Office of the National Quality Improvement Office
Disability Services
Community Operations
Health Service Executive
Upper Park Road
Killarney Co. Kerry V93CH69
Email: disabilitiesqi@hse.ie

Incidents where a resident goes missing

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Introduction:

These Guiding Principles are intended to support services when revising their 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 (Appendix III) along with the preferences and views elicited from disabled people living in residential care, staff and family members of people with disabilities. 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 and revision of 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

The local policy and procedure development or steering group should use this tool 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 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.

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"Incidents where a resident goes missing" Guiding Principles:

The National Guiding Principles Group, under the auspices of the National Quality Improvement Office, HSE Disability Operations, has identified seven guiding principles to assist organisations in developing and revising local policies and procedures for incidents where a resident goes missing. 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). Furthermore, there are ill-defined parameters of what is considered wandering or missing. There is a need for a shared understanding between people with disabilities, 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.

Guiding Principles:

1. **Choice** – In line with the Human Rights Approach and the Assisted Decision Making (Capacity) Act 2015, all individuals aged 16 years and over have the right to make their own choices in relation to all aspects of their life including the right to wander, be independent and take risks. Personal livelihood and freedom to leave and return home as they wish is a basic human right.

2. **Environment** – Environmental and sensory factors or needs: consider the mismatch between individual and environment as a reason why they want to be elsewhere, and if this is resulting in a need not being met, which can be supported. Personal preferences should be ascertained as part of the "discovery" process during the development of the individual's Personal Plan.

3. **Role in Community**– Social role and sense of community is important to individuals. Leaving home and participating in public engagements and everyday living greatly increases an individual's sense of value.

4. **Language –** Avoid use of clinical language (e.g. absconding) when describing a person who has left their home.

5. **Education for Service Users and Safeguarding**- Promote positive risk taking, undertake a collaborative risk assessment with the service user, then increase capability through education and support for individual e.g. understanding road safety, what to do if they are lost or afraid, emergency contact information.

6. **Education and Support for Staff -** As this is approach requires a change in thinking and practice, education and support for staff are critical, e.g. positive risk taking protocols, collaborative risk assessments, current photos of individuals, list of contacts the individuals are likely to be in contact with, promoting capability and noticing capacity changes, skills to improve confidence of individuals with a disability.

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7. **Education and Support for Families** – family or peers who might be worried or experiences in the past have made them anxious. Important to ensure they have knowledge of the ongoing supports given to individual, and that they have education to understand changing capacity and positive risk taking.

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APPENDIX I – Impact Assessment Tool

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 four 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, e.g.- 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.

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APPENDIX II – Audit Tool

Organisations/ Local Communication Policy Audit Tool: Incidents where a resident goes missing Policy

Guiding Principles to be included Incidents where a resident goes missing policy	Yes/ No	Action Required
Does the policy set out the rights of individuals to make their own choices to wander and be independent?		
Does the policy provide guidance on identifying reasons why an individual leaves their home e.g. where they are living and who they are living with?		
Does the policy promote the importance for the individual of having a social role and participation in their community?		
Does the policy refrain from using clinical language such as “absconding”?		
Does the policy set out how the person will be supported to make decisions around leaving their home?		
Does the policy provide guidance and education for service users on safeguarding and focussing on building capability with individuals to leave their home safely?		

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Does the policy address the culture change required and identify the training that will be provided to support staff?		
Does the policy address the culture change required and identify the emotional support that will be needed for family members and how this will be done?		
Have experts by experience or people with disabilities who use the service been involved in developing or reviewing the policy in a meaningful way?		

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Appendix III 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 GUIDING PRINCIPLES Group

Title of GUIDING PRINCIPLES: Visitors
DOMAIN 1: Scope and Purpose
1.1. The purpose of this GUIDING PRINCIPLES is: 1. To define best practice in relation to incidents where a resident goes missing. 2. To provide an opportunity to develop/ review the local "incidents where a resident goes missing" policy to ensure it is in line with best practice. 1.2. The scope of this GUIDING PRINCIPLES is: *1.2.1. Describe the population (staff, people who use services etc.) to whom the 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 GUIDING PRINCIPLES – who does this GUIDING PRINCIPLES not apply to* This 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.
1.3. OBJECTIVES *Report the overall objective(s) of the GUIDING PRINCIPLES:* • To provide Guiding Principles that can be used to support the development of "Incidents where a resident goes missing" PPPGs where they do not exist.

