

# **A Personal View on the Importance of User Control and Freedom for Personal Assistant Users**

**Date: 06<sup>th</sup> July 2020**

**By Michelle Daley**

**(Written for Independent Living Alternative)**

## **What can we learn from lockdown**

I want to begin by looking at the lessons we can learn from the Coronavirus lockdown as I believe it will help to facilitate and support my discussion. The purpose of the discussion is to illustrate the importance of user control and freedom for Personal Assistant (PA) users. In summary a PA is an assistant that helps PA users such as myself achieve independent living.

The 23rd of March will be remembered as a significant date in UK history for when the Prime Minister Boris Johnson put the country into lockdown (with some exemptions to essential workers) and everyone had to “stay at home”. We were only allowed to leave our home for limited times and purposes. A copy of the full transcript of the announcement is available from Gov.UK website. I believe that everyone had an immense and profound effect in relation to the lockdown because our Human Rights such as rights to liberty, private and family lives, freedom to worship and right to education as examples were all denied.

During lockdown we all experienced segregation, isolation, frustration, and for some of us fear, disconnection and feelings of being powerless. This is the sad reality for too many Disabled people. They exist (not live) in the confines of residential institutions or within their homes in communities segregated from society and their liberties dictated by professionals, service providers and other such agencies. The point being made here is that we can all emphasise and share in the experiences of

our freedom being limited and restricted to specific purposes. I will elaborate on this point later.

### **User control and freedom is an essential part of our lives**

The idea of user control is not an unknown concept to people. During the lockdown developers were encouraged to review and evaluate how to improve user control and this was particularly evident in the upscaling of virtual solutions to creating new ways to help improve remote working through the use of technology. There are various examples where we witness the upscaling of online communication platforms such as '**Zoom**' and '**Teams**'. Developers have created products that give user control the flexibility and freedom to share pictures and videos while also being able to edit and delete messages. The world has changed and the way we live means that we have become dependent, demanding products that give us user control but also flexibility and freedom. We cannot deny that for many of us digital applications and products have become an essential part of our lives. For many of us these products and applications have transformed the way that we work, socialise, communicate and manage our finances, and it would be very difficult to live without them.

### **Challenges of achieving user control for PA users**

I want us to further our discussion on user control and look at the challenges of achieving freedom for us as PA users. I was reminded in my recent review that there are two systems in how Human Rights is applied, one is for Disabled people and the other is for non-Disabled people. It is deeply demoralising to know that a system that is set up to support Disabled people operates from a premise of denying individuals their true Human Rights to achieve independent living. Disabled peoples rights to independent living will never be equal to non-Disabled people until it is positioned within the framework of Human Rights Act and the UN **Convention of the 'Right of Person with Disabilities'** (UN CRPD) (on Article 19 – Independent Living). The power that is held by the different Government departments are used to make

decisions about what is best for our needs and this must stop. The funding that finances these different Departments must be used to fund Disabled People's Organisations (DPO) to bring to an end this unfair practice and process that does not support our Human Rights. The review process is positioned to depict individuals as a "patient" and powerless, with the professionals seen as "experts" on what is best for our needs. This process renders me to a position of sub human stripping me of my identities as a Black Disabled Woman. My identity as a Black Disabled Woman is considered irrelevant, this is because the assessor carrying out the review is only concerned with satisfying their own quality outcomes.

It is atrocious that the Departments that are set up to support Disabled people disproportionately disadvantages us through its actions. Therefore contradicting and making a mockery of the Human Rights Act and UNCRPD. We need radical change and enforcement of our rights to be supported to achieve real independent living.

### **Empowerment and authority of user control for PA users**

I am of the view that user control is a highly positive connotation that is rooted in protecting individuals freedom and choice to enjoy life. If we are to improve the current system then it is paramount that we have a system that understands the experiences of a PA User in order to achieve user control.

There is no doubt that we must have a system with principles that is enshrined within our Human Rights while also incorporating the UNCRPD into our domestic laws. We want the negative bias towards Disabled people to stop. Disability Rights activists have repeatedly argued for years against the current system and we continue the struggle for "de-professionalism of independent living" (Oliver,1993).

We at **Independent Living Alternatives** along with the **Independent Living Movement** (ILM) and other prominent campaigners such as **Nasa Begum** and **Baroness Jane Campbell**, have repeatedly argued that as PA Users the authority over our lives must remain with us and we must be the decision-makers of the support and services we receive. From the delivery of these services to the

implementation, we want to be the ones to determine our own success that is about us and for us.

There are nuances that the current system does not understand and therefore ignores fundamental aspects which are significant to achieving positive user control and freedom for the PA user. At this point I feel it is necessary to refer back to my earlier point about the lockdown and restrictions placed on our Human Rights. It is through the lockdown that I believe everyone has learnt the importance of having choice, flexibility and freedom. I hope that this experience of lockdown can be used to strengthen the case to create solidarity across the different campaign movements to our fight for user control and freedom for PA users.

In summary, the importance of user control is that it gives freedom to the PA user without deleting our **intersectional** identities, rendering us as sub human by weakening our Human Rights. The very essence of user control is to give us equality, freedom and liberty through the use of a PA, where there is mutual interest and a clear understanding of expectations, with support tailored to our needs so that we as PA users can enjoy and live a life like others.

Our fight continues!

## **Reference**

1. Oliver M (1993). The Politics of Disablement. Hampshire, UK: Macmillan