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COMMUNITY HEALTHCARE

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CAVAN DONEGAL LEITRIM MONAGHAN SLIGO

SELF ADVOCACY STRATEGY

DISABILITY SERVICES

COMMUNITY HEALTHCARE CAVAN DONEGAL LEITRIM
MONAGHAN SLIGO [CH CDLMS]

(2023-2026) 3 Year Strategy

Table of Contents

List of abbreviations	2
Introduction.....	3
What is Self Advocacy.....	4
Importance of Self Advocacy	4
Need for Self Advocacy Strategy.....	5
Barriers to Self Advocacy	7
Stakeholder Engagement: Listening to what we heard.....	8
Our Values.....	10
Autonomy	11
Respect	11
Creative Responses	12
Mutual Support	13
Vision.....	14
Mission	14
Dimensions of the Strategy and the Strategic Priorities.....	15
1. Communication, Decision Making and Governance	15
2. Capacity building for disabled people.....	16
3. Inclusive Governance and Capacity building for staff and managers	16
Enablers.....	17
Implementation Plan	19
References.....	20
Appendix 1:	22

List of abbreviations

Abbreviation	Definition
CH CDLMS	Cavan Donegal Leitrim Monaghan Sligo
SWG	Strategic Working Group
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
PCP	Person Centred Planning
DPO	Disabled Persons Organisation

Inclusive Language

This Strategy acknowledges that there is no universally agreed consensus on which terminology to use in relation to disability (National Disability Authority, 2021). Some use “People-first language” to communicate appropriately and respectfully with and about an individual with a disability (Centre for Disease Control and Prevention, 2018). People-first language emphasises the person first, not the disability. For example, when referring to a person with a disability, refer to the person first, by using phrases such as, “a person with a disability”. The second approach is referred to as identity-first or social model language (National Disability Authority, 2021). Disabled Persons Organization use the word disabled person as opposed to people with disabilities when referring to disability to acknowledge that people are disabled by society (Disabled People Organisation, 2023). The Strategy respects the use of both connotations and uses “people with disabilities” and “disabled people” interchangeably throughout the document.

Introduction

Self Advocacy is the process of speaking up for oneself as a disabled person, making decisions about one's own life, and advocating for one's own rights, needs and interests. It depends on being aware of one's rights, needs, and goals, and communicating them effectively to others. It also involves working with other disabled people to identify and address systemic barriers to the realisation of these rights, in the policies and practices of agencies that affect the lives of disabled people. Participation in planning and decision-making with relevant agencies is a key means of addressing these barriers and enabling effective social inclusion.

This strategy details a comprehensive model of Self Advocacy and describes a framework for building and fostering a positive culture that enables the participation in planning and decision-making of disabled adults using the service in the Disability Services Community Healthcare Cavan, Donegal, Leitrim, Monaghan, Sligo [CH CDLMS]. The Self Advocacy Strategy considers the barriers that individuals face when advocating for themselves and sets out the future direction for enabling the participation of adults with disabilities using the service through effective Self Advocacy.

This document outlines the priorities, intended outcomes and high-level actions. The strategy is supported by an Implementation Plan that sets out the details, people responsible, and timeframes needed to implement the Self Advocacy Strategy in CH CDLMS Disability Service.

What is Self Advocacy

“Self Advocacy” and “Self Advocate” are terms that are commonly used within the community of people with an intellectual disability and people with a physical & sensory disability. In 2015 and 2016, Inclusion International (2016) undertook a worldwide survey of people with an intellectual disability and wrote a Global Report on Self Advocacy for Inclusion. In this document, it is outlined what “Self Advocacy” means:

“Self Advocacy is about having a voice (even when we cannot speak); being listened to and taking control of our own lives. Self Advocacy is about growing our confidence and belief in our abilities. Self Advocacy is about knowing our rights and that we must be included in all parts of the community, just like people without disabilities. Self Advocacy is about working together to make a change in our communities (p.4).”

(Joint Committee on Disability Matters, 2023)

Progressive stages of Self Advocacy are mapped out from “personal empowerment and building confidence”, through “peer support and self-help”, towards the more collective approach of “advocacy for action” (p. 15-16)” (Inclusion International, 2016).