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

- To provide a benchmarking tool for services where "Incidents where a resident goes missing" PPPGs 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 "Incidents where a resident goes missing" Guiding Principles are:

- Improved social interaction for individuals living in their homes with their community
- Improved safeguards in place to promote positive risk taking, build capability for individuals to safely leave their home. Improved environment to host visitors in individual's homes
- Improved communication between individuals with disabilities, their families (where appropriate) and staff regarding leaving their home.

1.5. QUESTIONS

Standardised systematic search strategies facilitate and improve rigor in research. PICO (Population, Intervention, Comparison, Outcome) was previously used by our group however we found it limited the types of articles to very quantitative research. A group member informed us of an alternative search strategy for more qualitative and mixed methods research – SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type).

1. Are certain cohorts (dementia, alzheimers) at a higher risk of going missing in disability services?
S: Individuals with disability going missing
P: High risk group(s), Dementia, Alzheimer's, setting/location
D: questionnaire, survey, interview, focus group, case study, observational, comparative studies
E: experiences
R: qualitative or mixed methods

2. What plans are in place for when individuals are missing & found?
S: Individuals with disability going missing
P: missing and found, plans in services
D: questionnaire, survey, interview, focus group, case study, observational
E: experiences
R: qualitative or mixed methods

3. How do you define when someone goes missing?
S: Individuals with disability going missing
P: parameters/definition of missing, length of time, where, etc
D: questionnaire, survey, interview, focus group, case study, observational
E: experiences
R: qualitative or mixed methods

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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. Marie Kehoe-O'Sullivan – National Quality Improvement Office – HSE Disabilities - Operations
2. Nicole Lam – National Quality Improvement Office – HSE Disabilities – Operations
3. Barbara Murphy – My Life
4. Margaret Meegan – St. John of God
5. Rosemary Murphy – HSE
6. Amanda Callan – Camphill
6. Stephanie Kilrane – AVISTA
7. Mary B O'Connor – HSE
8. Teresa Ennis – HSE
9. Joanne Fitzpatrick - National Quality Improvement Office – HSE Disabilities - Operations
10. Gethin White 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.

Two services offered to conduct service user consultations as is the norm with guiding principles, however on foot of suggestions from the working group consultations with the family and staff also took place. The additional consultations are supplementary and are meant to add to the rigor of defining nuanced and subjective nature of being "missing" which is oftentimes predicated on family and staff view. The individual/service user's views and preference should still take precedence in shaping the consultation outcomes.

Below is a summary of the 2 service user consultations and the prompt questions that were formulated by the working group and literature review:

1. Why is it important for you to leave your home?
    - To go and het a beer or dinner and be on my own with nobody else
    - To do my shopping, get my money, to do my activities
    - To meet my girlfriend and visit my family
    - Leaving the house is important to access my community, meeting family and friends, shopping, appointments with dentist, beautician and hairdressers. It gives me time to spend time independently with friends we go out for lunch and on hotel breaks
2. What do you think is important when you leave home?

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- To have my own money
- Stay wih staff, cross the road safely with staff, stay on footpath
- Tell staff where I'm going, bring m phone so I can call if there is a problem/change to my plan
- Bring my bus pass and money and covid passport with me

