



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Communications with Residents Guiding Principles



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Introduction:

These Guiding Principles are intended to support services when revising the local policies and procedures developed to meet the Schedule V requirements of the Health Act 2007 (Care and Support of Residents in Designated Centres for persons with disabilities) Regulations 2013.

The Guiding Principles –

The set of Guiding Principles has been developed following an international literature review which was validated using the AGREE tool along with the preferences and views elicited from service users. These Guiding Principles reflect the key elements that should be incorporated in your local policy and procedure. The references which were used to identify these principles are attached to the end of the Guiding Principles document.

Impact Assessment (Appendix I) –

This Impact Assessment has been developed to assist services during the implementation of the revised local policy and procedure and is intended as a guide to provide a structure for measuring the impact of the revised policy in four key areas:

1. Stakeholder Perspective
2. Internal Business Processes Perspective
3. Learning and Growth Perspective
4. Financial Perspective

This tool should be used by the local policy and procedure development or steering group when the policy revision is close to completion. There is an action plan to record what needs to happen under each of the four headings to support the implementation of the policy.

Audit Tool (Appendix II) –

This document is intended to act as an audit tool when a service is revising their local policy and procedure. The purpose is to ensure that each of the questions in the audit tool is addressed in the local policy and procedure. This includes a question at the end of the audit tool to ensure that experts by experience or people who use the service have been involved in developing or reviewing the policy in a meaningful way.

Verification of Literature using AGREE Tool (Appendix IV) –

This document is included in the packet to assure services that the Guiding Principles were developed in a robust manner and that the literature was validated against this accredited tool (AGREE) as well as giving a synopsis of the engagement with service users. It is for information purposes.

Communications with Residents Guiding Principles:

The National Guiding Principles Group, under the auspices of the National Quality Improvement Office, HSE Disability Operations, has identified 10 guiding principles to assist organisations in developing and revising local policies and procedures for communication with residents.

Guiding Principles:

1. **Definition** - Communication is defined as the giving and the receiving of information. An individual needs an opportunity to communicate, a way of communicating and a reason to communicate. Individuals defined communication as 'getting and giving information'. Service Users also noted that staff should "listen".
2. **Human Right** - Communication is a human right. Individuals who receive services have rights about what they communicate and how they are communicated with. Individuals reminded us that it is ok to keep some information private if they wish.
3. **Services' Responsibility** - Up to 90% of adults with an intellectual disability require support with communication. This means that services for adults with an intellectual disability have a responsibility to provide communication supports to people they support.
4. **Respect and Dignity** - Communication supports are respectful of the individual and their needs and preferences. Communication supports are individualised and support the person's dignity. Individuals identified that when communication goes wrong they feel sad, angry, upset, confused and frustrated.
5. **Total Communication** - A total communication approach is best practice when working with adults with an intellectual disability. This means using every available form of communication to help the person to understand and to be understood. Individuals described this as 'all forms of communication are respected'. Adults with intellectual disability should be supported to use "augmentative and alternative communication" (AAC) as part of a total communication approach. AAC may include the use of objects of reference, Lámh sign, Irish Sign Language, body language and facial expression, visual supports, communication devices etc.
6. **Role of frontline staff** - Staff at all levels in an organisation (but in frontline services in particular) are important communication partners and have a role in giving and receiving information. Staff should receive training in the provision and implementation of communication supports.
7. **Choice** - Service users should have a choice about how their communication supports are provided and by whom. The qualifications and role of the staff (e.g. Nurse, Social Care Worker, Care Assistant, Speech and Language Therapist, Clinical Nurse Manager) does not affect their ability to communicate; rather it is their interpersonal skills that make a difference. Individuals identified that staff members who know them best are the people who should help with communication supports.
8. **Access to a Multidisciplinary Team** - The research identifies that access to a Speech and Language Therapist (SLT), and their specialist knowledge and skills, is an important part of providing high quality communication supports and that access to a multidisciplinary team, including SLTs is critical. The most important thing for the individuals is that the staff who know them best and work with them everyday support them with their communication.

9. References

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Teaching intensive interaction to paid carers: using the 'communities of practice' model to inform training - Rayner - 2016 - British Journal of Learning Disabilities - Wiley Online Library (no date). Available at: <https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12111> (Accessed: 21 March 2019).