Importance of Self Advocacy

Self Advocacy is important because it empowers individuals to take control of their lives, influence decisions that affect them, and communicate their needs to others. It helps individuals to build self-confidence, self-esteem, and resilience. Moreover, Self Advocacy makes individuals more aware of their rights and opportunities, and it helps them to navigate complex systems such as education, healthcare, and employment (National Disability Authority, 2022).

Too often, disabled people and their organisations face barriers to their full and effective participation. These include inaccessible physical and online environments, inaccessible information and communication, and negative attitudes and stereotypes.

Anne Rabbitte T.D.

Minister of State at the Department of Children, Equality, Disability, Integration and Youth

Self Advocacy is particularly important for individuals with disabilities who may face barriers to achieving their goals such as inaccessible environments or discriminatory attitudes. People with disabilities may need to advocate for their rights in various contexts such as relationships, education, employment, healthcare, and community participation.

Need for Self Advocacy Strategy

HSE Corporate Plan (2015-2017) outlines, “For the users of our disability services, we will provide integrated services that meet the highest standards, where people are treated with respect and dignity and can live as independently as possible”. The Corporate Plan 2021 – 2024 acknowledges that there is not enough home-based support and a lack of person-centred and responsive support for people with disabilities and their families. Objective 5 of the HSE Corporate Plan (2021-2024) outlines that HSE will work to reimagine disability services, to be the most responsive, person-centred model achievable with greater flexibility and choice for the service user. The HSE Corporate Plan 2021 – 2024 requires the HSE to develop the structures to enable service users to become active participants in their care and support, not only through the

use of personalised budgets but also in the co-design of their services and reform of the Disability sector in line with the United Nations [UN] Convention, and in collaboration with government departments and agencies and disability services stakeholders.

The Chief Officer of HSE CH CDLMS established an independently chaired Strategic Working Group [SWG] in May 2021 in line with Objective 5 of the HSE Corporate Plan 2021-2024 to implement the recommendations arising from service reviews. The SWG developed a new vision for disability services. This is reflected in the Service Re-Design Plan of Disability Services in the CH CDLMS area. This vision is in line with national policy, based on a social and human rights model of service provision for people with disability as Ireland has ratified the United Nations Convention on the Rights of Persons with Disabilities. All people, including all people with disabilities, have the right to live with dignity and enjoy freedom. Article 19 recognizes the equal rights of all persons with disabilities to live independently and be included in the community. Article 26 states that the state bodies shall take effective and appropriate measures to help persons with disabilities attain maximum independence. The United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] outlines human rights including:

- Be treated as equals (Article 5)
- Equal treatment for women with disabilities (Article 6)
- Equal treatment for children with disabilities (Article 7)
- Change attitudes about people with disabilities (Article 8)
- Access (Article 9)
- Life (Article 10)
- Assistance in emergencies (Article 11)
- Be treated equally by the law (Article 12)
- Access to justice (Article 13)
- Be free and safe (Article 14)
- Not be tortured or treated cruelly (Article 15)
- Not be used or abused (Article 16)
- Be free from medical exploitation (Article 17)
- Move around freely (Article 18)
- Independent living and being part of the community (Article 19)

- Get around (Article 20)
- Be free to say what you want and to get information (Article 21)
- Respect for your privacy (Article 22)
- Marry and have children (Article 23)
- Education (Article 24)
- Health (Article 25)
- Services to help you be independent (Article 26)
- Work (Article 27)
- A decent standard of living (Article 28)
- Be involved in politics (Article 29)
- Be involved in sports and leisure (Article 30)



Barriers to Self Advocacy

Despite the importance of Self Advocacy, many individuals face barriers to effective Self Advocacy. Some of the most common barriers to Self Advocacy experienced by people with disabilities were highlighted at the Self Advocacy Learning Event organised by CH CDLMS Disability Services in December 2022. Barriers are also outlined in the guidance document Participation Matters published by the National Disability Authority (2022), in the Global Report on Self Advocacy published by Inclusion International (2016), and in the Inclusion Ireland Report - From Consultation to Co-Creation: A Guide to Effective Participation of Disabled People in HSE and HSE Funded Services in 2023. Some examples from the latter are included below:

1. Many individuals may not be aware of their rights, resources, and opportunities. They may not know how to communicate effectively, negotiate with others, or access information.