3. How do you make sure you're safe?
   - I take my phone, my reflector jacket if dark
   - Stay with staff all the time, don't wander off, don't talk to people I don't know
   - Walk slowly, wear safe shoes, watch out for obstacles or damage to pavements when walking, wear a mask and bring hand sanitizer, keep belongings safe in my bag, phone staff if you feel unsafe or in danger, go to a safe place if you feel you at risk such as a shop/security guard
4. Do you know what your job or the staff's job is to keep you safe?
   - Staff could support me by accompanying me to the pub and then I could ring them and they could collect me. I don't talk to strangers or take anything from strangers. I don't go with strangers
   - Yes my job is to stay with staff, they will look after me
   - staff can help me understand how I can keep myself safe and feel confident that I can go out myself. I should not put myself in dangerous situations where I don't feel safe, I have to take responsibility and plan any time I leave home.
5. What advice would you give to someone leaving home by themselves?
   - Take your phone, go somewhere you know, ask for help from someone familiar
   - Bring your phone, cross the road safely, tell someone before you leave the house where you are going
   - Ask where they are going and when they plan to be back, ask them to bring their phone in case of emergency and phone charger, bring money but not too much cash, have card on you, know your bus routes.
6. What does the word "missing" mean to you?
   - Can't find someone
   - Can't find something, lost
   - someone doesn't return at planned time , without a reason and cant be reached.
7. Who would you like us to tell if you got lost or left home for a while?
   - Have a plan to ring my familiar places and check if I'm there. If you can't find me and I don't come then ring the garda
   - The guards and my family and staff
   - If I got lost I would like the staff in the house to know so they could come and find me. And also my family members.

Nicole Lam conducted the family and staff consultation. The family members (3) were contacted through 3 different services. Below were the prompts used and a summary of their transcripts/responses with some quotes:

'Family perspective on "missing person" and positive risk taking

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1. What does it mean to you, if the residential care where you loved one lives, called to tell you that your family member was "missing"? (For example, if they are in the neighbour's house but you didn't know – are they still missing?)
   - For family, being missing means the individual went out and did not follow whatever previously agreed protocol they had with their staff "if he's not back by midnight they get onto the guards". However, this family member felt anxious about this arrangement noting that it is quite late depending on when the person left home. They noted that one time this individual was lied to and brought to another county by strangers and had the police involved causing great distress. It increased their fears that their loved one was too vulnerable to be independent.
   -
2. In what ways do you rely on the residential service to keep your family member safe? What are your expectations of the residential service.
   - Family members reported very mixed feelings to the idea of increased independence for their loved one. One person in particular stated that the service greatly reduced the number of staff from 6 to just 1 who is supervising them and that because "he's been made independent", he is able to freely leave the home whenever and staff are not made aware. This family member was of the view that since the individual is "independent" the service has little to no say in keeping the individual safe. The family member did not trust the service to keep the individual safe as they allowed him to go to the pub all day and felt they should have made the individual go elsewhere

3. Are you aware of the changes in thinking that have occurred over the past number of years (as a result of the UNCRPD, Assisted Decision Making etc.) where services are moving away for an overly protective role to one that encourages people to be supported to take some risks (as we all do) but to do so in a manner where they are supported and enabled to do so? What are your thoughts on this?
   - When asked about the legal ramifications, one family member indicated that they were not in favour of increasing independence and positive risk taking. The family member felt it would mean increased danger and they were most concerned about their safety because of increased independence. "I know there's a risk with everything even for ourselves, in everything we do but we can say, well if I do that, that's dangerous but M doesn't see danger until something happens. And he never could, M you could say it to him but he could never see it, until something happens and then he gets himself all up into a heap you know?"

4. What are your main fears about safety and knowing the whereabouts of your family member? How can we balance those concerns with their right to be independent and move about freely both in and outside of the home in which they live (in the same way that you or I can)?
   - One person drinks when he goes into town on his own and has to cross multiple roads, which greatly distresses his family as he ended up lost at

the police station on 2 occasions. They felt that their family member had no capacity to learn to be safer, "he just won't he won't follow the rules".

The staff consultation was completed in one service with a mixture of 2 PICs, 1 senior management member. Below are the prompts:

Staff perspective

1. What does it mean to you that someone is missing?
    - This varied depending on the person and staff were aware the shift away from using language like absconsion etc. They noted that for some people they were at greater risk and more likely to be at risk if they were alone in a unfamiliar surrounding so "missing" depends on the danger the staff think the person might be in or if it is unusual/unlikely behaviour of an individual to be not at a certain place at a certain time with certain people. It showed that staff understood the complexities in defining missing and the difficulty of their job to note and awareness of individuals and their disabilities and associated behaviour.
    - One staff member experienced 2 instances of missing persons. One was at a shopping centre and after 15 minutes of searching for the person who was non-verbal with security and surrounding shops, they were unable to find them and that's when they are considered missing because the person did not return to the staff or service. Another case was when someone did not return home after 24 hours, they were older but staff gave them a bit more time before calling the gardai. The definition of missing changes depending on the person and context.

