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### 1. Welcome

Welcome to our 2023 edition of the National Disability Quality Improvement Office newsletter.

**We begin this newsletter by acknowledging your exceptional work to support disabled persons during COVID, often at great personal cost.**

We hope this newsletter provides an accessible way to access the Guidance Documents.

### 2. International Day of Persons with Disabilities, December 3<sup>rd</sup>, 2023

The theme for IDPwD 2023 is 'United in action to rescue and achieve the Sustainable Development Goals (SDGs) for, with and by persons with disabilities.' The 2023 theme for IDPwD asks everyone to work together to make the world better and fairer for people with disabilities.

The theme talks about the Sustainable Development Goals (SDGs). The SDGs are seventeen actions countries want to work on by 2030 to make the world better and fairer for everyone. It is important that people with disabilities are part of this work and have a big say in what happens.



International  
Day of  
Persons with  
Disabilities  
3 DECEMBER

You can learn more about the SDGs here:

- [The seventeen goals – Sustainable Development:](#)
- Take Action for the Sustainable Development Goals – [United Nations Sustainable Development](#)
- [Student Resources – United Nations Sustainable Development Goals:](#)
- Do you know all 17 SDGs? [Video](#)
- [Easy Read:](#) How well are countries doing to make the world better and fairer for people with disabilities?

### 3. Meet our team

#### **Marie Kehoe-O'Sullivan – National Disability Specialist**

I have worked in the field of quality improvement in health and social care for the past thirty years and as a registered general nurse for the ten years before that; the first twenty years were spent in the USA, and I have now been home in Ireland for twenty-two years. I was the Regional Quality & Safety Manager in the HSE South prior to joining HIQA in 2012 as the first Director of Standards & Quality Improvement. My team developed national standards in both health and social care (including disability services) and then supported services to meet those standards.

I returned to the HSE in July 2017 to lead the Quality Improvement Team in Disability Services. My goal in this role is to lead a team that is committed to empowering disabled people to live lives of their choosing and to support families and services to ensure that people with disabilities have equal rights in society in accordance with their own will and preferences.

All our work is developed in close collaboration with disabled individuals, their families, and staff members. I can be contacted at [mariet.kehoe@hse.ie](mailto:mariet.kehoe@hse.ie) or 087-1523454.



#### **Sandra Ferncombe – Healthcare Lead**

I joined the National Quality Improvement Team for Disabilities in July 2023 as Project Lead in Healthcare. I have a BSc in Intellectual Disability Nursing and have worked in the Disability sector for 19 years.

Those years have provided me with extensive knowledge and have afforded me the opportunity to support and work directly with Adults with an Intellectual Disability. In 2014, I took on a Senior Management Role. This involved supporting Adults with an Intellectual Disability to avail of services across Residential, Respite and Day Services. This role also afforded me the opportunity to become actively involved in service development and quality improvement.

I look forward to using the experience I have gained throughout my career to contribute to creating valuable resources that will improve the quality of care and enhance service user experience. I can be contacted at [Sandra.Ferncombe@hse.ie](mailto:Sandra.Ferncombe@hse.ie) or 087-4850974.



## Joanne Fitzpatrick – Project Co-Ordinator

For over the past 30 years, I have been committed to working in the Health Service in public and private hospitals in the UK and Ireland. I hold a BSc (Hons) in Health Service Management.

Throughout my career, I have collaborated with the Chief Executive's Office ERHA and have gained extensive experience in various teams such as Planning & Commissioning, the Service Improvement Team, and the National Disability Information Unit.

My interests are health promotion, physical activity for disabled persons, and quality improvement. You can easily contact me at [joanne.fitzpatrick@hse.ie](mailto:joanne.fitzpatrick@hse.ie) or 087 6277326 from Monday to Wednesday.



## Ronan Halpenny – Social Care Lead

Coming from a Social Care background, I have had the privilege of working in the disability sector in Ireland for over twenty years, in frontline and mid/senior management roles in voluntary (Section 38/39) and state agencies.

