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Personal Assistance Is a Form of Resistance

Hello. It is a pleasure to be with you all. As mentioned, my name is Miro Griffiths. I am a teaching fellow in Disability Studies at the University of Leeds, and my research, advisory work, and involvement in projects in the UK and across Europe focus on disabled people's marginalisation. I am a strong supporter of the European Network on Independent Living, as it is essential that organisations controlled and organised by disabled people have the central role in highlighting and addressing the key issues associated with disabled people's emancipation within society. Too often the voices of disabled people's organisations are side-lined due to the dominant, powerful and often toxic narratives purported by traditional charities and professionalised non-disabled lobbyists. Today, we are here to discuss personal assistance and we have had excellent presentations detailing the significance of disabled people accessing the right level of support to have prominent and respected positions within society, as well as the recent developments within the European Union and Commission that will impact on the promotion, availability, and resources allocated to advancing personal assistance support to all disabled people.

My role here is to reflect on the future of personal assistance in Europe, with a particular reference to the catastrophic impact looming because of the ridiculous decision by the UK to leave the European Union. Much of what I say will be critical, stated with concern and worry, and will not cause surprise amongst this room. We are fully aware of the crisis surrounding disabled people's emancipation. Our rights are being eroded and our voices are being silenced. There are: extensive cuts to public services, a refusal to develop effective social policy to address disabled people's support requirements, stricter eligibility criteria is used to reduce access to support, and all of this is happening at the same time that the media, the states throughout Europe, and other agenda setting platforms, question our value to society. This has led us to be in a position where disabled activists, their organisations, and researchers and policymakers committed to improving disabled people's social position, are constantly attempting to justify why personal assistance schemes are important, why we need protection through legislative frameworks, and why we need opportunities to influence political bodies, social policy processes, and bureaucratic structures.

This leads me to my first point in my reflection which is that in order for there to be an extensive, accessible, resourced personal assistance schemes throughout Europe, our campaigns, commentary, and vision has to extend beyond our usual networks and typical voices. There must be a ground swell of support and recognition of the significance of personal assistance that goes beyond our existing disabled people's movements across Europe. We desperately need more politicised disabled people, non-disabled allies, unions, occupational groupings, and transnational communities to embrace what personal assistance is attempting to address. This is where our campaigns and messages must be precise and clear: society is

organised in a deeply unjust and inaccessible way, for the majority of people, but through disabled people's demands and campaigns there is an opportunity to consider how society should be organised to take into account individual and collective variations in the way we want to be and the things we want to do. If society is to be fair, safe, accessible, and inclusive for all, it requires an exploration and embracement of being and existing in various ways. This means challenging the normative expectations, practices and ideas associated with performing daily activities, deciding on what you want to do in the short-term and long-term, and what you want to prioritise in your life.

Social policy pertaining to disabled people's lives is inherently ableist, and there is a desperate need to demonstrate how specific contemporary policies that affect disabled people's lives reinforce normative ideals. Through our campaigning, demands and ideas, disabled people's activism has illustrated the destructive impact of institutionalisation, oppressive "caring" regimes, and the continuation of assessing impairment and health-related aspects in order to make judgements on what disabled people should receive in terms of support. But we have to go beyond our typical activist strategies and illustrate to disabled and non-disabled people alike that sustaining programmes of institutionalisation, painful and ineffective therapies, rehabilitation and cure initiatives at the expense of personal assistance schemes can no longer be tolerated. We need figures from across society to document, highlight, and challenge the continued violence experienced by disabled people through the continuation of these oppressive programmes. Exclusion and oppression does not happen by accident, there are deliberate decisions taken by powerful figures and groups, who prioritise certain outcomes and resources, which in turn means disabled people are prevented or restricted in their access to personal assistance. It is essential that our campaigns, strategies, and research aims, explore why and how mass populations across Europe tolerate this explicit injustice encountered by disabled people.

I am not convinced by prioritising the need to show the economic gains through the provision of personal assistance, such as those who promote the "purple pound" argument. Instead, personal assistance - through the different forms of assistance that can and should be available, through the different methods utilised to develop and offer personal assistance schemes, as well as the different reasons for having assistance - provides a mechanism for disrupting the idea that there is a normal way to behave, perform, act, and do things in everyday life. It is the moral, social, and ethical need to radically overhaul the way we understand support, care, and interdependency, that should be the driving principles of advancing personal assistance.