2. Individuals with disabilities sometimes face discriminatory attitudes and behaviours, which can undermine their confidence and ability to advocate for themselves.
3. In many situations, individuals may face power imbalances, such as with authority figures or systems of oppression. These power imbalances can make individuals feel powerless and discouraged from advocating for themselves.
4. Many individuals may fear the consequences of speaking up or challenging the status quo. They may worry about retaliation, rejection, or loss of support.

(Inclusion Ireland- A Guide to Effective Participation, 2023)

Stakeholder Engagement: *Listening to what we heard*



Findings from the Self Advocacy Learning Event

organised by CH CDLMS in December 2022, identified the challenges faced by people with disabilities in speaking up for their rights and things that are important to them. The findings identified the need to create time, space and opportunity for people with disabilities to speak up and raise awareness of the challenges.

The Self Advocacy Learning Event identified that for people with disability, an Advocacy Group was important so that they could discuss things that are important to them in a safe place supported by people close to them.

It was also identified that Self Advocacy will build a better trusting relationship between the person using the service and the keyworker, making the keyworker's role more rewarding.

Developing a framework and clear guidelines for Self Advocacy which can be used by staff and keyworkers was recommended by service managers to embed Self Advocacy in CH CDLMS.

The findings from **Disability Action Plan 2022 – 2025**, Report on the Public Consultation identified that individuals with a disability wanted choice and control, wanted services to focus on rights and change the service culture.

The **HSE Better Together: The Health Services Patient Engagement Roadmap** provides the essential

guidance and tools for healthcare staff to create a strong culture of meaningful patient engagement, where patient engagement is encouraged, expected and respected. The Roadmap also outlines many

benefits of meaningful patient engagement, including enhanced person-centred care where patients are actively encouraged and given the tools and autonomy to self-manage and lead their own care and better health outcomes (HSE, 2022). [Whilst “*patient*” is the term used in the Better Together Health Services Patient Engagement Roadmap, it is acknowledged that “*patient*” is not the appropriate term used for people accessing HSE Disability Services.]



The **Transforming Lives Programme** (Working Group-3, 2018) (Effective Participation in Decision-Making, (2018) was established to implement the recommendations of the ‘Policy Review of Disability Services in Ireland’. The report on Future Needs for Disability Services outlines that in the disability sector in Ireland, the emphasis is shifting from meeting care needs alone, to supporting people with disabilities to achieve the goals set out in their person-centred plans (Working Group 1 Report on Future Needs for Disability Services DoH, 2016).

The **National Disability Authority's (NDA) Participation Matters Guidelines** details consultations with people with disabilities which were undertaken on behalf of the NDA as part of the Outcomes Project. In these consultations, the participants suggested that supports are required to achieve the outcomes. Some of the suggestions are included below:

- having the right staff to give good supports
- being involved in choosing the staff that support them
- having staff with the right skills and attitudes
- having staff that know the people well and understand them
- having assistance with communication where that is needed and
- having advocacy support

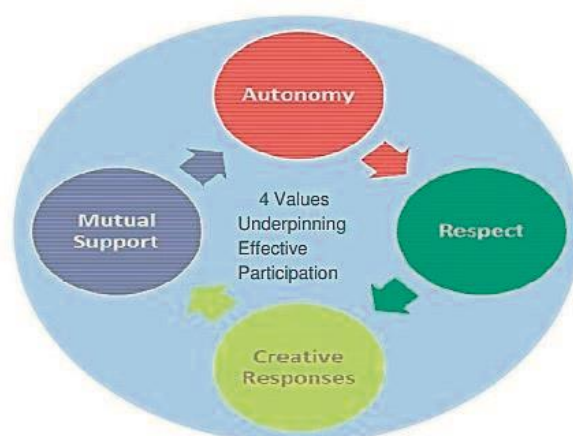
(National Disability Authority, 2022)

The Transforming Lives programme, consultations with people with disabilities undertaken on behalf of the NDA, and the findings from Disability Action Plan 2022 – 2025 and the ratification of UNCRPD, reinforce the need for Self Advocacy Strategy and an implementation plan for CH CDLMS Disability Services.