I have extensive experience delivering residential/respite services in regulated settings and ensuring that high quality supports are delivered to the wonderful men, women, and young people that we support.

I joined the HSE during the pandemic in September 2020 as a Case Manager in the Disability Team in Dublin North West and I have a particular interest in quality, safeguarding, and legal elements in cases. I am very happy to have the opportunity to join the National Quality Improvement Team for Disabilities for the next chapter of my Social Care journey. I plan to put a strong emphasis on embodying the spirit of the UNCRPD in my work and ensuring that disabled people are actively involved and consulted about projects that I participate in with the team. I can be contacted at 087 486 4727 or [ronan.halpenny@hse.ie](mailto:ronan.halpenny@hse.ie)



## Nicole Lam – Guidance & Research Lead

I joined the Disability Quality Improvement team in 2019 through the HSE GradLink programme after I graduated from my MA Intercultural Communication and Education from Durham University, UK, and BA Sociology and Social Policy from Trinity College Dublin.

My passion was always to work with marginalised populations and enacting change through research. I was fortunately placed in this team and have been able to work towards my goal since then and learned so much about disability justice and empowerment through actively collaborating with disabled people and disabled person's organisations, services and staff, and other relevant stakeholders.

Conducting research with and for disabled people is a privilege especially when there is a lack of research in this area. I am excited to continue this journey and look forward to learning more from everyone. For anything relating to research and guidance development, I can be contacted via [Nicole.Lam@hse.ie](mailto:Nicole.Lam@hse.ie) or 087 7147622



## Karen O'Sullivan – Admin Support

I worked in administration for many years before I decided to retrain as a Special Needs Assistant in 2013.

In March 2023, I began working as an admin support in the HSE National Disability Services Quality Improvement Office. I support Marie to organise supports for survivors of Thalidomide. In addition, I provide admin support to Expert Advisory Groups including *Records Management*, *Guiding Principles*, *ADMA*, and the *Health Passport*.

I also manage our website, so if you need to access any documents, please feel free to contact me. To contact me, you can call me at 087 4607069 or email me at [karen.osullivan13@hse.ie](mailto:karen.osullivan13@hse.ie)

## 6. Work Completed (from Action Plan 2023)

### 6.1 Guiding Principles

Two further Guiding Principles (GPs) were completed this year and signed off by the Independent Governance Group. These can be found on our website under Guiding Principles. The two new GPs are:

- **No. 3 When a resident goes missing – Lead Nicole Lam**

These guiding principles are underpinned by human rights principles and as such will require a change of culture as there has been an historical over-emphasis on restraint and clinical language (absconding) and ill-defined parameters of what is considered wandering or missing. There is a need for a shared understanding between disabled people, their families, staff, regulators, and law enforcement as to what constitutes what “safe wandering” might look like for different people and avoid defaulting to restrictions or infantilisation.

- **No. 7 Residents’ personal property, personal finances, and possessions – Lead Nicole Lam**