2. Are you aware of the changes in thinking as a result of the UNCRPD and Assisted Decision Making (Capacity) Act in moving away from being paternalistic to a social model? What does that mean to you?
    - Staff are aware of the changes, but feel the supports are not sufficient. They mentioned the lack of training and the culture is still very much medical, the institutional culture is difficult to change.
    - The staff feel it is difficult to balance being a service user's advocate and having to safeguard them
    - There is a missing persons profile, which is distributed to staff and they look in the area, but if it's in the city centre that is more difficult. The gardai is contacted.The profile contains a photograph, height, eye colour, hair colour, address, contact numbers of management team, clothes worn on the day; indicates areas they might go.
    - Everyone has a profile, but one staff member felt that someone like a wheelchair user shouldn't have one because if they went missing, the staff lost them. This reveals an attitude about missing as an action taken by the service user rather than a complex number of things. While staff noted the changes, one member still talked about those who "absconded regularly" should have an up to date profile and have that noted.

3. What are your fears about people going missing?

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- With all the aforementioned constraints one staff mentioned feeling like they are "set up to fail" by the institutions and HIQA and they fear that instead of learning from errors that the institutions will always be punitive. They mentioned feeling obviously very responsible for their service users' safety.

4. How do we balance that with their rights to be independent?
   - The management in particular feel that services and their role as set out by regulations are at odds with the social model and thus, puts them in a bind in trying to balance the person's rights.
   - Staff feel that people still did things for service users when they could do it for themselves and so in terms of autonomy, they felt it was hard because their peers had enabled the service users for such a long time. Moving individuals into the community is a step forward but then there are less staff available to them and it is very frustrating for staff who feel this was overlooked by the service. Staff said their main priority was letting people live and make mistakes as long as they learn from it and not deadly. Risk taking is encouraged by them, but staff think it depends on the confidence of each other to enable service users (not all staff are as confident to support service users). They said that it does not mean everything needs to be risk assessed, but that formalised processes are good indicators and give staff and service users a degree of confidence to keep pushing boundaries and testing capabilities.

5. Do you feel supported by your workplace? (governance, peers, environment)
   - The staff members did not feel very supported by the institutions but did feel peer support was good. One person did mention the high rate of staff turnover and cited burn out as a huge issue, making it even more difficult to have continuous training and a stable environment for service users.
   - On the day of an incident, it can be very distressing for staff as the definition is so nuanced and contextual but the staff might not have been there very long or experienced so they wouldn't have the depth or breadth of knowledge.
   - Another staff feel that this service in particular is still quite restrictive and institutional – compounded by the nature of the buildings and campus plus the nature of the individuals' disabilities. Some staff have been at the service for 40 years, no degrees but lots of experience and then some with formal training but no experience and it is difficult to teach good judgement.
   - From the management's perspective, they feel that their hands are tied that if there are no consequences to mistakes then their governance maybe questioned by family or public especially when they view the context as very individualised but they want to move toward risk sharing. Echoing what the staff said earlier, the management agreed that quality of staffing varied greatly between shifts and staffing. They do agree that a punitive reaction is not conducive to creating a risk tolerant culture or positive risk taking.

Office of the National Quality Improvement Office
Disability Services
Community Operations
Health Service Executive
Upper Park Road
Killarney Co. Kerry V93CH69
Email: disabilitiesqi@hse.ie

DOMAIN 3: RIGOUR OF DEVELOPMENT

3.1 SEARCH METHODS

Report details of the strategy used to search for evidence:

A literature search was 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:

17 articles were found by the HSE librarian through the SPIDER search, 13 were available for review. 2 articles were not relevant and another 2 were too clinical. In total, nine articles were included in this literature review. As discusses throughout the literature, there is a lack of understanding in missing persons research and none of the nine articles reviewed are specific to disability services or settings. However, it is the best available data we have on a cohort (people with dementia) who have been better studied than people with disabilities.

