



Resident's personal property, personal finances, and possessions



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1. Introduction to Guiding Principles:

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.

2. Context:

The National Guiding Principles Group, under the auspices of the National Quality Improvement Office, HSE Disability Operations, has identified eight guiding principles to assist organisations in developing and revising local policies and procedures for Resident's personal property, personal finances, and possessions. 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, in particular 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 this document, 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 very 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.

3. “Resident’s personal property, personal finances, and possessions”

Guiding Principles:

1. **Choice** – In line with the Human Rights Approach and the Assisted Decision Making (Capacity) Act 2015, all individuals **aged 18 years**** and over have a right to own their own property and possessions, and have control over their money. It is critical that the individual’s will and preferences are taken into account.
2. **Capacity** – In accordance with the Assisted Decision Making (Capacity) Act 2015, all individuals **aged 16 years** and over are presumed to have capacity to make a decision, unless and until the contrary is shown. The first step must always be to support people to make their own decision independently. This may involve drawing on informal supports (circle of support, peers, staff, multi-disciplinary team and people who know the person best) in order to understand the person’s will and preferences. The person may have particular communication needs and these should be facilitated. Where such supports are insufficient, the person may benefit from the formal supervised supports available under the Assisted Decision-Making (Capacity) Act 2015. The Decision Support Service will be able to provide further information about accessing an appropriate arrangement to support a person’s decision-making about money, property and financial affairs.
3. **Person-Centeredness**– Exploring with the individual what they wish to possess or spend their money on, for example, going out for coffee, clothes, holidays, ways of expressing themselves – tattoos, piercings etc. Control of finance and belongings is intrinsically tied to human value, the concept of self, autonomy and quality of life.
4. **Capacity Building** – Individuals may be overwhelmed by sudden and increased access to their finances or property and will require support and education on rights and responsibilities associated with having money or owning/renting property. A total communication approach – where appropriate resources are used depending on the individual (ranging from Irish Sign Language, picture stories, Easy Read, etc.), to best communicate concepts to the individual. In line with HIQA Reg 9.2(a) “participate & **consent, with supports** / to decisions about their care & support”.
5. **Education and Support for Individual on Money Management** – Promote positive risk taking, undertake a collaborative risk assessment with the service user, understanding their legal right to make “risky” or “unwise” decisions with their money or belongings and supporting them through those choices.
 - a. Education on the concepts such as budgeting, saving, cash, tapping/online or virtual purchases, proportional cost of items, the consequences of decisions, ATM machines, online and phone banking – working with local bank staff and introduce them to staff.
 - b. Regarding more impactful decisions, services might deem it appropriate to involve more supports

6. **Safeguarding**- to support service users to be able to manage their money in safe way. Where safeguarding concerns arise work collaboratively with the service user to reduce or eliminate the risks.
7. **Education and Support for Staff** - As this approach requires a change in thinking and practice, education and support for staff is critical, e.g. positive risk taking protocols, collaborative risk assessments, personal expenditure plans, promoting capacity and noticing capacity changes, skills to improve confidence of individuals with a disability.
8. **Education and Support for Families** – support for family or peers who may be uncomfortable with this change. Important to ensure they have knowledge of the ongoing supports given to individual to help them manage their personal property, finance and belongings. This is vital to ensure that good working relationships between families and the service provider are maintained and to ensure the supported individual maintains positive relations with family and positive view of service provider.

**Children cannot take legal title to real property (land) until they are 18 years old. The property is held in trust from them until them (for example, if they were left property in a will). They can hold a bank account but banks seem to have different age limits for when children can hold a bank account for themselves

4. References

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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.

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			
Co-decision maker			
Clinical staff			
Frontline staff			
Local Managers/ PIC's			
Senior Managers/ Regional Managers			
CHO Disability Managers			
National Disability Team			
HIQA			
Voluntary Agencies			
Insurance carrier			
Other agencies / service providers			

Actions required relating to stakeholders:

- 1.
- 2.
- 3.