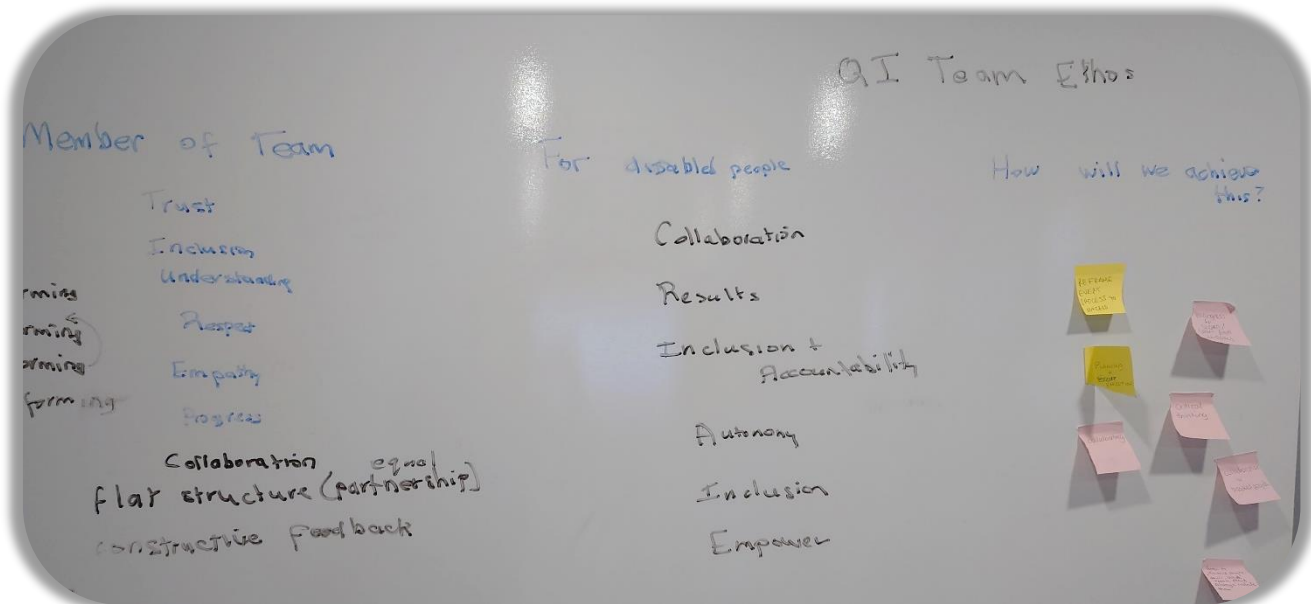
These guiding principles are underpinned by human rights principles and as such will require a change of culture as there has been a historical assumption that a person with an intellectual disability is unable to manage their property, finances, and possessions. These assumptions have sometimes resulted in “communal” possessions – clothes, furniture etc. and individuals were unaware if they had any money and often their money was managed by their family or service provider. This was done in good faith, but it resulted in material deprivation and paternalistic attitudes and deprived the individual of their rights.

This will require a culture change, with families who may see this as an attempt to take control away from them – control that they viewed as supporting their loved one. This cultural change is also required from the wider community including banking and other financial institutions and it should be recognised that will require more targeted efforts from services and individuals to work with those institution.

While that work is beyond the remit of these Guiding Principles, it is recognised that challenges concerning the prevailing use of the term “next of kin” (NOK) and the Patient Private Property Accounts (PPPA) exist:

- Traditionally, the NOK is a person nominated by a resident as the person who would be informed in emergencies etc. However, the NOK has no legal status and thus cannot make decisions on behalf of person with disability. The term “nominated person” is used instead of NOK. This nominated person (formally known as NOK) may be particularly important in a person’s life and may be an appropriate person to provide information. Furthermore, this nominated person may become a formal support under the ADMA but this is not automatic and can only be done so in line with the Decision Support Services, the forthcoming ADMA codes of practice and in line with any court appointed formal support if relevant. The term Next of Kin should NOT be used in any documentation.

The relevant legislation and the HSE Patient Private Property Guidelines policy should apply to people whose finances are managed within a Patient Private Property Account (PPPA), and access to these funds must considered within this context.



On 20 November 2023, the whole team participated in an exercise to collectively develop our team ethos. Here is what we produced:

## 4. Our Disability QI Team Ethos

As a dynamic team, we believe in partnership, understanding, and mutual respect.

We will collaboratively work with disabled people and DPOs, using a human rights-based approach to promote the following for disabled people:

- Autonomy
- Inclusion
- Accessibility
- Self-determination
- Empowerment

We aim to achieve this through:

- Meaningful engagement
- Openness and willingness to learn from mistakes.
- Active listening
- Commitment to the UNCRPD

## 5. Our Website

Our [website](#) is now live and can be accessed by everyone. On here, you will find the following headings:

### 5.1 [Health Passport Intellectual Disabilities](#)

this will allow you to access a Word version of the HSE Health Passport and guidance to download the App. NOTE – the passport is currently being revised and we will alert you when the final version is on the website.

