



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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11th December 2019

Deputy James Browne
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: james.browne@oireachtas.ie

Dear Deputy Browne,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 49401/19

To ask the Minister for Health the position regarding State funding of the national platform for self advocates; and if he will make a statement on the matter.

HSE Response

The HSE acknowledges the role and contribution of non-statutory agencies including advocacy organisations in the development and provision of health and personal social services and is committed to the development of effective working relationships as enacted by the Health Act 2004. However, having regard to the availability of resources, it is important to avoid the potential for duplication and confusion concerning the area of advocacy.

During 2019 several advocacy organisations including Inclusion Ireland and Disability Federation of Ireland (DFI) received HSE funding to ensure that the voices of people with disabilities are heard when it comes to changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability in Irish Society. Many other non statutory agencies, funded by the HSE also have a role in upholding and protecting the rights and dignity of people with disabilities, although this may not be their primary role and functions.

The role of service users through advocacy in informing health and personal social services provision is well documented. Effective service user involvement enables services to anticipate problems, avoid complaints, develop appropriate and effective service provision and it guarantees that service users will be at the centre of efforts to improve the quality and safety of service provision for many years to come.

Service User Involvement in Disability Services

Across the large HSE residential services, each individual setting is progressing the development of a family forum with the support of Inclusion Ireland and putting in place processes to support meaningful engagement by the service users in the design and operation of the services that affect them. This is being managed in a range of ways appropriate to the resident population, such as self advocacy groups, engagement with independent advocates, parent and sibling groups and the roll out of supported self -directed living that enables each person to direct their own life. These developments are in keeping with the National Standards for Residential Services for Adults and Children, and the overall *Transforming Lives* programme across the disability sector that is focussed on delivering person-centred services.

The Connect Family Network

The HSE has engaged Inclusion Ireland to establish a national network of family support groups in the disability sector; the Connect Family Network. The Connect Family Network will endeavour to bring about greater participation of persons with a disability and their family members in the design and delivery of disability services and supports.

Research has shown that service and policy development is much more effective when the people who use services are involved from the outset.

The Connect Family Network will not replace any organisation, but will aim to enable a coherent and combined family voice to be heard by service providers and policy makers. Supports to family support groups will include information provision, facilitation of networking opportunities, capacity building training and support for families to have their voices heard in policy formation and implementation.

Inclusion Ireland has developed and disseminated information when meeting with the families of service users in residential services, to assist them in their understanding of current policy in the development of disability services. Information has been handed out on Congregated Settings, HIQA, Long Stay Health Charges and New Directions.

Inclusion Ireland has also facilitated focus groups for self advocates across Ireland. In these focus groups persons with a disability were facilitated to voice how they experience residential services.

The HSE has also commissioned SAGE to pilot a Disability Advocacy model of service in Community Healthcare Organisation Area 5 and that work is underway.

Throughout the large HSE residential services, there is a particular focus on meaningful service user and family engagement as part of the process to look at moving towards a person centred model of service, both through changes in day services under the *New Directions* policy and changes in residential services under the *Time To move On From Congregated Settings* policy. The development of communication and engagement processes are being guided by best practise and the approach of “one-family” and “one-person” at a time is considered most appropriate, supported by the larger forum and group arrangements.

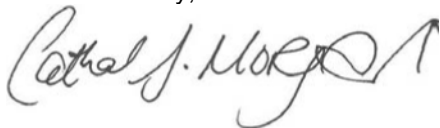
In this context, the HSE has requested Chief Officers to set up Local Consultative Fora with subgroups on Time to Move on from Congregated Settings, New Directions, Progressing Disability Services for Children and Young People and a fourth subgroup on Service User Involvement.

National Platform for Self Advocates

The National Platform for Self Advocates is an independent advocacy organization which was set up as a forum for people with Intellectual Disability. Inclusion Ireland facilitated the process of setting up this national platform, although it has its own unique identity and is outside the remit of agencies involved in direct service provision. One of the roles of the Platform was to disability proof national policy from an intellectual disability perspective.

The HSE supports the work of the National Platform for Self-Advocates, but is also very conscious of the need to deliver disability policy on a more sustainable footing given the significant levels of need for increased and more effective services and supports to enable people with a disability to live independent lives in their own community. Hence, it is important that organisations such as the National Platform for Self-Advocates look to other funding streams such as the Department of Rural and Community Development's Scheme for Community and Voluntary Organisations. The HSE understands that funding of €18.5m over the coming three years has been approved for this Scheme.

Yours sincerely,



**Dr. Cathal Morgan,
Head of Operations - Disability Services, Community Operations**