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

Operations Management: delivering services to service users:

- Is there a current practice/ procedure that needs to change?
- Do we have a governance structure to support the implementation of the policy?
- Do we need to develop/ update assessment process associated with this policy?
- Is there a new/ updated referral pathway required?
- Do all staff know how to access information/ training/ support to implement the policy?
- Do we have a review process in place for the policy?
- Do we need resources (eg- new equipment/ access to computers, access to documents/ etc)

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

- What will the impact be on the compliance levels?
- Does it have an impact on GDPR compliance?
- Does it have an impact on Assisted Decision Making (Capacity) Act 2015
- Does it support compliance with the Health Act?
- Does it support the introduction of New Directions for Day Services?
- Are there other regulatory implications? (eg- Health and Safety Legislation, Safeguarding Policy requirements,
- Are there regulatory risks associated with implementing the policy?

Actions required relating to internal processes:

- 1.
- 2.
- 3.

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

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

What data is available and what data is required?

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

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

Training: Are education and training interventions required?

Do we have a training provider who will provide training?

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

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

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

Is it going to be 'mandatory' training?

Can we do some online elements?

Is the training based on the Policy?

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

Are there role specific HR implications?

Do job descriptions need to be updated?

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

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

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

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

Actions required relating to Learning and Growth:

1.

2.

3.

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

Have we considered the financial implications associated with the policy?

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

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

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

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

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

Are there risks associated with finances?

Actions required relating to Finances:

1.

2.

3.

References:

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APPENDIX II – Audit Tool

Organisations/ Local Communication Policy Audit Tool: “Resident’s Personal Property, Personal Finances and Possessions Policy”

Guiding Principles to be included Resident’s Personal Property, Personal Finances and Possessions policy	Yes/ No	Action Required
Does the policy set out the right of individuals to own their own property and possessions and have control over their money?		
Does the policy ensure that a person’s capacity is presumed until the contrary is shown and that informal supports and appropriate communication tools are used to ascertain the individual’s will and preferences about their personal property, possessions and their money?		
Does the policy give guidance to staff to utilise the Decision Support Service (DSS) if, following the use of available informal supports, the person has not been able to make a decision about personal property, possessions and their money?		
Does the policy promote the importance of ascertaining what the individual would like to possess or how they would like to spend their money?		
Does the policy set out how the person will be supported and enabled to make decisions about their possessions, property and managing their money and focussing on building capability with individuals to make these decisions?		

Does the policy identify the education and supports that individuals may need on money management – budgeting, using online or phone banking etc.?		
Does the policy provide guidance on safeguarding, the individual’s right to make “risky” or “unwise” decisions about their possessions, property or money and how to support them with these choices?		
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?		

Appendix III AGREE Tool

Preparation for validation of research - adapted from Agree Checklist¹

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

<p>Title of GUIDING PRINCIPLES: Residents personal property, personal finances and possessions</p>
<p>DOMAIN 1: Scope and Purpose</p>
<p>1.1. <u>The purpose of this GUIDING PRINCIPLES is:</u></p> <p>1. To define best practice in relation to Resident’s personal property, personal finances, and possessions.</p> <p>2. To provide an opportunity to develop/ review the local “Resident’s personal property, personal finances, and possessions” policy to ensure it is in line with best practice.</p> <p>1.2. <u>The scope of this GUIDING PRINCIPLES is:</u></p> <p>1.2.1. <i>Describe the population (staff, people who use services etc.) to whom the GUIDING PRINCIPLES will apply</i></p> <p>This policy applies to all:</p> <ul style="list-style-type: none"> • Staff • Volunteers • Students on placement <p>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.).</p> <p>1.2.2. <i>Outside the scope of the GUIDING PRINCIPLES – who does this GUIDING PRINCIPLES not apply to</i></p> <p>This guiding principles does not apply to services:</p> <ul style="list-style-type: none"> • 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.
<p>1.3. OBJECTIVES</p> <p><i>Report the overall objective(s) of the GUIDING PRINCIPLES:</i></p> <ul style="list-style-type: none"> • To provide Guiding Principles that can be used to support the development of “Resident’s personal property, personal finances, and possessions” PPPGs where they do not exist.

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

- To provide a benchmarking tool for services where “Resident’s personal property, personal finances, and possessions” 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 “Resident’s personal property, personal finances, and possessions” Guiding Principles are:

- Ensure the rights of individuals to make choices regarding their own possessions, property and managing their money.
- Improved safeguards in place to promote positive risk taking, build capability for individuals to manage their own money, possessions and property.
- Improved communication between individuals with disabilities, their families (where appropriate), and staff regarding the individual’s right to make their own choices regarding money, property and their belongings.

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. How is financial control a human right?

