

Applying the Principles of Open Disclosure in a Service for Individuals with an Intellectual Disability



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ST MICHAEL'S HOUSE

Why is OD important in Disability Services?



- 70,000 people with ID in Ireland
- SMH is a non-statutory agency (Section 38 agency)
- In human services things go wrong- how we respond is a significant and important part of service provision
- Cradle to Grave supports

A case study



- Trust in Care investigation
- Findings- abusive interactions did occur
- Open Disclosure Team established
- Individual OD Meetings with adults who use services FIRST
- Individual meetings with families
- Follow up with individuals
- Follow up with families

The Stages of the process:



- Trust in Care investigation
- Disciplinary Process
- Open Disclosure

Our Key Question?



How we can meaningfully openly disclose and apologise to adults with an intellectual disability who have highly complex communication support needs, when something has gone wrong?

Open Disclosure meetings with adults



- Decision 1- What supports were needed to support open disclosure ?
- Decision 2- Who would disclose?
- Decision 3- How can we make this meaningful?
- Decision 4- Where would open disclosure take place?
- Decision 5- What supports would be needed after the disclosure?

Open Disclosure meetings with families

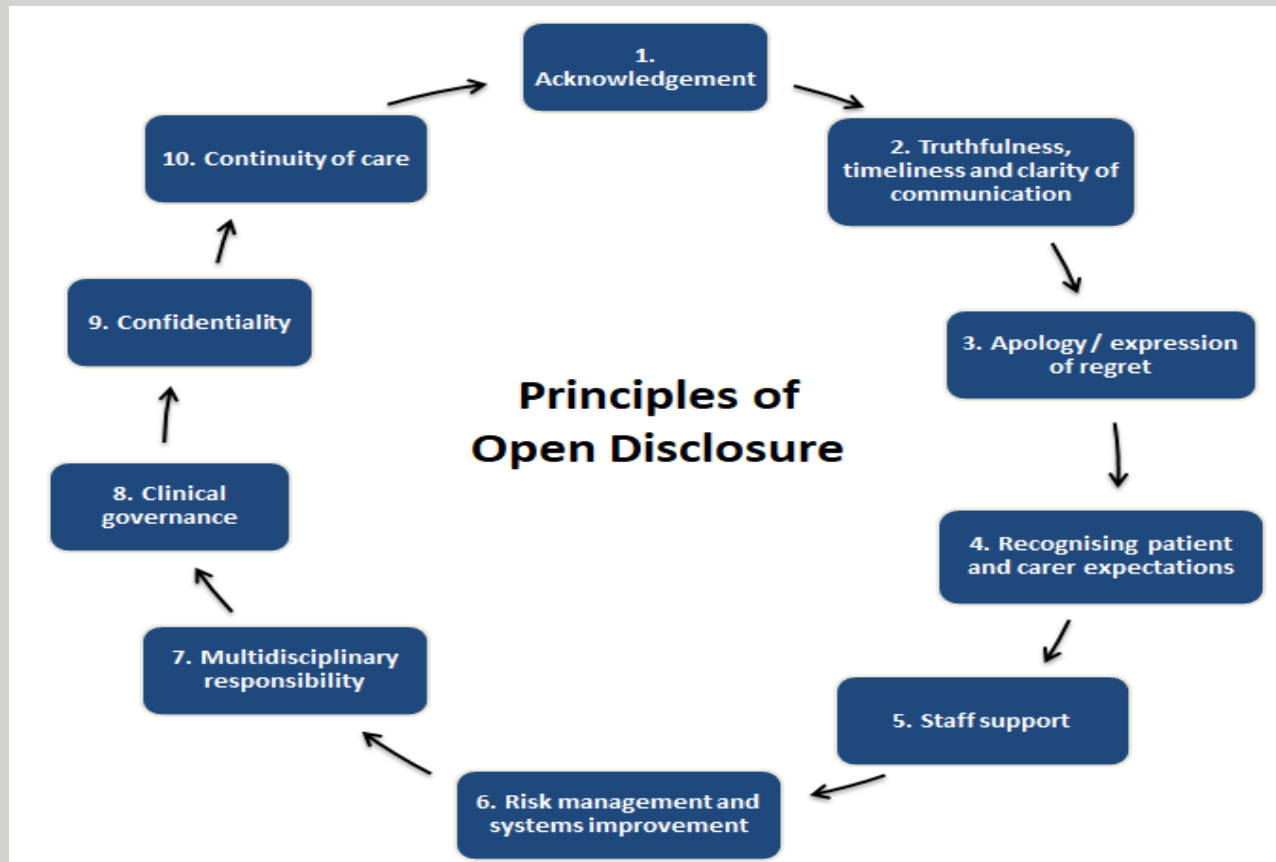


- Decision 1- Who would we disclose to?
- Decision 2- Who would disclose?
- Decision 3- How can we make this meaningful?
- Decision 4- Where would open disclosure take place?
- Decision 5- What supports would be needed after the disclosure?

Principles of Open Disclosure



- Discussion about OD principles:



Easy Read Policy in Practice



This information is about the Open Disclosure policy.



Open Disclosure means you are told if something goes wrong or someone makes a mistake with your care.



This information is from St. Michael's House



The Information Transformers helped to put this Easy to Read booklet together

SMH Guide for Staff

To be read with SMH Easy Read OD Policy and the HSE National OD Policy



Open Disclosure- A guide for Staff

To be read in conjunction with the national HSE Open Disclosure Policy (2019)

What is Open Disclosure?

Open Disclosure involves:

- Communicating with service users and families in an open, honest, empathetic and transparent manner following adverse incidents.
- Issuing service users and their families with an explanation, acknowledging what has happened, and providing a meaningful apology when they are harmed or following an adverse incident.