The United Nations Convention on the Rights of People with Disabilities (no date) *Disability Justice*. Available at: <https://disabilityjustice.org/the-united-nations-convention-on-the-rights-of-people-with-disabilities/> (Accessed: 21 March 2019)

APPENDIX I – Impact Assessment

Impact Assessment:

The purpose of an impact assessment is to ‘assist leaders to fully understand the extent and complicity of the change’ and will ensure that an integrated approach to managing the change is adopted (McAuliffe *et al.*, 2006). The Balanced Score Card provides a structure for measuring Impact (Kaplan & Norton, 1993). It has 4 key areas and as the name suggests we need to keep a balanced approach to all four. We also need to pay attention to how these interact with each other- for example training and education for staff may be a requirement to introduce something new- how does that impact on finances?

- **Stakeholder Perspective:** This perspective is about how the Policy will impact on stakeholders.
- **Internal Business Processes Perspective:** This perspective ensures the stability and sound operation of your business. What systems/ structures/ referrals/ recording do you need to change or introduce to fully implement this policy?
- **Learning and Growth Perspective:** This perspective consists of training and improvements required for the workforce to implement the policy. It ensures that your employees have the skills to implement the policy. This area also considers the need for data relating to the implementation of a policy- do you need records of how the policy is implemented, eg- the number of referrals to a department, the number of staff who have been trained? Do you need an audit tool?
- **Financial Perspective:** This perspective indicates whether your Policy impacts on the bottom line. Not for profit companies consider the financial perspective last. This however is often a challenging area in public service and requires attention before a policy is ‘launched’ into a system that is not financially able to support its implementation/ sustainment.

There are a series of questions for each of the four areas of the Balanced Score Card that should be considered by a Policy Steering Group/ Policy Development Group when the policy is close to completion. There is an action plan to record what needs to happen under each of the four headings to support the implementation of the policy.

1: Stakeholders; who does the policy impact on? What level of impact is there? How do we engage with the stakeholders to maximise the positive impact of the policy and minimise the perceived negative impact of the Policy?

Name of Stakeholder	How much are they affected? High/Med/Low	How much influence do they have on the implementation of the policy? High/Med/Low	Do we have a plan to engage with/ inform this stakeholder about the policy?
Service Users			
Families			
Clinical staff			
Frontline staff			
Local Managers/ PIC's			
Senior Managers/ Regional Managers			
CHO Disability Managers			
National Disability Team			
HIQA			
Voluntary Agencies			
Other agencies / service providers			

Actions required relating to stakeholders:

- 1.
- 2.
- 3.

2: Internal Processes: How will this Policy impact on internal processes?

Operations Management: delivering services to service users:

Is there a current practice/ procedure that needs to change?

Do we have a governance structure to support the implementation of the policy?

Do we need to develop/ update assessment process associated with this policy?

Is there a new/ updated referral pathway required?

Do all staff know how to access information/ training/ support to implement the policy?

Do we have a review process in place for the policy?

Do we need resources (eg- new equipment/ access to computers, access to documents/ etc)

Regulatory Requirements – Does this Policy support compliance with a set of regulations?

What will the impact be on the compliance levels?

Does it have an impact on GDPR compliance?

Does it have an impact on Assisted Decision Making (Capacity Act)

Does it support compliance with the Health Act?

Does it support the introduction of New Directions for Day Services?

Are there other regulatory implications? (eg- Health and Safety Legislation, Safeguarding Policy requirements,

Are there regulatory risks associated with implementing the policy?

Actions required relating to internal processes:

1.

2.

3.

3: Learning and Growth: How will this Policy impact on learning and growth needs in the organisation?

Data: Is there accurate, timely and complete information available to make management decisions?

What data is available and what data is required?

Can we leverage the data we have to support the implementation of this policy?

What data will help us to report on the implementation of this policy?

Training: Are education and training interventions required?

Do we have a training provider who will provide training?

Have we considered how many staff will need training and education?

Can we record staff training and include it in HR records?

Are there 'backfill' costs for staff to attend the training?

Is it going to be 'mandatory' training?

Can we do some online elements?

Is the training based on the Policy?

HR/IR: Are there IR/ HR issues to be dealt with?

Are there role specific HR implications?

Do job descriptions need to be updated?

Do we need to engage with representative bodies/unions/professional bodies?

Are the management team clear about the processes for implementing this policy and their role in it?

Do we have a HR process to manage people who do not implement the policy?

Do we need new posts to support this policy? Do we have agreement that these posts can be filled?

Actions required relating to Learning and Growth:

1.

2.

3.

3: Finances: How will the implementation of this Policy impact on Finances?