Our Values

As outlined by Working Group 3 of Transforming Lives Report (2018), the four core values that will motivate, guide and direct the effective participation of people with disabilities, in decision-making are autonomy, respect, creative responses and mutual support.

“These four core values are indivisible, i.e. they cannot be seen in isolation from each other. They are at the heart of effective participation in decision-making” (Working Group 3, 2018).



These values will be the guiding principles in formulating this strategy which will play a pivotal role in the lives of individuals with disabilities by providing a range of services and support, ensuring that they have a fair opportunity to live their lives fully and independently.

Autonomy

“The value of autonomy recognises the right, the freedom and the authority a person has to make their own choices. This will include the provision of supports, if required for this to be realised” (Working Group 3, 2018).

I Want to Manage my Own Budget

My doctor has advised that I go swimming regularly. I have explained that I can't go without a Personal Assistant. However, at the moment the HSE will only fund primary care hours (9.00-5.00pm) so there is no financial support for what are called 'social hours'. I cannot employ a Personal Assistant. This has to change, I want to manage my own budget and choose my own service provider/support.

Member (Working Group 3, 2018)

Respect

“Respect is an empowering value in relationships. Respect means that mutual trust exists between people, which recognises, values and reflects people’s lived experiences and fosters their growing confidence and expertise. Respectful dialogue listens to what people with a disability have to say and trusts people to know what they themselves need on a personal level” (Working Group 3, 2018). This will include:

- Respectful decision-making processes at all levels.
- Ensure a person’s entitlement to privacy and confidentiality.
- Ensure there is no discrimination or harassment.

- Recognise and value the diverse/multiple identities of people with a disability to ensure their full and effective participation in decisionmaking.

(Working Group 3, 2018)

Creative Responses

“Creative responses are a way of thinking outside the box and not presuming that one size fits all. The value of creative responses is visible when decisions recognise the uniqueness of each individual, acknowledge their individual needs, and respond creatively to those needs. It is about working in a different way and finding a way forward when the way might not be clear. Responding creatively to facilitate the range and style of communication needs will ensure that each person's input is received clearly and fully” (Working Group 3, 2018).

Processing Information

*It is not enough just to present autistic people with information...
Time must be given to supporting people to process it. It is also
really important to contextualise the
information so that people understand its relevance to them.*

*Visualisation is as important as vocalisation when
communicating with autistic people. It is not that people do not
want to participate - they might just not get the context or that
it is relevant to them.*

Member (Working Group 3, 2018)

“It means moving away from the more static approach of committees and consultation to using more responsive and innovative ways of engaging. This could involve thematic days, road shows, online forums and arts and cultural opportunities” (Working Group 3, 2018).

The Value of Creative Responses

Everyone has their own needs and they are different for every person. So the response has to be different for every person.

Consultation Feedback (Working Group 3, 2018)

“If creative responses are valued at this level, they can give rise to more appropriate and meaningful policy development, implementation, monitoring and evaluation” (Working Group 3, 2018).

Mutual Support

“In relation to persons with a disability the value of mutual support recognises that people are not just individuals requiring individual respect. People are also relational and interdependent with valuable contributions to make to their own lives and those of their communities” (Working Group 3, 2018) (Effective Participation in Decision-Making, 2018)

The Value of Mutual Support

The HSE and others – we should all be working together to make sure that we have the power to make decisions. Sometimes we need supports to fully make a decision and sometimes we make the wrong decisions in life but either way it was me that made the decision.

Consultation Feedback (Working Group 3, 2018)

Vision

Our vision is that disabled people in CH CDLMS will:

- Exercise decisive influence in the planning, evaluation and delivery of the HSE funded services that support them
- Begin to experience supports and services that are significantly more accessible, responsive, effective, efficient and equitable.