- To discuss, in collaboration with service users and families, the actions required to prevent or reduce the risk of the adverse event reoccurring. This is to ensure organisational learning.

Principles in Practice

1. Acknowledgement

Rights based- a right to an acknowledgement

10. Continuity of Care

Cradle to grave/ ongoing relationship with service users and families/ need to repair to ensure wellbeing of the service user. Complexities of longevity of service provision often raised issues previously dealt with.

2. Truthfulness, timeliness and clarity of information

Total communication approach to optimise understanding

3. Apology

Service users received apology first

4. Recognising Service User and Carer Expectations

Letters to family members included recognition of their feedback and learning into tangible actions.

Service users expressions/signals- needed reassurances that staff would not return

9. Confidentiality

All staff briefed again on confidentiality. Maintained for investigation (due process given) however, fallout for service user?

8. Clinical Governance

MDT involvement from outset, welcomed by MDT

7. Multidisciplinary Responsibility

Holistic supports in place from SLT, Social Work and Psychology

6. Risk Management and Systems Improvement

Ongoing tracking of actions and recommendations to prevent reoccurrence and enhanced systems for governance and meetings with staff

5. Staff Support

Support sheets and scripts for staff, follow up supports after the meetings

Rights Based Acknowledgement



- **Right of the person to receive an apology**
- **Assumption of capacity to receive an apology**
- **Supports to understand the apology**
- **Follow up supports**
- **Communication at the person's level**

1. Acknowledgement (Rights Based)

Do I have any rights when it comes to Open Disclosure?



Everyone has rights.

A right is something a person has which should not be taken away.



You have the right to be told if something goes wrong or there is a mistake with your care.



Staff in St. Michael's House must tell you.



You have the right to be told things in a way that you understand.

1. Acknowledgement (Rights Based)



You should be given a chance to think about the information.



You should be told what happened.



You have the right to be cared for and to have medical help if you have been hurt.



This might mean help from staff if it is a small injury, or from a doctor or hospital if it is more serious.