Have we considered the financial implications associated with the policy?

Consider: staffing, new equipment, training, new data collection systems, computers/
hardware/software/

Where will the costs be located: Locally? Regionally? Organisationally? Nationally?

Is there an agreement in place to fund the implementation of the policy?

If funding is not available are we going to do it anyway? – is this sustainable?

Do we need to pilot it and examine the cost of implementation before a wider role out?

Are there risks associated with finances?

Actions required relating to Finances:

1.

2.

3.

References:

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APPENDIX II – Audit Tool

Organisations/ Local Communication Policy Audit Tool:

Guiding Principles to be included in Communication Policy	Yes/ No	Action Required
Does the policy define communication and does it include getting and giving information?		
Does the policy identify Communication as a Human Right?		
Does the Policy set out the services responsibility to meet service users' communication needs?		
Does the Policy require that communication supports are respectful and support the person's dignity?		
Does the Policy identify that all forms of communication are respected, including augmentative and alternative communication (AAC)?		
Does the policy set out the role of all frontline staff as communication partners?		
Does the policy identify that service users should have a choice about how their communication supports are provided and by whom?		
Does the Policy include information about how to access SLTs and a MDT for Communication Supports?		
Does the policy specify staff training in the provision and implementation of communication supports?		
Have experts by experience or people who use the service been involved in developing or reviewing the policy in a meaningful way?		

APPENDIX III – Verification of Literature using AGREE Tool

HSE Disabilities - Operations National Quality Improvement Office GUIDING PRINCIPLES Subgroup

Preparation for validation of research - adapted from Agree Checklist¹

To be used by working groups to document and present research undertaken in developing a set of Guiding Principles for review by the Expert Group within the National Guiding Principles Group

Title of SET OF GUIDING PRINCIPLES: Communication

DOMAIN 1: Scope and Purpose

1.1. The purpose of this SET OF GUIDING PRINCIPLES is:

1. To define best practice in relation to communication with adults with an intellectual disability
2. To provide an opportunity to develop/ review Communication Policies to ensure they are in line with best practice.

1.2. The scope of this SET OF GUIDING PRINCIPLES is:

1.2.1. *Describe the population (staff, people who use services etc.) to whom the SET OF GUIDING PRINCIPLES will apply*

This policy applies to all:

- Staff
- Volunteers
- Students on placement

involved in supporting adults with a primary diagnosis of an intellectual disability in HSE provided and HSE funded day and residential services.

This includes adults with a dual diagnosis of intellectual disability and another diagnosis (e.g. physical disability / sensory disability, autism spectrum disorder, mental health diagnosis etc.).

1.2.2. *Outside the scope of the SET OF GUIDING PRINCIPLES – who does this SET OF GUIDING PRINCIPLES not apply to*

This set of Guiding Principles does not apply to services:

- Supporting children with an intellectual disability.
- Supporting adults with physical or sensory disabilities who do not have a primary diagnosis of intellectual disability.
- Supporting adults with autism spectrum disorder diagnosis who do not have a primary diagnosis of intellectual disability.

¹ Agree Enterprise Website – Appraisal of guidelines, research and evaluation

1.3. OBJECTIVES

Report the overall objective(s) of the SET OF GUIDING PRINCIPLES:

- To provide a Set of Guiding Principles that can be used to support the development of Communication PPPG's where they do not exist.
- To provide a benchmarking tool for services where Communication PPPG's do exist to allow the existing policy to be reviewed to bring them in line with best practice.

1.4. OUTCOMES:

The Outcomes of the Implementation of the Communication Guiding Principles are:

- Improved communication supports for adults with an intellectual disability.
- Increased use of effective communication supports by staff, which are respectful of the person and based on the individual's needs and preferences.
- Improved staff knowledge and skills to deliver high quality communication supports.
- Improved staff's understanding about the importance of implementing rights based communication supports.