Mission

Our mission is to create the conditions so that:

Disabled people and disabled people's organisations are supported to participate effectively in the planning and evaluation of HSE-funded disability services and supports at all levels from person-centred plans, through frontline operations, to senior management.

Management and staff within the HSE and HSE-funded service providers are supported and empowered to co-create with disabled people a mutually beneficial rights-based culture of support and respect within and across the service delivery systems.

Dimensions of the Strategy and the Strategic Priorities

1. Communication, Decision Making and Governance

CH CDLMS will establish accessible communication systems and inclusive governance and management structures for the planning, development and quality improvement of disability services.

Strategic priorities

CH CDLMS will work in close consultation and collaboration with disabled people, Disabled Persons Organisations (DPOs) and other representative groups to:

- A. Ensure that information on services for adults with disabilities in CH CDLMS will be available to and accessible to all. This will also include information on disability services that are available to adults with disability who live in each area of CH CDLMS, and the access pathways and decision making processes for access to these services.
- B. Develop more effective and accessible processes for gathering information about the quality of service delivery as experienced by disabled people and for involving disabled people in the analysis of this information and the identification of systemic issues that need to be addressed.
- C. Support the development of an accessible infrastructure for representative advocacy that will enable effective participation by disabled people in planning and decision-making at local and regional levels
- D. Inform all relevant stakeholders including all funded agencies and invite them to engage with CH CDLMS Self Advocacy Strategy Group to support the development of an infrastructure for representative advocacy.

2. Capacity building for disabled people

CH CDLMS will collaborate with relevant agencies to develop and implement structures, training, supports and resources that build the capacity of disabled people to make and assert choices at a personal level and to participate collectively in planning, evaluation and decision-making processes at a system level within HSE and HSE-funded services, and the wider community.

Strategic priorities

- A. Build on existing and emerging models of good practice to develop and extend effective Person Centred Plan (PCP) processes throughout CH CDLMS.
- B. Resource appropriate supports and rights-based training that builds the capacity of disabled people to make and assert choices at a personal level.
- C. Resource the availability of appropriate supports and deliver training that enables disabled people to participate in planning, evaluation and decision-making within HSE provided and HSE-funded services in CH CDLMS, and in the wider community.

3. Inclusive Governance and Capacity building for staff and managers

CH CDLMS will support managers and staff to develop a culture and a model of service delivery that is person-centred, participative and rights-based.

Strategic priorities

- A. Provide appropriate supports and deliver disability equality training that builds the capacity of staff and managers to facilitate the effective participation of disabled people within the governance of the services that they deliver.
- B. Develop action learning forums that enable staff and managers to reflect on and share their learning and experience about developing a person-

centred, participative and rights-based culture within the services that they provide.

- C. Review job descriptions, recruitment processes and in-service training processes for staff to ensure that they uphold the values and opportunities for participation by disabled people in this strategy.

Enablers

The priorities identified in this Strategy document are supported by overarching enablers to support and sustain change. The enablers outlined here will provide the necessary supports for implementing the Self Advocacy Strategy in CH CDLMS.



Inclusion and Co-Design: Everyone in CH CDLMS will advocate the inclusion of adults with disabilities in decision-making. There needs to be a willingness and acceptance from staff and management in CH CDLMS that the adults using the service have a right to be involved and this should be incorporated into the everyday working of all professionals. Adults should be facilitated to decide on their priorities and their decisions through their involvement.

Support the development of Self Advocacy Groups: Self Advocates should be facilitated to have their own groups with structured meetings. CH CDLMS should provide help and support to develop this across the region.

Implementation Plan: will serve as a key enabler for the implementation of the Self Advocacy Strategy in CH CDLM. The Implementation Plan will outline the stages of implementation, setting key milestones to be met within agreed timeframes and identifying leads responsible and accountable for reporting on the outcomes.

Engagement and Communication: Implementing the Self Advocacy Strategy will require extensive engagement and communication at various levels which will be outlined in the Implementation Plan. Clear communications about the strategic priorities and the specific role of each stakeholder group, and lead, will be an essential enabler of success in the implementation of the strategy.