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OD Resource Tool Box-

Picture Agenda



SERVICE USER APOLOGY MEETING- RESOURCES



This meeting is about

St Michaels House



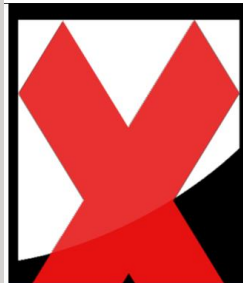
We want to say

sorry to you



Some staff did things

that you were not happy
with



St Michaels House
would like to make sure

that these things DO
NOT happen again



These are some
good things

we have done to
make things
better



A New Staff team

How did we ensure a total communication approach was used?



- Individual communication styles
 - Support plans
 - Hospital Passports / Hospital Liaison nurse
 - Use of photos/ objects of reference
 - Symbols
 - Lamh
 - Communication Passports

Supporting communication.. Why?



- Communication supports are a human right
- ADM requires us to provide information in a way that suits individual
- HSE Communication Guiding Principles for Disability services
- HSE Provision of Information Guiding Principles for Disability services
- St. Michael's House Ethical Decision Making Framework

2. Truthfulness, timeliness and clarity of information

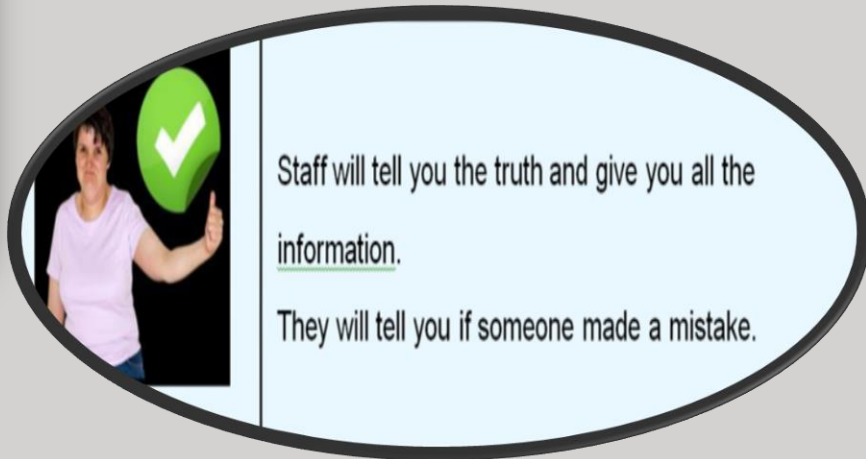
What is this information about?



An important part of Open Disclosure is how staff communicate with you and give you information.



It is important to find out what happened when something goes wrong.



Staff will tell you the truth and give you all the information.

They will tell you if someone made a mistake.



Staff in St. Michael's House will organise the meeting.



They will gather information for the meeting.

2. Truthfulness, timeliness and clarity of information



You should be told as soon as possible after something has happened.



Staff will support you to understand information if there is a meeting.
Meetings will usually be with you and your supporter.



You have the right to be told things in a way that you understand.

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Using Lamh (sign language for people with ID)



Sorry



R.H. 'a' handshape, palm to
self on chest. Make a
circular motion on the chest
once.

ISL
Social

3. The Apology



You have the right to be told if something goes wrong or there is a mistake with your care.



Staff in St. Michael's House must tell you.



Staff will treat you with respect.



They will treat you as an adult.



St. Michael's House will support staff to say sorry if something goes wrong or a mistake is made.

3. The Apology



Open Disclosure can be about saying sorry.

- Managers and staff in St. Michael's House should know when and how to say sorry to you.



You should be told what will happen next and what will be done to make things better.

3. The Apology



The Open Disclosure meeting



If you agree, staff might invite other people that are important to you to the meeting.

For example, your family.



The meeting will be in a place where you feel comfortable.

For example, your home, day service, or community.