### 5.2 [Guiding Principles](#)

this is the area where you will find all the Guiding Principles that we have developed to support staff when they are developing or revising their Schedule V policies as required by the Health Care Act (Care and Support of Residents in Designated Centres for persons (children and adults with disabilities) Regulations 2013. You will also find the Standard Operating Procedures that we use when developing these Guiding Principles. These Guiding Principles are independently audited to ensure that all local Schedule V policies are aligned with the National Guiding Principles. We are also planning that the local Schedule V policies (following assurance that they are aligned with the National Guiding Principles) will be independently audited to measure the impact of the revised policies on the lives of people with disabilities living in designated centres.

### 5.3 National Frameworks & Policies

The [National Framework for Medicines Management for Disability Services](#), as well as the [National Policy for Food & Nutrition for Disability Services](#)

### 5.4 Risk Management

We have developed a number of documents to support disabled people to proactively take risks as you make decisions on how you wish to live your lives.

[Supporting Me to Live Safe and Well](#): helps staff or family to talk through with you, what dreams and goals you have, and support you to live those dreams and goals while being aware of the risks and how to reduce those risks.

[My Health Check](#): supports you before you go to your GP so that you and your key worker/family member/carer can discuss what is important to you or concerning you regarding your health.

### 5.5 Newsletters

This is where you will find our newsletters. Now that we have our team in place and the website up and running, we would be hoping to send out at least two Newsletters per year to keep you updated on work that we are doing.

### 5.6 Webinars

any webinars that we develop will be recorded and made available for viewing here.

### 5.7 Accessible Information

Any resources produced for the Accessible Information Expert Advisory Group will be available here.

## 6. Work Completed (from Action Plan 2023)

### **6.2 Framework for Medicines Management in Disability Services – Lead Marie Kehoe-O’Sullivan**

The Framework was launched on March 21, 2021, and work has been underway ever since to develop a national QQI Level V Curriculum to support the implementation of this Framework by offering a standardised curriculum to all staff who do not have a nursing degree (as it includes pharmacology in its education programme) that will be administering medicines to people with disabilities. This curriculum has now been developed by the Centres for Nurse and Midwifery (CNMEs) and has been accredited by QQI. This course is not mandatory but will be available free of charge to any staff currently employed by HSE, and Section 38 and 39 providers. It will be rolled out in Q1 of 2024. An information online webinar was held on October 10th and a recording of this webinar will be made available on our website under “Webinars”. An information leaflet will also be developed and sent to all Provider Organisations as well as the contact details of the 7 CNMEs across the country who will be delivering the course.

## 7. Updates on Work Underway (from Action Plan 2023)

### **7.1 Guiding Principles**

We are currently working on two Guiding Principles as follows:

- **No. 10 (Component Only) Garda Vetting of Staff – Lead Sandra Ferncombe**

The Standard Operating Procedure on the management of Garda Disclosures required within HSE Designated Residential Services for Older Persons and People with disabilities which was published in 2018 is currently being revised. We are in the process of reviewing all updated relevant legislation and policy documents, including Data Protection Act, Breach management policy, regarding this SOP. Through consultation with relevant agencies and regulatory bodies, we will establish a guiding principle to provide guidance and information for all staff involved in Garda Vetting for staff and volunteers working in Designated Residential services in both older persons and people with disabilities.

- **No. 14 The creation of, access to, retention of, maintenance of and destruction of records. - Lead Ronan Halpenny**

While the title of this project is complicated, this project can be referred to as “Records Management.” The aim of this project is to develop a set of guiding principles on Records Management for designated centres supporting disabled people in Ireland. A designated centre is a residential or respite service that is formally registered with HIQA under Health Act regulations in 2013 and is subject to regular inspections. This project commenced a few months ago and the Expert Advisory Group has been busy meeting monthly to work on the principles. We are finalising the topics that will be covered in the research part of the project. The research includes a national and international literature review and focus groups with disabled people, to establish best practice and gather information about what is important to disabled people in relation to their records.



