 members to join funding panels, and 50 to have responded to research support requests.

PIER members are also involved in a range of research advisory groups. Our increasing knowledge and research passion is also shared in wider inclusion opportunities across the PPI ecosystem and beyond.

The fact that I have personally continued, to be a PIER member for so long, says it all. A reflective and safe space has been created, where our voice has had influence and impact.

I have seen that active inclusion as research partners, really delivers:

Control shifts to collaboration

Rigour is brought to the work

Knowledge and expertise is valued equally

Decision-making improves

Measurements move to those of what really matters

There are so many benefits to reap from engaged research.

And to close…

In an unpredictable and post-truth world, facing global trade wars, I want to finish with a quote, from an American President.

One who understood what being different felt like. One who had polio paralysis. One who served his country for 12 years - from the Great Depression through to World War II.

These are the very words of wisdom, from Franklin D. Roosevelt, that we need today.

“[These unhappy times, call for, the building of plans, that…build from the bottom up and not from the top down, that put their faith, once more in the forgotten man at the bottom of the economic pyramid.](https://libquotes.com/franklin-d-roosevelt/quote/lbj6o2f)”

“We must and shall choose the path of social justice…, the path of faith, the path of hope, and the path of love toward our fellow man.”

Together, we can all, as an inclusive research community, develop evidence-based recommendations and projections, to inform future Programme for Government considerations, on how best to lift up, those who have for so long, been ignored and unfairly left behind.

Thank you.