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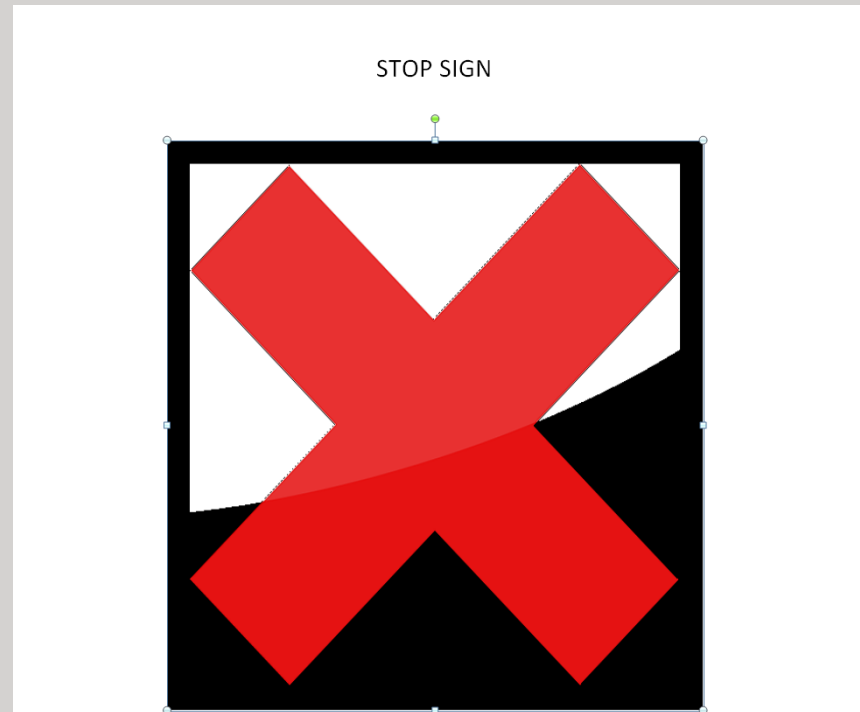
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Stop Sign – for Service Users Requesting the Meeting to End



4. Recognising Service User and Carer Expectations



Staff will communicate information in the best way for you.

This could be words, Lámh signs, photos, pictures, symbols or things.



Staff will tell you the truth and give you all the information.

They will tell you if someone made a mistake.

4. Recognising Service User and Carer Expectations

How will staff give me information?



Staff will answer your questions.



They will be kind.

They will take time to sit and talk to you.



You should be told what will happen next and what will be done to make things better.

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Support script for staff



Script



- I am very sorry on a professional level and on a personal level to hear that something happened
- This must be very upsetting for you.
- I do know that the organisation is deeply sorry for this and is putting steps in place to make sure that this doesn't happen again.
- I have the name and number of the support person if you would like to talk it over, receive more detail or even more support- I can give it to you

Support sheet for Staff

What to Expect



- The service users may be upset/ out of sorts/ may wish to talk to staff/ key workers about the open disclosure/ pictures or resources they were shown
- Family members may ring or visit more frequently than usual
- Family members may ask your opinion of the service / seek reassurance. They may need reassurance that the organisation is working as hard as it can to redress the issues.

5.Staff Support



St. Michael's House will support staff to say sorry if something goes wrong or a mistake is made.

Staff Guidance and Support



Open Disclosure- A guide for Staff

To be read in conjunction with the national HSE Open Disclosure Policy (2019)

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Learning from Service Users and Families-

Reiterating this in letters to families-

We have also listened to your helpful suggestions about stabilising the staff team in XXXX so that familiar staff members work there”

We will also review the arrangements on the bus to make sure that the staff who are on the bus work as a team to support each other

We know that we will help to build confidence in the service and the matter of people for us

We will ask the Social Work Department to arrange to meet you about XXXX future need for residential care. We know that this is important to you and your family for the future”.

“We will continue to strengthen the oversight and governance arrangements in our services so that these type of incidents don't happen again”.

6. Risk Management and Systems Improvement



Staff will need to make a plan.

This should make sure it doesn't happen again and say how to make things better.

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Multi-Disciplinary Approach (discussion?)