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 missing adults with disability. Large scale studies were not identified. It was difficult to analysis the validity of smaller scale studies or qualitative research as the parameters of validity is different for experiential studies for a target population, especially one that is under-researched. Most of the research examined older persons with dementia who went missing rather than disabled people specifically. However, it does not mean the features of why someone goes missing and how they are defined differs hugely considering the antecedents and predictors that are discussed in the demographics, it could be mapped onto the disabled population.

3.3.2 Are the results applicable to the population?

The demographics of people who went missing were as follows: people who live at home whether alone or with others (Furumiya & Hashimoto, 2015), people with Alzheimers and dementia (Kikuchi, Ijuin, Awata, & Suzuki, 2019; Neubauer, Miguel-Cruz, & Liu, 2021; Petonito, et al., 2013), usually a lapse in supervision

(Rowe, 2012), male, with decreased cognitive capacity, ongoing trauma including abuse, family conflict, unsatisfactory treatment by medical professionals, desire for adventure or fresh start, frustration, boredom (Taylor, Woolnough, & Dickens, 2018).

3.4 FORMULATION OF RECOMMENDATIONS

3.4.1 What are the recommendations?
The GUIDING PRINCIPLES are attached as a separate document.

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, including people with disabilities, families and staff.

The recommendations will be discussed and agreed with members of the National Guiding Principles subgroup.

NEXT STEPS:

A webinar will be held to launch these Guiding Principles – speakers will include people with disabilities, family members and staff. A follow up survey will be conducted one year from the launch to evaluate the impact and use of the Guiding Principle and identify if there are any revisions required.

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)

When someone goes missing
Authors discussed the availability of GPS or radio frquency devices worn by the person that can make their location identifiable by their family or institution (MacAndrew, Schnitker, Shepherd, & Beattie, 2018). Others talked about the use of social media as the most common and effective method to alert the public, with police resorting to Twitter and Facebook to get information, recruit more eyes on the ground, (Neubauer, Miguel-Cruz, & Liu, 2021) whilst Rowe (2012) highlighted the importance of preparing a list of contact numbers for individuals that can assist immediately with a search in the local area. Rowe (2012) also detailed the importance of having a current photo of the person, a form of ID on the person at all times, discourage them from driving in general, take 20 minutes to examine the place last seen, look in secluded areas and structures such as

garages. Preventative strategies include dementia education for staff and person, to understand the difference between wandering and missing, ongoing assessments of cognitive capacity and noticing changes in cognitive capacity. Wider education and awareness about what a missing person with dementia might look like and to de-stigmatise dementia was also valued highly. However, multiple authors discussed the "right to go missing" (Bonny, Almond, & Woolnough, 2016), and that policies must be examined to determine if they are safeguarding or subjecting people to increased surveillance and restriction on their mobility as it is important to preserve their personhood (Greene, Clarke, Pakes, & Holmes, 2019; Petonito, et al., 2013).

Research also examined the reasons why caregivers might not report the person missing to the police. Literature stresses the importance of rapid response and intensive searches as missing people with dementia may succumb to death or harm relatively quickly (Greene, Clarke, Pakes, & Holmes, 2019). The likelihood of positive outcomes decline as time elapses between the person going missing and family or caregivers calling law enforcement (Rowe, 2012). The caregivers are often afraid to call for various reasons including not wanting it to reflect badly on them, embarassment, guilt (MacAndrew, Schnitker, Shepherd, & Beattie, 2018). On the other hand the person could just be walking or exercising and there is fear that the person might be upset if the police is called. Managing this and conflict between the prevention of harm and protection of a person's right to autonomy is difficult (Greene, Clarke, Pakes, & Holmes, 2019). In an interview with 15 family caregivers, they considered the persons' vulnerability and assessed potential harm or risk and also the length of time passed from the last time they saw the person. 3 key factors prompted the caregiver to call the police: to protect the person from emotional and physical harm, expectation that the police will help with advice or alleviate sense of helplessness, expectation that the police would be successful as a last resort. However, there were inhibiting factors as to why caregivers did not contact the police: feelings of embarassment and guilt, fear or disapproval or judgement by the police, fear or negative reaction from person with dementia, and quite importantly – distrust of police and desire to protect the person who may be heighted or in distress, there was a lack of confidence in how police might interact without distressing person further, " if they see somebody acting strage they might automatically jump on them, handcuff and taser them or whatever else they might do", a quote from a caregiver (Greene, Clarke, Pakes, & Holmes, 2019). Other consequences for the care givers include ambigious loss and state of not knowing, family members can view police response as lacking in urgency, dismissive or insenstive (Taylor, Woolnough, & Dickens, 2018).