S: People with disabilities

P: financial control, human rights, restrictive practices, human rights based approach

D: questionnaire, survey, interview, focus group, case study, observational

E: experiences, frameworks

R: qualitative or mixed methods

2. What are some barriers to disabled people gaining financial control and autonomy?

S: people with disabilities

P: financial control, barriers, culture, family, banks, laws, services

D: questionnaire, survey, interview, focus group, case study, observational

E: experiences

R: qualitative or mixed methods

3. Are resources on financial autonomy for disabled people available to the general public and financial institutions?

S: public, financial institutions, banks

P: understanding of financial control, autonomy for disabled people, human rights, public views, education

D: questionnaire, survey, interview, focus group, case study, observational

E: experiences, resources, educational tools

R: qualitative or mixed methods

4. How can services support further financial autonomy for people with disabilities?
 S: People with disabilities, services, staff
 P: supporting financial control, autonomy, human rights, communication tools, supports, training
 D: questionnaire, survey, interview, focus group, case study, observational
 E: experiences, tools
 R: qualitative or mixed methods

5. How do countries comply with the UNCRPD regarding financial control?
 S: people with disabilities/countries
 P: laws, compliance with UNCRPD, financial control, legal rights,
 D: questionnaire, survey, interview, focus group, case study, observational, comparative study
 E: experiences, tools, laws
 R: qualitative or mixed methods

6. How is personal property and ownership respected under a human rights based approach?
 S: people with disabilities
 P: personal property, possessions, ownership, HRBA, communal items
 D : questionnaire, survey, interview, focus group, case study, observational
 E: experiences
 R: qualitative or mixed methods

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. Nicole Lam – National Quality Improvement Office – HSE Disabilities – Operations (Chair)
2. Marie Kehoe-O’Sullivan – National Quality Improvement Office – HSE Disabilities - Operations
3. Lisa Lavelle – AVISTA
4. Ned Rispin – Clann Mor
5. Sinead Foskin – Camphill
6. AnnMarie Nolan – HSE CNS Behaviour Support
7. Bridget McDaid – HSE Safeguarding Officer
8. Geraldyn Jackman – Cheshire
9. Mary B O’Connor – HSE

10. Selina Doyle – Federation of Voluntary Provider Organisations (Director of Wellness, Culture & Integration St Patricks Centre)
11. Lila Carey - Federation of Voluntary Provider Organisations (Human Rights Officer, Avista)
12. Gethin White - HSE Librarian supported literature search

External Consultants:

1. Tim Hanly – HSE National Safeguarding Lead
2. James O’Gorman – HSE Finance Manager
3. Caoimhe Gleeson – HSE Human Rights and Equality Office
4. Bernice Evoy – Head of Legal & Regulation – Banking & Payments Federation of Ireland
5. Aine Flynn – Decision Support Service
6. Carol Grogan – HIQA Chief Inspector
7. Aonghus Hourihane – HIQA Regional Manager
8. Ciara McShane – HIQA National Operations Manager

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.

The guiding principles were developed to take account of the service users views and the information in the literature. Two service user consultations took place in 2 separate services. A set of prompt questions were given to the services to ask the service users.

1. What do you own that is important to you?
2. How do you keep your own things safe?
3. Does anyone take your things?
4. What do you do if your things get damaged or broken by someone else
5. Do you have money?
6. Do you know where your money is?
7. Can you get your money when you want to use it?
8. Do you know if other people can get your money or spend t?
9. Is there anything else that is important to you and how do you keep it safe?

Service 1 – 20th July 2021 via Zoom with 5 service users

Service users outlined the importance of their own bedroom, phone, television, furniture, tablet, money in their credit union and bank and having control over it. They did not like to tell people where their belongings were or let them interfere

with them. Another person kept their belongings in a safe. No one reported belongings being taken by someone else and they all knew to either report to staff or sit down and have a chat with the person if someone broke or damaged their belongings. They all knew where their money was and most had no difficulty withdrawing or managing their money. In response to “do you know if other people can get your money or spend it” they all said no, and some added:

- *No, I have to sign for it. There is no chance for anyone to spend it.*
- *No. it is all locked away. I have an accounts book and it all tracked. Got the exact amount written down.*
- *I would know by the bank statements, I would know if I had overdrawn. If my bank card was missing it. And by staff checking my accounts book.*

This shows their awareness of checking and management of finances. In relation of other things that were important to them, service users mentioned the following:

- *Passport, stored in a locked press.*
- *Medical card, in my wallet.*
- *ID card, I hold on to it myself.*
- *Keep social media safe,, don't share passwords.*

3 people have social media.

