<u>Provision of Information to Residents</u>
<u>Guiding Principles</u>

Contents

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1.0 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 in respect of the Designated Centre; '*the provision of information to residents.'*

The Guiding Principles –
The set of Guiding Principles has been developed following an international literature review which was validate 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.

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Verification of Literature using AGREE Tool (Appendix III) –
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.

2.0 Provision of Information to Residents – Guiding Principles

The National Guiding Principles Group, under the auspices of the National Quality Improvement Office, HSE Disability Operations, has identified eight (8) guiding principles to assist organisations in developing and revising local policies and procedures for the provision of information to residents.

Guiding Principles:

1. **Why is providing information important?**
   a. It is a basic human right that adults can get information that will support them to make decisions
   b. It helps them know about things that are important to them.

2. **What information?**
   a. All important information will be shared with adults (for example, it is very important that they are informed about COVID-19 and how to protect themselves, that they are aware of their appointments so they can be ready etc.)
   b. This information will be given in a way the adult wants and in a way they understand.
   c. This information must be correct, make sense and enough time given for it to be explained.
   d. Right information, in the right way, at the right time.
   e. Example of information that must be given are: contract of care and residents guide

3. **Who should be involved in providing information?**
   a. All adults can choose who they would like to give the information to them, for example familiar staff or a family member.
   b. This choice must be respected.
   c. Information that is given that is personal and sensitive should be done in private (for example about adult's health, a family member being unwell, a staff member leaving).

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    d. The adult should be supported immediately after getting news that may cause distress

4. Who should receive the information?

    a. In line with the Assisted Decision Making (Capacity) Act, it is essential to assume each person has capacity to receive and understand information. All information must be provided to the adult in the first instance and they may wish to share it with family/friends

5. How should information be presented?

    a. Information should be shared in a way that makes sense to the person receiving it, for example:
        i. Easy to read document
        ii. A Youtube video
        iii. A plain English document
        iv. Someone sits down and explains information with the adult
    b. The same information can come in many ways

6. Empowering adults to source information

    a. Adults will be supported to get information about things they are interested in
    b. Staff will be trained to give support to adults to get information from different sources, for example:
        i. The internet
        ii. Social media (i.e. facebook)
        iii. Newspapers
        iv. Writing letters
        v. Asking for an update on something

7. Staff support

    a. Staff should be trained on how to present information in a way that suits the adult and in a way they understand

8. Safety

    a. Feedback from adults who use services said that this guiding principle was an important part of providing information
    b. It is important that personal information should always be kept safe and secure.
    c. Personal information should be kept in line with GDPR, be kept private, and not shared with people who do not need to know the information.

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3.0 References

Chinn, D. (2019). Talking to producers of Easy Read health information for people with intellectual disability: Production practices, textual features, and imagined audiences. *Journal of Intellectual & Developmental Disability*, 410-420.

Chinn, D. (2020). An empirical examination of the use of Easy Read health information in health consultations involving patients with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 232-247.

Goodwin, J. (2015). Easy Information about research: getting the message out to people with learning disabilities. *British Journal of Learning Disabilties*, 93-99.

Kim, H. N. (2019). Understanding of how older adults with low vision obtain, process, and understand health information and services. *Informatics for Health and Social Care*, 70-78.

Laragy, C., David, C., & Moran, N. (2016). A framework for providing information in individualised funding programmes. *Qualitative Social Work*, 190-208.

Rodgers, J., & Townsley, R. (2005). Commissioning Information for People with Learning Difficulties. *Journal of Integrated Care*, 44-48.

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APPENDIX I – 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.

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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.

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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.

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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.

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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:

Kaplan, R. and Norton, D. (1993). Putting the Balanced Scorecard to Work. [online] Harvard Business Review. Available at: https://scanmail.trustwave.com/?c=6600&d=mtOP3Hd_PgUW7QSSAIx5Gk_RqyLJQxm3v9 5eDITWTQ&s=343&u=https%3a%2f%2fhbr%2eorg%2f1993%2f09%2fputting-the-balanced-scorecard-to-work [Accessed 8 Jan. 2018].

McAuliffe, E. *et al.* (2006) *Guiding change in the Irish health system*. Report. Health Service Executive (HSE). Available at: http://www.lenus.ie/hse/handle/10147/78553 (Accessed: 8 February 2018).