1.5. QUESTIONS

Report the policy questions - PICO (Population, Intervention, Comparison and Outcome) covered by the SET OF GUIDING PRINCIPLES, particularly for the key recommendations:

The Communication Principles are based on three Clinical Questions and a research strategy for each was developed:

1. Provision of effective communication supports for adults with an intellectual disability:

P: Adults with Intellectual Disability

I: Communication supports

C: N/A

O: Improved Communication Supports

2. Provision of effective communication supports within a Rights Based Approach:

P: Adults with Intellectual Disability

I: Rights Based Communication Supports

C: N/A

O: Improved Communication Outcomes

3. The role of frontline staff in providing communication supports and the role of the Speech and Language Therapist in providing communication supports:

P: Adults with Intellectual Disability
 I: Communication supports provided by frontline staff (Nurse/Social Care worker/direct support worker, health care assistants)
 C: Communication Supports provided by Speech and Language Therapist
 O: Improved Communication

DOMAIN 2: STAKEHOLDER INVOLVEMENT

2.1 GROUP MEMBERSHIP

Report all individuals who were involved in the development process. This may include members of the steering group, the research team involved in selecting and reviewing/rating the evidence and individuals involved in formulating the final recommendations.

The working group is comprised of:

1. Elaine Teague – HIQA Officer St. Michael's House.
2. Christine Delany – Speech and Language Therapist who is representing the Speech and Language Therapy (SLT) Adults with Intellectual Disability (AID) Special Interest Group (SIG).
3. 2 Person's in Charge (PIC) of a residential setting.
4. Brendan Leen HSE Librarian supported literature reviews

2.2 TARGET POPULATION PREFERENCES AND VIEWS

Report how the views and preferences of the target population were sought /considered and what the resulting outcomes were.

Consultation with Service Users took place over 3 facilitated sessions. Service users shared their views of communication before they were given any information from the literature. The set of guiding principles was developed to take account of the service users views and the information in the literature.

The Service Users' set of rules are

- Communication is about getting information and giving information.
- People communicate in different ways: talking/ signs/ pictures/ using their body/using their phone/ computer/ laptop.
- All ways of communicating are important.
- Staff who know you well can help with communication. Staff who do not know you can not help as much.
- Staff need training to be good at communication.
- It is ok not to communicate some information. It is private.
- It is good to have rules for staff about communication.
- The rules are for all staff
- The rules should be:

- Staff must listen
- Staff make good eye contact
- Staff must let you talk and do not interrupt.
- Staff should not rush someone or tell them to hurry up.
- Staff should communicate in a way that makes sense to the person. No point in writing things down if someone cannot read.
- If staff don't follow the rules there is a problem.
- When communication goes well people feel listened to and feel good about it.
- When communication goes wrong people feel
 - Upset
 - Sad
 - Angry
 - Frustrated
- People need to be given a lot more information about the service and staff changes.

DOMAIN 3: RIGOUR OF DEVELOPMENT

3.1 SEARCH METHODS

Report details of the strategy used to search for evidence:

A review of Gray Literature was conducted, including communication policies in existence in Intellectual Disability Services in Ireland, as well as international SLT professional bodies' position papers on communication with adults with intellectual disabilities e.g. Royal College of Speech & Language Therapists (RCSLT) and the American Speech & Hearing Association (ASHA).

A primary literature search was conducted and a secondary search on roles of staff with different skill sets was undertaken. The two literature reviews were conducted by the HSE librarian including a full search of CINAHL, MEDLINE, SOCINDEX and EBSCO DISCOVERY.

3.2 EVIDENCE SELECTION CRITERIA

Report the criteria used to select (i.e., include and exclude) the evidence. Provide rationale, where appropriate:

The primary literature review identified that Article 19 of the UN's Universal Declaration on Human Rights (1948), as well as Article 21 of the UN Convention on The Rights of People with Disabilities (2006), have both significantly influenced how communication is viewed. Communication is considered within the literature as a human right.

In 1992 the 'Communication Bill of Rights' was developed by the National Joint Committee for the Communication Needs of Person's with Severe Disabilities (NJC) and updated in 2015 and is considered a core document for people who provide communication supports to adults with intellectual disability. These Guiding Principles were developed using a Rights-Based Approach to Communication. That is to say, this policy is in line with the perspective that communication is a Human Right.

Articles relating to provision of services in acute settings/ respite settings or other short stay settings were reviewed and not included in the development of the SET OF GUIDING PRINCIPLES due to the nature of the short term relationships in these settings.

A significant number of articles were 'case study' based and described one or two person's experience of communication supports. These case studies do not provide generalised results however there are no systematic reviews or meta analysis relating to the topic, so common themes from these case studies were identified and included in the development of the SET OF GUIDING PRINCIPLES. It is important to note that the individualised nature of communication supports indicated in the case studies highlights the challenges of conducting a meta-analysis or systematic review.

Many articles described how service users communicated pain/ distress/ discomfort and how this may be interpreted as behaviors that challenges. This body of literature also identified poor wellbeing as the communication driver. This body of literature provided insight into some communication strategies and these were included when relevant.