The staff member used this opportunity to reiterate the importance on not putting any personal details such as your phone number or address on social media.

Service 2 – Zoom conversation with 3 residents

Below is an edited transcript of the conversation

What do you own that is important to you?

Echo ,

and I have my alexa,

my tv.

I have Bruno(he is pet Guinea pig ,loved by all !)

Skybox

And your card(Bank Card) is important too.

Absolutely your Bank Card is important and where is that kept is that important to you ?

In our room,in our money box.

And how do you keep it safe ? *We always lock our boxes.*

And who holds the key? *We do ,we are in charge of the key.*

How do you keep all the other things safe that you own ? *We keep them in our rooms,you see no one would come into our rooms without our permission .If*

staff wanted to go into our rooms they would have to ask, they would have to knock.

Is that a rule here ,for staff and other people that live here that they have to knock ?*Yes.*

Fantastic, and does everyone stick to that rule ?*Yes,cos if I was not in my room staff would come to me and ask me if it was ok if they went into my room.*

We talked about how you keep your things safe ,what would happen if someone was to take away your things ?*That's illegal, Is it ?I suppose seating someone else property is illegal.*

What would you do if that was to happen here? *Well it did happen here,not to our property but somebody took money out of our accounts .*

And how did that make you feel ?*Angry and annoyed Upset and shocked.*

Same with me.

We weren't expecting that that person would do that ,not to us.

And if that was to happen now ,what do you think you would do ?

Id ring the guards, well I would anyway.

I would tell the staff.

Hopefully it wont happen again.

What have done since then that makes it a little bit safer to keep an eye on our money ? *We got online Banking, nobody other than PIC know the PIN,none of the other staff know it.*

And do you think online banking makes it easier to keep an eye on your money?

Yes cos we have the banking app on our phones.

When we spoke about this last week you told me it was a little bit hard to set that up though ?*yes it was.*

Oh Jesus Christ it was.

I found it really really hard.

I was on the phone for ages,it was all confusing.

If you ask for a small bit of help, they(Bank staff) lose the head with you and they won't continue the call.

If they think that someone is helping you ,they stop the call.

And do you think that's fair ?*No it not fair cos some people need support when they are doing that kinda of stuff ,I think.*

I thought that was a very interesting point when we discussed it last week, its something that helps you keep your money safe yet it was very hard to set up.*Yes we got there in the end*

If somebody was to damage or break your things what would you do ?

I would talk to the PIC or if she was on holiday I would talk to the Service Manager.

Some of these questions probably don't apply to you but they may be important for other people, such as do you have money?

Like xx needs helps with her money.

Yes ,she still keeps her money box in her room and that's important.

XXX is a young lady who likes to have money in her purse all the time.

When she moved there was a different set of rule in the new house?

Yes she wasn't allowed to have her money box in her room.

You know the money you own can you get it whenever you want?

Yes

Yeah.

And you spend it on whatever you want ?

Yes Id say whatever we want ,within reason I guess.

Who helps you keep it within reason?

Well I wouldn't want to wake up in the morning and say to staff that I'm booking a Caribbean cruise.

But if you did want to book a cruise what would you do ?

Save up,I believe they are very expensive.

We are going away in August..

When it comes to holiday do you have to save up for them ?

Yes,were going to X in November.

And to X in December.

Staff help us to budget for the holidays.

Do you get a say in how other money is spent in the house for example?

Yes we do we have residents meetings and talk about it.

Do you have it written down anywhere so staff know how you like to spend your money or what kind of help you need?

PIC goes through it the new staff first and then we let know too.

We use a calculator to do the receipts with staff,

We sign our own receipts .

I tell them when they come in.

Would you be interesting in learning more about managing your money ?

They do QQI course in it ,I would like to do that.

Is there anything else about your money and the thing that you own that are important.

If people ask you for money just say no. Tell them no that's my money for my things and they should use there own.

You all save up as well don't you ?

Yes I have a credit union account,I save money up in the credit union.

Is there anything that you would like to tell me ?

No,

I cant think of anything else.

What was like to be involved in this?