This leads me to my second point, which builds on the arguments made by various Disability Studies scholars who focus on the dilemma surrounding crisis driven agendas and long-term visions. Through no fault of our own, our discussions on personal assistance have tended to - across Europe - become trapped in debating and reacting immediately to the challenges associated with retaining or achieving incremental progress to offer personal assistance. Whilst necessary, this does take considerable attention away from the long-term vision we want to present that will realise full, accessible, inclusive support options for disabled people. Again, this is not a direct criticism of the way we have organised ourselves or how we have responded to the deliberate strategies and policy decisions to remove support or dismiss our needs. Rather, it is a call for space, resources, and interested groups to consider the short-term responses required to protect and advance personal assistance schemes, whilst also ensuring a commentary continues that reflects on what it is we are trying to achieve at the conceptual level. Personal assistance does not remain at the operational level, to merely address identified needs of the individual. It is part of a concept, vision for realising disabled people's emancipation. Thus, it must be open to debate and consideration and form part of our long-term strategy to build an inclusive society for all.

At the same time as debating how to create progressive forms of taxation or how to redistribute existing funds to ensure sustainable and effective personal assistance schemes, I want us to consider what is meant by interdependency, explore ideas of social justice, and reflect on what do we mean by disabled people's

inclusion. Failing to do this will result in substantial risks of understanding inclusion, embracing social justice, and supporting the notion of fairness and equality within the existing economic, political, social, and cultural structures.

The future of personal assistance must remain a priority but it should form part of our political discussions that seek to question what is wrong with the way society is currently organised. This means the future of personal assistance can take one of two directions: firstly, it can be framed, understood, and developed within the existing parameters of how society is organised. As a result, our work and ideas must align with the contemporary economic and political objectives of the state, the market and what families/individuals want and desire. Or, as a second option, the future of personal assistance becomes a form of resistance and an opportunity to challenge the way we have currently organised the social world. This would mean creating a radical agenda for designing, developing, and delivering personal assistance which directly challenges how society currently functions. Such an agenda would then form part of the alternative visions for a preferred and possible future for how society is structured.

I am concerned that the second option may be perceived as too abstract, too distant from the conversations that take place in the corridors of state bureaucracy and service delivery. Nevertheless, the long-term vision of what is to be achieved through personal assistance must, in my opinion, be understood as a form of resistance to the contemporary factors that perpetuate disabled people's marginalisation. We must consider how, in our vision of personal assistance, we are able to directly resist and challenge notions of, for example, "who deserves support and who doesn't deserve support", "how individuals should contribute financially to their own support", or "why support should be conditional on the basis of achieving predetermined outcomes set and measured by professionals".

Of course, we need to engage with specific examples as to how personal assistance schemes can be formed, funded, organised, and delivered. These need to form part of our discussions, campaigns, and demands. Yet against the backdrop of dismissing human rights violations towards disabled people, reducing the role of the state in funding services, and disabled people's organisations not being central to the provision and monitoring of personal assistance schemes, there are deep concerns that we are prioritising the incremental steps whilst ignoring the deliberate push backs that weaken and undermine our demand for personal assistance for all. Individuals and families are too worried to demand self-directed support, for fear of losing existing, minimal support. People are pressured to appear grateful for accessing basic support. Campaigners and survivors of institutions are told to accept 10, 20, 30 year strategies in order to realise a change in how support is provided. Disabled people and their families experience clusters of discrimination and oppression, which makes it difficult and often impossible to seek justice and identify the appropriate steps to challenge professional decisions.

The point I am trying to make is that absolutely, we should organise, strategise, and contribute to the evolving contemporary policies that affect the provision and availability of personal assistance, but that should not come at the expense of having an accessible, resourced space where we can debate and consider what is it we want to achieve through personal assistance. As a movement, we have competing ideas and perspectives as to what disabled people's inclusion means, we have different definitions of social justice and emancipation. There must be desire and opportunity to debate such terms and consider how personal assistance forms part of those ideas and visions. The political and social left-wing are in crisis because there are sporadic, often challenging ideas and visions for how society is structured. There is no coherent vision to offer those that are marginalised, those that are exploited, and those who want something different. I believe this is reflected in the way we organise ourselves within disabled people's social movements. We need clarity and a coherent vision as to what independent living means, what personal assistance provides, and what we expect from the various actors across the social world: the state, the market, the family.

