



INDEPENDENT LIVING  
MOVEMENT IRELAND  
FREEDOM • RIGHTS • EMPOWERMENT

[www.ilmie.ie](http://www.ilmie.ie)

**(Image shows ILMI logo with Text: Independent Living Movement Ireland.  
Freedom, rights, empowerment and website address [www.ilmie.ie](http://www.ilmie.ie))**

**Independent Living Movement Ireland submission on the Department of  
Health's Public Consultation on Draft Regulations for Providers of Home  
Support Services**

**July 2022**

**Summary**

ILMI recognises that the Draft Regulations are specifically applicable to older people's care and not assisting disabled people to live independent lives with choice and control. Although the draft regulations make reference to disabled people it does not apply to disabled people receiving such services.

ILMI strongly recommends that a separate document is developed from a human rights perspective, which gives due recognition to the unique nature of disability services and the role they can play in our lives as disabled people when we are involved in the process.

Although Personal Assistance Services (PAS) are separate from Home Support Services (HSS), the two are often conflated as being the same thing. Many disabled people access both supports, and many service providers provide both services. There is a very real fear that restrictive "risk averse" practices which could be adopted for HSS will eventually become the norm for PAS. Given that some agencies use the same staff for PAS or HSS, there is an additional fear that HIQA standards will be applied "across the board" for all supports for disabled people.

It is imperative that this new document is written in accordance with HIQA's own Guidance on a Human Rights-based Approach in Health and Social Care Services and most importantly that it is written in direct consultation with disabled people themselves and Disabled Persons Organisations (DPOs). After consultation with our members ILMI have

highlighted issues and recommendations that should be considered when developing a specific document for disabled people.

## **Introduction to Independent Living Movement Ireland**

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. ILMI works with disabled people on a cross-impairment basis. Central to the way we work is to ensure that policy and legislative discourse and decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected.

Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

## **Social model of disability**

The UNCRPD at its core is framed through an understanding of disability known as the social model of disability. From ILMI's perspective, it is vital that there is a clear and full understanding of what the social model of disability is and how it should inform future discussions on policy development and improvement and policy implementation.

The social model looks at how society is structured and how it disables people. It is not based on a person's impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of Independent Living Movement Ireland.

## **Language and representation of disabled people**

Independent Living Movement Ireland recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term 'disabled people' has been used throughout the submission in accordance with the UPIAS classification of disability and impairment

which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, people experiencing emotional distress and physical and sensory impairments.

## **Context**

ILMI has a strong position on independent living supports such as Personal Assistance Services (PAS). PAS gives disabled people choice and control over their lives. Currently there is no legal right to a PAS in Ireland. ILMI has been campaigning for legislation and investment into the PAS. See our PAS NOW campaign [here](#)

In February and March 2021, ILMI conducted 12 facilitated consultations with an open call to disabled people through our online newsletter (eBulletin) and social media channels. As part of this process ILMI had the opportunity to consult with hundreds of disabled people on many issues that impact upon our lives. One specific consultation space covered Article 19 of the UNCRPD, which includes PAS and independent living supports. You can read that document [here](#) Please note page 29 of this report addresses article 19 of the UNCRPD and Independent Living.

In addition, most recently ILMI consulted their members on the Draft Regulations for Providers of Home Support Services. From this consultation ILMI recommends that a separate document is developed from a human rights perspective. The following considerations should be taken into account when developing a specific document for disabled people. See details below.

**1. Issue:** The Draft Regulations are rooted in the medical model of disability and are highly medicalised in their approach. They provide no recognition of disabled people's rights under the United Nations Convention on the Rights of Persons with a Disability (UNCRPD).

### **Recommendation:**

- Implementation of these regulations would lead to over-medicalisation of our services. The current recommendations need to be re-written from a social model of disability and a human rights perspective and in accordance with HIQA's Guidance on a Human Rights-based Approach in Health and Social Care Services. It is vital that the disabled person, as the expert in their own needs and requirements, is involved in this process from the outset.

## **2. Issue: The Draft Regulations confuse the Home Support Service (HSS) and Personal Assistance Service (PAS).**

### **Recommendations:**

- The current HSS does not allow for Independent Living (IL). To ensure PAS is regulated and provided for it requires its own definition, which is agreed by all stakeholders with the disabled person central to the entire process.
- Both services are provided within the disabled person's home. Although there is recognition that this is also the Home Support Worker or Personal Assistant's workplace there needs to be sensitive consideration for the fact that it is an individual's personal space and in many cases private home. ILMI participants recognises workplace rights, but these roles only exist to give disabled people their rights to live independently and ILMI recommends that this needs to be prioritised

**3. Issue:** Given the current staff issues both HSS and PAS are experiencing, there are serious doubts about the ability to apply these regulations to either service.

### **Recommendations:**

- Existing services are being curtailed due to a lack of available qualified staff. Issues surrounding PAS and HSS pay rates and career progression pathways need to be addressed before any new recommendations can be introduced.
- Under these regulations there is an overwhelming sense that provision of either HSS or PAS is a tick the box exercise, with individuals required to fit neatly into particular categories. Where a disabled person requires support under a number of different impairment types it is difficult to evaluate outcomes. To ensure outcomes can be measured it is important that there is recognition of the high variance of disabled people's needs and their intersectionality and how this will be accounted for.

**4. Issue:** There is an over-emphasis on the need for specific qualifications (e.g. FETAC Level 5), which provide little tangible benefit in the delivery of services to the disabled person.

### **Recommendations:**

- FETAC Level 5 is entirely based on the medical model of disability. There is no real reference to Independent Living.

- The qualification criteria needs to be reassessed to provide real tangible benefits to all stakeholders. Any revised training element must include significant on-the-job training, given the high degree of variance from one service to another.

**5. Issue:** The division of services by age category causes significant anxiety to disabled people. It also increases the administration required to ensure continuity of services throughout a disabled person's life.

**Recommendation:**

- The segregation of services by age category needs to be removed. All required supports (education, employment, PAS etc.) should follow the individual throughout their life and not cease and transfer to another department once an age bracket is reached.

**6. Issue:** Service providers can implement additional regulations that further curtail Independent Living. The regulations can vary greatly between service providers, with specific restrictive policies relating to medicine management, personal grooming or consuming alcohol. Similarly, many service providers don't view "social hours" with the same level of priority as "personal care".

**Recommendation:**

- Central to any discussion is that these are supports that are supposed to liberate disabled people to participate in society by providing supports for them to do the things that they cannot do for themselves, inside and outside of the home. Additional regulation is likely to restrict services that were developed by disabled people to give them choice and control over their lives.
- Service providers should not create barriers to such aspects of life. Originally the PAS was set up to give disabled people choice and control over their lives. Unfortunately, with the emergence of many private PAS providers, there is an evident erosion of true PAS. It is recommended that service providers should enable disabled people to become self-directed leaders of their own service where possible, to be able to live their best lives.