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Appendix II – Audit Tool

Organisations/ Local Communication Policy Audit Tool: Provision of Information

Guiding principles to be included in Provision of Information policy	Yes/No	Action Required
Does the policy outline that provision of information is based on human rights?		
Does the policy identify that providing information that is important to the person is required?		
Does the policy outline that all important information will be shared?		
Does the policy include that information provided will be correct and will make sense to the person?		
Does the policy outline that right information will be provided in the right way and at the right time?		
Does the policy outline that enough time must be given to allow the information to be explained to each individual?		
Does the policy outline that adults can choose who they would like to provide them with information and that this is respected?		
Does the policy incorporate a statement about information that is given, that is personal and sensitive, should be done in private?		
Does the policy include providing supports to adults immediately after getting news that might cause them distress?		
Does the policy outline that all information must be provided to the adult in the first instance and they may wish to share it with family/ friends?		
Does the policy include that information should be shared in a way that makes sense for the person receiving it?		
Does the policy outline that adults will be supported to get information about things they are interested in?		
Does the policy include a statement about staff being trained/guided on how to present information in a way that suits the adult, and in a way they understand and from different sources?		
Does the policy include the importance of keeping personal information safe and secure?		
Does the policy outline that personal information		

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should be kept in line with GDPR, be kept private and not shared with people who do not need to know the information?		
Is the policy underpinned by the principles of person centeredness?		
Does the policy indicate personal preferences from SU and what should be indicated as important to the individual? (It is imperative that the policy should require finding out the personal preferences of the person and identifying what is important to them).		
Is the Provision of Information policy in **accessible** and diverse formats to suit individuals?		
Is the policy culturally appropriate? (i.e gender and racially appropriate)		
Have experts by experience or people who use the service been involved in developing or reviewing the policy in a meaningful way?		

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Appendix III – Verification of Literature using AGREE Tool

Preparation for validation of research - adapted from Agree Checklist[1]

To be used by working groups to document and present research undertaken in developing a policy for review by the Expert Group within the SET OF GUIDING PRINCIPLES Group

Title of SET OF GUIDING PRINCIPLES: Provision of Information
DOMAIN 1: Scope and Purpose
1.1.   The purpose of this SET OF GUIDING PRINCIPLES is: To define best practice in relation to provision of information to adults with a disability.   To provide guidance and support to services to ensure compliance with regulations in relation to provision of information.   To provide services with a structured approach to developing/reviewing Provision of Information 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 and students on placement who provide support to adults with a disability.   *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 that support children with a disability.
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 provision of information policies locally where they do not exist.   To provide a benchmarking tool for services where Provision of Information policies 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 Provision of Information Guiding Principles

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

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are:

- Improved provision of information to adults with a disability.

- Increased use of effective provision of information supports by staff, which are respectful of the person and based on the individual's needs and preferences.

- Improved staff knowledge to deliver high quality information in a person centered way.

- Improved staff's understanding about the importance of implementing a rights based approach to providing information.

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 Provision of Information Principles are based on two Clinical Questions and a research strategy for each was developed:

P: Adults with Disability (physical/learning/intellectual/sensory)

I: Provision of information (or providing information/ giving information)

C:

O: Improved understanding/better understanding/improved knowledge/

P: Adults with Disability (physical/learning/intellectual/sensory):

I: Information required to improve support services

C:

O: Better understanding of options/ supports available

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:

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Marie Kehoe-O'Sullivan – HSE National Quality Improvement Lead – Disability Services

Elaine Teague- Director of Quality and Safety St. Michael's House

Adrienne Smith- Person in Charge- Camphill Communities

Barbara Murphy- Director of Care -Moorehall Living,

Eucimea O Leary- Occupational Therapist- St. John of God's Service

Nicole Lam – Research Officer – National Disability Operations, Quality Improvement HSE

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.

Data Collection on Information available to Residents on 19th Nov 2020 - 5pm -8pm

Data collected by Care Managers

The data collection took place over 6 households.

A total of 14 residents took part.

1 resident required one to one support with a familiar member of staff utilising ISL (Irish Sign Language)

1 resident requested to complete the research in their bedroom away from group.

3 residents opted to decline.

Question	Answer
1. Is it important to get information about where you live?	Residents like to receive information regarding their home, their locality and both their residential and day services.
2. If you didn't get information would it bother you? EG. about COVID-19, appointments, New Staff	All residents reported that it is very important that they are informed about COVID-19 and how to protect themselves, their appointments so they can be ready. They voiced strongly a right to know what is happening in their life.