Inputs: It is acknowledged that financial, human and physical resources will be required to achieve the outcome and successful implementation of the Self Advocacy Strategy. The Self Advocacy Strategy Group will review existing resources and identify supplementary resources required for the successful implementation of the Strategy.

Implementation Plan

The Self Advocacy Strategy [June 2023 – June 2026] recognises the significant ongoing work across CH CDLMS to drive a culture of promoting Self Advocacy and it outlines three strategic dimensions with strategic priorities. A detailed phased implementation plan identifying several strategic actions associated with these priorities will be developed. Each action at the implementation stage will be assigned to responsible leads and will be further developed into critical and smart actions with start and completion dates.

References

Centre for Disease Control and Prevention, 2018. *Communicating With and About People With Disabilities*, s.l.: s.n.

Disabled People Organisation, 2023. *Consultation and Feedback*, s.l.: s.n.

Effective Participation in Decision-Making, 2018. *Effective Participation in Decision-Making for People with Disabilities and Families Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff*, Dublin: HSE.

HSE, 2022. *Better Together: The Health Services Patient Engagement Roadmap*, s.l.: HSE.

HSE Corporate Plan, 2015-2017. *HSE Corporate Plan*, s.l.: HSE.

HSE Corporate Plan, 2021-2024. s.l.: HSE.

HSE Values in Action, 2019. *Values in Action - Our People, Our Culture*, s.l.: HSE.

HSE, 2018. *Ordinary Lives in Ordinary Places*, s.l.: HSE.

Inclusion International, 2016. *Self-Advocacy for Inclusion*, London: University of East London.

Inclusion Ireland- A Guide to Effective Participation, 2023. *From Consultation to Co-Creation: A Guide to Effective Participation of Disabled People in HSE and HSE Funded Services*, Dublin: Inclusion Ireland.

Inclusion Ireland, 2023. *Inclusion Ireland - Self-Advocacy*, s.l.: Inclusion Ireland.

Joint Committee on Disability Matters, 2023. *Inclusion Ireland Opening Statement*, Dublin: Inclusion Ireland.

National Disability Authority, 2021. *NDA Advice Paper on Disability Language and Terminology*, Dublin: NDA.

National Disability Authority, 2022. *Participation Matters Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*, s.l.: NDA.

Steering Committee Enabling Masterplan , 2017-2021. *Caring Nation, Inclusive Society*, Singapore: Government of Singapore.

Wolfensberger, W., 1983. Social Role Valorization: A proposed new term for the principle of Normalization. *Mental Retardation*, 21(6), pp. 234-239.

Working Group 1 Report on Future Needs for Disability Services DoH, 2016. *Transforming Lives - Progress Report*, s.l.: HSE.

Working Group 3, 2018. *Effective Participation in Decision-Making for People with Disabilities and Families Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff*, Dublin: HSE.

Appendix 1

Consultation process

A consultation process was undertaken to provide an opportunity for disability stakeholders including Section 38 and 39 agencies providers, to review and comment on the draft Self Advocacy Strategy and its implementation.

Feedback from the consultation was used to inform the development of the final draft of the Self Advocacy Strategy prior to its review and approval by CH CDLMS Strategy Group.

Three consultation workshops in different areas of the CHCDLMS region were held with Self Advocates, with the support of Inclusion Ireland

A consultation was undertaken with the Sligo Disabled Persons Organisation – a Sligo-based cross impairment DPO supported by the Independent Living Movement Ireland

Four Consultation workshops were held with members of Disability Federation Ireland based in CHCDLMS

CH CDLMS Self Advocacy Strategy Sub-Group

The development of this strategy was initiated by the CHCDLMS Strategic Working Group which established a Self Advocacy Strategy sub-group, chaired by the Head of Disability Services, to oversee the drafting of the strategy.

The members of this working group are:

Edel Quinn – Chairperson, Head of Disability Services CH CDLMS

Denise Curran – General Manager, Disability Services CH CDLMS

Bernie Donaghy - General Manager, Disability Services CH CDLMS

Mary McGroarty - General Manager, Disability Services CH CDLMS

Caroline Bradshaw - Patient & Service User Engagement

Barry Lynch – Inclusion Ireland

Arindam Ghosh – Project Manager Service Improvement