*That was great
Really enjoyed that.*

The core themes from the Service User Engagements can be summarised as such:

1. Control of belongings/finances and knowing the location of their belongings/finances
2. Social media is a form of “personal property”
3. Trusting relationship with staff
4. Understanding their legal rights to privacy and control over belongings/finances
5. Challenges navigating banking (online and phone)

After being presented with the results of the service user engagement, the members of the group decided a consultation with staff and family would be invaluable for the development of this guiding principle. However, it must be reiterated that the service user engagement is still central to this process and the staff and family consultations are supplementary. Nicole Lam conducted both staff and family consultations.

Staff engagement – focus group comprised of 10 members of one service

Core issues:

1. Support and advocacy Bureaucracy – receipts, forms, and HIQA. Staff detailed how challenging it was to deal with all the paperwork in order to provide sufficient evidence to HIQA and to be legally compliant. They felt it was a somewhat hindrance to their work and normalising the living of individuals. However, they did voice their understanding as to why these safeguards were necessary and accepted the concessions.
2. Challenges in normalising social events – having to sign receipts or service users wanting to pay for drinks/meals but it being a complicated situation made it difficult to have “normal” and casual social outings.
3. Challenges with family members – some staff reported that family members wanted to retain control and would be overbearing with choices of the individual, some families were not accustomed to and were uncomfortable with individuals wanting to make “unwise” or what they viewed as extravagant decisions like throwing a large party.
4. Support and advocacy – staff felt they were relatively supported by their service but that it was difficult to balance what they knew is best and what they were asked to do under the law versus the reality of dealing with the

banks, family and HIQA. However, they did manage to navigate those challenges and showed their understanding of the system as they recalled a time when they sought external advocate supports.

Family engagement – via phone call with 2 different family members of one service

Core themes:

1. Trust in service relationship: the families feel very fortunate to have the support of services and see the growth of their family member since entering the service, they show a lot of trust in the service in relation to handling of finances and possessions.
2. Contradictory views: growth and independence versus paternalistic attitudes. While family members talk about the growth of the individual and how they have increased their independence, they also state they do not think they are capable of controlling their finances;

“she doesn’t have a much of an interest in decision making to tell you the truth,...– she doesn’t know anything like the value of money... eh not really because I handle her finances, she wouldn’t a hope in heal with dealing with a financial institution now – so if you have your full faculties its very difficult to deal with them”

3. Financial control and oversight. Family members still retain a lot of oversight into the finances of the individual

4. Lack of understanding in decision making supports/legal rights

This view was repeated throughout when asked if they were aware of the legal rights of the individual under ADM and UNCRPD:

“no I’m not, but her faculties and facilities to deal with this are quite limited ya know? You can have a million rights but if you’re not able to, like you need the support of the guardian or a carer to do that on your behalf – no matter how much rights you have.”

5. Banks – mixed negative views, family members feel that the technological advances have made the challenges even greater for individuals and that it is really difficult for them to learn, staff turnaround and closing down of local branches (lack of in person support) is making is increasingly difficult for individuals to control their finances. The family members and individuals will get used to a helpful staff member but the changes will make it difficult for them to get familiar with a new person.

<p>DOMAIN 3: RIGOUR OF DEVELOPMENT</p>
<p>3.1 SEARCH METHODS <i>Report details of the strategy used to search for evidence:</i></p> <p>A review of Gray Literature was conducted, including Visitors policies in existence in Disability Services in Ireland was undertaken.</p> <p>A literature search was conducted by the HSE librarian including a full search of CINAHL, MEDLINE, SOCINDEX and EBSCO DISCOVERY.</p>
<p>3.2 EVIDENCE SELECTION CRITERIA <i>Report the criteria used to select (i.e., include and exclude) the evidence. Provide rationale, where appropriate:</i></p> <p>34 articles were identified in the search conducted by the librarian, 13 were omitted based on unavailability of text or relevance. For example, some articles were found on employment and health outcomes as a result of having the keyword “finance” in the search.</p>
<p>3.3 STRENGTHS & LIMITATIONS OF THE EVIDENCE <i>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</i> <i>Key questions to answer:</i></p> <p>3.3.1 Are the results valid? The literature review did not identify any systematic reviews or meta analysis in relation to with adults with disability and financial autonomy. Large scale studies were not identified. It was difficult to analysis the validity of smaller scale studies. However, the validity of the search is not measured by finding large scale quantitative research studies as our experience in the area of disabilities research has shown that it is an under-researched area and that the majority of our focus is on experiences. Hence, qualitative research is more applicable to the validity of our conceptual understanding of the subject matter at hand.</p> <p>3.3.2 Are the results applicable to the population group? The evidence used to develop this Guiding Principles relates specifically to adults with disability</p>
<p>3.4 FORMULATION OF RECOMMENDATIONS</p> <p>3.4.1 What are the recommendations? The GUIDING PRINCIPLES are attached as a separate document.</p>

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. External subject experts were also utilised as consultants for the Guiding Principles.