Research articles when selected for inclusion were further benchmarked against best practice documents developed by different national associations of Speech and Language Therapists e.g. The Royal College of Speech & Language Therapists (RCSLT), the American Speech and Hearing Association (ASHA) etc.

NOTE: The Irish Association of Speech and Language Therapists (IASLT) are currently developing a position paper which will outline SLT service provision for communication with adults with intellectual disability within an Irish context. This document is not completed and therefore could not be used to aid in the development of the SET OF GUIDING PRINCIPLES. When this document is completed, it will impact on best practice for SLTs and other stakeholders in Ireland. Future reviews of this SET OF GUIDING PRINCIPLES must ensure that the IASLT document and the SET OF GUIDING PRINCIPLES policy are aligned.

3.3 STRENGTHS & LIMITATIONS OF THE EVIDENCE

Describe the strengths and limitations of the evidence. Consider from the perspective of the individual studies and the body of evidence aggregated across all the studies. Tools exist that can facilitate the reporting of this concept. GRADE is a commonly used tool with further information available through this link:

http://ktdrr.org/products/update/v1n5/dijkers_grade_ktupdatev1n5.pdf

Key questions to answer:

3.3.1 Are the results valid?

The literature review did not identify any systematic reviews or meta analysis in relation to communication with adults with and intellectual disability. Large scale studies were not identified in relation to communication with adults with an intellectual disability. It was difficult to analysis the validity of smaller scale studies. As outlined above, the literature included in the development of the SET

OF GUIDING PRINCIPLES was in line with best practice documents developed by different national associations of Speech and Language Therapists e.g. The Royal College of Speech & Language Therapists (RCSLT), the American Speech and Hearing Association (ASHA) etc.

3.3.2 Are the results applicable to the population group?

The evidence used to develop this PPG relates specifically to communication supports for adults with an intellectual disability.

3.4 FORMULATION OF RECOMMENDATIONS

3.4.1 What are the recommendations?

The SET OF GUIDING PRINCIPLES are attached as a separate document.

Note: The resourcing of Speech and Language Therapist in the provision of communication supports to adults with an intellectual disability requires further consideration. The literature reviewed identifies that SLT have a critical role in providing high quality, person centered communication supports. However, it is important to acknowledge that in the current environment it is not always possible to access an SLT for communication supports. The SET OF GUIDING PRINCIPLES should include information for frontline staff on how to improve general communication supports in the absence of SLT inputs.

3.4.2 Describe the methods used to formulate the recommendations and how final decisions were reached. Specify any areas of disagreement and the methods used to resolve them:

Recommendations were drafted by members of the working group and discussed with stakeholders.

NEXT STEPS:

The recommendations will be discussed and agreed with members of the Speech and Language Therapist (SLT) working with Adults with an Intellectual Disability (AID) Special Interest Group (SIG)

3.5 CONSIDERATION OF BENEFITS AND HARMS

Report the benefits, side effects, and risks that were considered when formulating the recommendations: (may not be required)

The literature identifies significant benefits resulting from the provision of effective communication supports to adults with an intellectual disability. The literature also

identifies many risks associated with not providing effective communication supports to adults with an intellectual disability. The literature does not identify any harms in the provision of effective communication supports. It is important to note though, that if communication supports are introduced and not implemented consistently, it can result in harm for a person (Primarily noted in the literature: confusion, frustration, behavior that challenges).

3.6 EXTERNAL REVIEW

Report the methodology used to conduct the external review: (discussion points only)

This SET OF GUIDING PRINCIPLES will be reviewed by the Speech and Language Therapist working with adults with an intellectual disability special interest group (SLT AID SIG).

This SET OF GUIDING PRINCIPLES will be reviewed by the HSE Policy and Procedure Working Group (chaired by Marie Keogh O Sullivan)

3.7 COMPETING INTERESTS

Confirmation that full group has completed a Declaration of Interest form: Yes/ No

Any other information to bring to the attention of the Subgroup:

It was agreed to provide Plain English set of guiding principles that can be translated into EASY read/ Lamh symbols/Objects of reference/U- tube videos/ DVD's etc...by individual organisations to best suit the needs of the individuals they are supporting.

Signed: 
Lead for Working Group

Date: March 15 2019

For further information on these Guiding Principles please contact Marie Kehoe-O'Sullivan, National Quality Improvement Office, HSE Disabilities mariet.kehoe@hse.ie 087 1523454