I cannot talk about the future of personal assistance without mentioning the United Kingdom's impending exit from the European Union. Disabled People's position in a post-Brexit UK is precarious to say the least. Accounts by prominent disabled activists and user led organisations, reinforced by academic and grey literature, states that disabled people's quality of life, social position and rights will be undermined. This will lead to disabled people experiencing further marginalisation and will certainly undermine our demands and strategies for personal assistance.

As a starting point, we must recognise that the UK government did not react with horror following the concluding observations from the United Nations Committee the Rights of Persons with Disabilities, which indicated that austerity measures "have created a human catastrophe for disabled people". This was dismissed by the current government as they revelled in a sense of British exceptionalism, suggesting that UK social policy pertaining to disabled people's inclusion in society should be celebrated and used as good practice by others across the globe.

This is significant insofar that The United Nations Convention on the Rights of Persons with Disabilities, which the UK has signed and ratified, is all but dismissed by the UK government. There appears to be little learnt by policymakers interrogated by the committee and I cannot see how principles and commentary found in the general comment in article 19 have been or will be satisfactorily embedded within UK social policy. Furthermore, the Equality Act legislation within UK achieves very little as its foundation is built upon the subjective stance of "reasonable adjustments", whereby those with considerable power determine if the marginalisation experienced by disabled people can be justified on the grounds of too much cost, too many resources or too much disruption to everyone else. This means our opportunities to reflect, develop and propose radical or reformist approaches to the provision of personal assistance depends on whether it aligns with current political and economic objectives of the state. Even the legislation that mirrors the EU treaties is likely to be shredded by the current government, once we leave the EU, as the government will attempt to concentrate more power by arguing that sovereign rule will improve people's life chances.

Notable commentary was provided by Baroness Jane Campbell and Lord Low; their comments, which suggest deep concern for disabled people's social position in a post-Brexit United Kingdom, echo the views from established campaigners and Disabled People's Organisations throughout the Disabled People's Movement. Whilst European Union treaties do not, satisfactorily, deal with disabled people's everyday marginalisation and the aspirations within European legislation, there is much to gain from using the Union as an entity that can protect disabled people from further isolation, exploitation and discrimination.

A fixation on State sovereignty would lead to further dismantlement of support systems, the removal of human rights safeguards and a reinforcement of nationalist - and ultranationalist - principles. Aside from one hustings event and a few articles by the prominent journalist, John Pring, the referendum campaigns failed to analyse or highlight the effect a British exit would have upon disabled people's quality of life. Effectively, there is a disregard for the needs of a marginalised group, which will result in opportunities to entrench ableist ideals within our state structures.

Clearly, the key issues affecting disabled people are not a priority within the negotiations and discussions taking place over the exit from the European Union; as a result, the impact that the exit will have on personal assistance in the UK remains unmonitored, dismissed and irrelevant to those in considerable positions of power and influence. Take for example disabled people who employ non-UK nationals to be their PAs. It is expected that because of the restrictions placed on mobility across geographical borders, many current and potential workers will be subjected to policies and procedures designed to limit migration into the UK. This will have an impact on the geographical locations where PA users employ considerable numbers of non-UK nationals. Furthermore, potential workers will be restricted from moving to the UK to find personal assistance work because of the regulations that require individuals to have certain levels of cash savings. This will significantly undermine the demands aspirations for personal

assistance, as the counter argument will be that the market is non-existent and therefore alternative forms of support will be explored, most notably traditional forms of care and institutional settings.

I hope that my reflections have provoked some thoughts and ideas. In summary, there is a need to illustrate how personal assistance is necessary and useful to developing an inclusive, accessible and fair society for all - disabled and non-disabled people. It should be perceived as an example of disrupting normative values and expectations that conform people to behave, act, and think in ways that perpetuate social injustice and marginalisation. We must consider how the concept of personal assistance can inject alternative ways of organising society. To achieve this, as activists and social movements, we need to create accessible and resourced spaces to debate and explore what we mean by key terms such as: social justice, personal assistance, independent living, interdependency, inclusion. Doing this will ensure that we have a clear and coherent vision for what we expect and demand from the state, the market, the family, the unions, and the occupational groupings in order to realise personal assistance for disabled people. If change is not realised then the continuation of violent and oppressive regimes that segregate, institutionalise, and eradicate us will be accelerated. The time for apathetic responses to disabled people's emancipation is over. Change is possible and necessary; it requires all of us to consider what and how we resist current practices that restrict and deny us access to personal assistance, at the same time as developing a clear and coherent vision for realising disabled people's emancipation.

Thank you for your time.