- **Director of Service**
- **Director of Quality and Safety**
- **Director of HR**
- **Service Manager**
- **Clinical Services-**
 - ✧ **Social work**
 - ✧ **SLT**
 - ✧ **Psychology**
- **Risk and Incident Manager**

7. Multidisciplinary Responsibility



Staff will give you the name and number of a support person, this is someone to help you.

In the HSE Open Disclosure Policy the support person is called a Designated Person.



The support person will talk to you about what happened.

This person might be a social worker, manager, or someone from the clinic.



Staff will communicate information in the best way for you.

This could be words, Lámh signs, photos, pictures, symbols or things.

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8.Clinical Governance



St. Michaels House will give training to staff so they understand the Open Disclosure Policy.



St. Michael's House will support staff to say sorry if something goes wrong or a mistake is made.



St. Michael's House will help staff to understand the laws on Open Disclosure.



Staff will keep notes from the meeting.
You will get a copy of these in a way that you can understand.



Staff will tell you if they need to get more information about what went wrong.

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St Michaels House will keep checking this policy
and will make changes to make things better.

Reflection



Open Disclosure & Ethical Decision Making

Following OD families suggested/ requested additional safeguards be implemented.

We want to work with families to reassure them.

Some types of suggestions-:

One family wanted 2 staff to be present with their family member, one of whom should be a nurse, at all times -during personal care/ medication administration/ lunch/outings

One family wanted the person moved to another day service

Ethical Decision Making



A: The Decision

(reasonableness, openness, transparency)

1. What decision(s) need(s) to be made?
2. Why do we need to make this decision?
3. Who needs to be involved in making this decision?
4. What options are there (including not acting)?
5. Consider the risks and benefits of all options.

B. Involvement of the Person in the Decision Making Process

(inclusiveness, person-centredness, consent)

1. Have you established what the person's will and preference are in this situation?
2. What steps need to be taken to support the person to engage in the decision making process?
3. Has the person been provided with appropriate information about the situation, in a way they can understand?
4. Nominate a support person for the service user, agreed in advance with an alternative.
5. Support person explains decision(s) and options to the service user.
6. Presume person has capacity to make their own decisions unless/until the contrary is shown.

Ethical Decision Making



C. Make a Decision

1. Does the proposed measure *minimise harm* (to the person and/or others)?
2. Is the proposed measure *proportionate* (to the benefits of doing it and the risks of not doing it)?
3. Is it *fair and reasonable*? (Does it treat the person as equal to all others and is it based on best available evidence and sound clinical judgement?)
4. Are we fulfilling our *duty to provide care* (to the person, staff and others)?
5. Is the decision making process *open and transparent*?
6. Have all key stakeholders been included in the decision making process?
7. Consider whether consultation with the SMH Ethical Advisory Committee is required (i.e. Is the decision complex? Are there varying views? Are there consent issues?)

D. Make a Plan to Review/Revise the Decision

(responsiveness, accountability)

Is the decision making responsive? (How will it be revisited as the situation changes? How will complaints/appeals be managed?)

What are the systems of accountability? (Who is responsible for the decision? Who has oversight?)

How has all of this recorded in the person's file? (rationale for decision and the process)

Decision Making- Support of 2 staff required?

What decision needs to be made?

Does the person want/
require 2 staff

Risks and Benefits of the
Decision

Involvement of the Person in the Decision Making Process

The person's will and preference?

Provide information and support
person for the person

Make a Decision

Does the decision Minimise harm?

Are measures proportionate?

Make a Plan to Review the Decision

Is the decision making
responsive?

What are the systems of
accountability?

Continuous learning....



- Each situation is different
- Open Disclosure is part of 'how we do business'
- Question is not 'Should we open disclose'- it is 'HOW will we disclose'
- Share the learning is important in the sector/ for the sector
- Sharing event with National Federation of Voluntary Bodies in 2019.
- Poster presentation at SCA event in 2019

Conclusion:



Open Disclosure-

**It is the right thing to do &
it is important to do it right!**

Questions?