## **7.2 Accessible Information – Lead Nicole Lam**

The Accessible Information Expert Advisory Group aims to create a suite of medical information for disabled people in a wide range of formats. This workstream came about on foot of a document entitled “GP communication with disabled people” we co-produced with the Irish Council for General Practitioners (ICGP) and the Inclusive Research Network (IRN). It was identified that after being diagnosed with a condition or illness, GPs do not have suitable information to give to disabled people in the form of Easy Read documents or links to videos with Irish Sign Language. The EAG has chosen constipation as the first topic, and we currently have a Plain English word document, an Easy Read document, and a screen reader friendly version available on our webpage shortly.

## **7.3 [HSE Health Passport](#) – Lead Sandra Ferncombe**

The Health Passport was launched in June 2019 and is intended to impact and benefit people with intellectual disabilities, their families and carers, GPs, health and social care professionals in hospitals and designated centres.

We are in the process of reviewing and updating the Health Passport, and particularly, the App, with a focus on further development through collaboration with relevant stakeholders.

Our aim is to identify the most effective ways to support and implement a national standardized HSE Health Passport for people with intellectual disabilities across the island of Ireland.

## **7.4 Promoting Healthy Relationships and Sexuality - Lead Ronan Halpenny**

The purpose of this project is to develop national principles for Promoting Healthy Relationships & Sexuality for disabled people in Ireland. We commenced this project in November 2023, and we are currently populating the Expert Advisory Group for the project. We plan to have significant representation and participation in the project from Disabled Person Organisations (DPOs) and disabled people from throughout Ireland. This is a very exciting project for us and ties in with many areas of the UNCRPD. This project will be aligned with work currently being undertaken by QPS-Community Operations on sexuality in Designated Centres.

## **7.5 Assisted Decision-Making (Capacity) Act Lead - Marie Kehoe-O'Sullivan**

The Assisted Decision-Making (Capacity) Act (ADMA) 2015 came into effect in its entirety on April 26, 2023. In preparation for commencement, several national and local groups were put in place to identify the impact that commencement would have on disabled people, their families, carers, and organisations that provide specialist disability services. Once such national group was the Disability Reference Group which was set up in May 2022 and is comprised of disabled people, DPOs, Provider Organisations and HSE.

This group has undertaken a survey, and numerous focus groups with key stakeholders to identify the issues that are of concern regarding the implications of the ADMA and plan how to develop supports to disabled people, families, carers, and Provider Organisations. This work is ongoing, and it is intended that an e-leaflet will be published by year end which will be able to signpost people to the information that is relevant to them. Work will continue on this group to ensure that all information is available in accessible formats for disabled people.

## 8. National Sharing Day 2024

Save the Date – National Sharing Day 2024 will take place in Dublin Castle on **Thursday, 26th September 2024**. We will be issuing a call for submissions in March 2024 and are currently planning this event.

Our broad theme is going to be “How the implementation of the Assisted Decision-Making Act has impacted on disabled people.”

## 9. Planning for 2024

If you have any ideas on issues that you would like us to focus on, resources or tools that you would find helpful, or if you are aware of best practice and resources that you are willing to share, please feel free to contact us at [disabilitiesqi@hse.ie](mailto:disabilitiesqi@hse.ie)

We appreciate your feedback regarding our work, or any topics covered in this newsletter. If you encounter any issues accessing the newsletter or require it in a different format, please do not hesitate to inform us. Furthermore, we encourage you to suggest specific areas that we should prioritise for the year 2024.

If you would like to receive updates from us, please share your contact information to be added to our DisQI Distribution List. This means that we can notify you of any new website content, calls for submissions, or upcoming events.

Till next time,  
Marie, Joanne, Nicole, Karen, Sandra and Ronan.

Would you please take a moment to complete our [short survey](#)?

Your feedback will help us improve our newsletters in the future.