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3. Name some ways you get information	Television, letters in post, Telephone, Staff, Radio, Family, Social Media (Facebook), Communication apps (WhatsApp, facetime, viber), service created individualised Information videos about COVID-19 and easy read leaflets
4. Which way do you prefer?	6 residents stated reported they like to receive their information from staff, family or television
5. Who do you like, to give you information about you?	All residents said in varying replies - Familiar staff and/or family
6. Who should get information?	All residents- everyone is entitled to receive their own personal information. And that everyone is to receive information about what is happening in the world
7. What if the information is bad news? (EG. staff leaving or retiring) How would you like to receive this information?	Residents reported that they would like to receive this form of news: • Personal Bad News; on a one to one basis from familiar staff (keyworker) or family member • Bad news about staff: either one to one or during a house meeting from familiar staff
8. What could you do if you did not understand the information or you forgot what it was about?	Residents reported if they did not understand, they would ask for the information to be reported or for easy read information to be given. If they forgot what was said, they would also ask a staff member who was there.
9. Do you think technology can help you/others understand information better?	Residents voiced they liked information videos and information from the television as they could see what was happening.

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Additional Feedback:

- One resident enquired who teaches staff to keep their personal information private, to make sure their information is not shared with other house mates. This resident was guided with the steps MyLife as an employer takes in educating staff to ensure confidentiality is upheld to the highest standard. Same addressed and clarified with easy read information.

- One resident raised how they had received easy read information about a surgical procedure they were having carried out and that it allowed them to give their own consent.

- One resident spoke about online social media and information sharing, how it is very important to only be friends with people you know. Expressing knowledge of the dangers.

- Another resident also spoke about a role they enjoyed carrying out before COVID-19, shredding in the office. That it was very important the pages where shredded so no one outside of MyLife could see important information.

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 provision of information policies in existence in Disability Services in Ireland, as well as internationally.

A primary literature search was conducted and a secondary search on improved information supports for adults with a disability was undertaken. The two literature reviews were conducted by the HSE librarian including a full search of CINAHL, MEDLINE, SOCINDEX and EBSCO DISCOVERY.

A review of relevant regulations was undertaken.

3.2   EVIDENCE SELECTION CRITERIA

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

The literature search identified seven academic articles related to the search. Each of these was reviewed and six were included in the analysis as one was deemed irrelevant. Fullmer & Majumder (1991) was excluded as it focused predominantly on information technologies and the costs of acquiring different types of telecommunications in the early 90's.

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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

The literature review did not identify any systematic reviews or meta analysis in relation to provision of information to adults with a disability. Large scale studies were not identified in relation to provision of information.

Six academic articles and four pieces of grey literature were included in the evidence base. Laragy, David & Moran (2016) considered a wide range of literature and more importantly their research targeted often marginalized and unheard groups of disabled people based on gender and geographical location. They reviewed qualitative studies (semi-structured and focus group interviews) which provide rich data on experiential knowledge, making their data very applicable to this target population and "hard to reach" groups. On the other hand, Rodgers and Townsley's (2005) work is much more focused on information provision and does not provide detailed methodologies, opting to distil findings in a short and succinct paper.

Chinn's (2020) research using conversational analysis highlighted the under-use of Easy Read leaflets by health professionals despite encouragement to use the materials, and that specialist intellectual disability nurses were more likely to use Easy Read formatted resources than in their interactions. It also raises an issue with patients who requested more information who were ignored by their GPs. However this study has limitations in terms of generalizability as there were no controls for the types of disabilities each patient had.

A major strength of Goodwin et al. (2015), is that Julian Goodwin himself is disabled and is the main author of this paper, as much of the academic literature is not written by disabled people themselves. Part of the issue with inclusive or participatory research is the imbalance of power, so having disabled people researching and speaking about themselves, and addressing existing barriers is invaluable.

The use of convenience sampling in Kim's (2019) research is a limitation as the sample may not be truly representative of the population. Furthermore, the study did not measure the degree of blindness in the participants or their capacity in understanding language and images. However, it does not negate the finding from the ten individuals which suggested that older adults with low vision might not want to disclose their visual impairment and that health professions should show initiative in suggesting alternative health information that is not overly text-heavy or text based.

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3.3.2 Are the results applicable to the population group?

The evidence used to develop this Guiding Principle relates specifically to provision of information for adults with a disability.

3.4 FORMULATION OF RECOMMENDATIONS

3.4.1 What are the recommendations?

The SET OF GUIDING PRINCIPLES are attached as a separate document- when they are completed.

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

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)

3.6 EXTERNAL REVIEW

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

This GUIDING PRINCIPLES were reviewed by the HSE Guiding Principles Working Group (chaired by Marie Kehoe- O'Sullivan) and will be reviewed by the Independent Governance Review Group for Disability Services Quality Improvement chaired by Dr. Philip Crowley.

3.7 COMPETING INTERESTS

Confirmation that full group has completed a Declaration of Interest form: Yes

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

For Further Discussion and Consideration: .

Signed: *Marie Kehoe-O'Sullivan*   Date: 19 February 2021
Lead for Working Group

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