Consequences of going missing

While all authors appreciate the positive health benefits of wandering, they all note the negative outcomes that can often occur when it becomes unsafe and adverse outcomes are experienced (and becomes risky behaviour) (MacAndrew, Schnitker, Shepherd, & Beattie, 2018). Researchers noted the that people have gone missing and resulted in malnutrtion, increased fall risks, injury, exhaustion and even death. Furuyima and Hashimoto (2015) notes that the regional

charcteristics such as the environment is important to consider what potential risks are present, for example, Kochi prefecture has low population density rivers and extensive mountain ranges. They noted that falls were most frequently associated with the cause of death (drowning and trauma). Kikuchi, et al., (2019) highlighted that most common cause of death was hypothermia in their research which determined that 40% went missing in winter.
Greene, et al., (2019) also highlighted the potential knock on effect of missing incidents can trigger loss of independence for the person – it could trigger institutional placements or within their own homes they could be locked in and restricted or infantilised. Furthermore, the consequences of being missing for the person include fear, anxiety, endangerment, fear of confrontation with the police, family or friends (anti detection strategy may include sleeping rough). Positive consequences include sense of freedom, seeing relatives, spending time at home, relief from unit (Taylor, Woolnough, & Dickens, 2018).

Defining missing persons
There is no single unifying theory of missing people. Taylor, Woolonough, and Dickens (2018) note the lack of research on missing adults as most research concentrate on children. As a result, the concept of missing person is underdeveloped and contradictory, with considerable gaps in literature (particularly for Disabled people who are pathologised). Missing persons as a concept commenced in literature in the 60s and only drew an increased number in research in the past 5 years. Furthermore, older research discusses perspectives that rely on very clincial or medical models such as mental health settings and talk about “absconsion” as one of many conflict acts, others are aggression, rule-breaking and treatment non-compliance. These models explains, understands, prevents and reduces these “unwanted behaviours” by use of coercive and restrictive containment interventions (seclusion, medication, locked doors).
Typologies of missing persons vary from missing continuum, to usually 3 or 5 types including dysfunctional, escape or unintentional (Bonny, Almond, & Woolnough, 2016). Researchers also differentiate between missing and wandering, largely referring to missing when there is an element of potential harm or more negative consequences involved (Furumiya & Hashimoto, 2015; Greene, Clarke, Pakes, & Holmes, 2019). Some people might be lost but not consider themselves missing, and Greene et al., (2019) highlights that missingness is defined from the perspective of the reporting person rather than the “missing person” considering themselves missing.
Researcher mainly differentiate between wandering and missing person by the safety or the person however, safe limits is not easily defined (MacAndrew, Schnitker, Shepherd, & Beattie, 2018). Missing is largely characterised by unusual circumstances or contexts that suggest that they may be subject to risk of harm. Wandering is considered broadly to be aimless movement or repetitive pattern such as pacing, excessive walking. This becomes muddied when some authors expand the definition to those to leave a safe environment or become lost in the community (Furumiya & Hashimoto, 2015) while Rowe (2012) would suggest that the person usually stays in their residence. Furthermore, not only is wandering potentially beneficial as a type of exercise, wandering can also be a

Office of the National Quality Improvement Office
Disability Services
Community Operations
Health Service Executive
Upper Park Road
Killarney Co. Kerry V93CH69
Email: disabilitiesqi@hse.ie

source of sensory stimulation, a strategy to cope with loneliness or stress, or to meet a need as environmental factors play a role: proximity to others, sounds, light, crowding (Petonito, et al., 2013; Rowe, 2012).
3.6 EXTERNAL REVIEW *Report the methodology used to conduct the external review: (discussion points only)* This GUIDING PRINCIPLES will be reviewed by the HSE Guiding Principles Working Group (chaired by Marie Kehoe- O'Sullivan)
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: None at this time

Signed: Marie Kehoe-O'Sullivan

Date: 20/01/23

Lead for Working Group