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)

Conceptual analysis

The authors note the importance of understanding the balance between relational and liberal autonomy when discussing self-determination versus the physician's for disabled people (Brannmark, 2017). Autonomy is socially embedded and shaped by relations to others, it is an ongoing process of interactions – not a choice made in a silo with disregard for all others (Hilberink & Cardol, 2019). The liberal understanding of autonomy as purely independence can sometimes obscure this aspect of dependence and need for support – that is not necessarily at odds with relational autonomy. Brannmark notes that is particularly important when discussing the choice made by disabled people in situations of highly asymmetrical power (with a doctor who has a higher status and are supposed to be trusted to have more knowledge). Autonomy supports are not homogenous, just as disabled people and their needs vary vastly, this makes it difficult to meet those needs and to study the efficacy of those supports (Jackson, 2018; Frielink, Schuengel, Embregts, 2017). Moreover, Jackson (2018) discusses the important of having more than one built environment as the current one caters mainly to non-disabled people. To ensure our built environment is accessible to everyone, we must engage with people with disabilities directly – which is historically a very uncommon activity.

Historical models of disabilities

Many of the articles highlighted the fact that the societal view of what constitutes a disability and how disabled people were treated has changed dramatically over

the past 200 years and continues to change (Jackson, 2018). The charity model also known as the moral or religious model can be characterised as one that cares and protects disabled people as “vulnerable others” by controlling, segregating this population in institutions for “defective” people. The medical model is a normative model that classifies deviance or deficiency compared to the societal norm. In this model, a person is impaired, which means they can be diagnosed and cured or rehabilitated through interventions made by all-knowing professionals. The social model examines the imbalances of power, knowledge and rights of the status quo, and understands that disabilities are a social construct arising from barriers within an oppressive society rather than the fault of a disabled person. Thus, the responsibility is with our society to dismantle barriers that construct disabilities. More recently we have relational models of disabilities which highlights the mismatch between the person and the environment, situations, and relations. The UNCRPD exemplifies the human rights model, which is established in response to the power imbalances that continue to constrain marginalised groups to fully participate in society at the highest legal level. Devi (2013), describes the importance of article 12 in the UNCRPD for rejecting the patronising assumption that people with ID are incapable of making decisions about their lives.

Choice and autonomy

Carey’s (2021) article demonstrates the importance of choice for disabled people who have been severely limited in choices historically whether they were devalued or unacknowledged. There needs to be a shift away from “best interests” approach to a rights based one that is supported by the Assisted Decision Making (Capacity) Act 2015 and the UNCRPD, but this seismic shift in theory and legal approach is not yet fully realised in the practical or cultural sense. Carey concludes that service providers must understand that rights are inalienable and should be embedded within the cultures of the institutions. Due to the historical exclusion of disabled people from exercising choice, it is increasingly an issue for a new ageing cohort of people with ID (a modern phenomenon). Choice can be described in this sense as an opportunity to make a selection free from coercion. Learning and acquiring new skills for self-determination is possible later in life and will likely improve quality of life – it is also a human rights issue. O’Donovan, McCallion, McCausland and McCarron (2020) found that choice was more available to older people living independently or with family than in residential or community group homes – this is consistent with findings from IDS TILDA. This was true for key decisions like where people lived, who they lived with, where they kept their money. They note that supports needed included: advocacy, access to personalised budgets, support living environments, opportunities for enhanced engagements and activities of daily living. Farr, Cash, and Harper (2019) is a report that examines 3 features of banking that could be improved to better serve people with mental health disabilities. They note that the needs of individuals are not static so supportive banking features should be flexible enough to facilitate people’s needs. Another aspect of financial independence discussed was that of inheritance and poverty (Groce, London and Stein, 2014). Disabled people are among the poorest population in the world, lacking social supports, education, and legal right to appeal to injustices at every level. The structural violence of trans-generational wealth or poverty affects people over the course of their lifetimes. The inequity of

distribution of inheritance often reflects the pre-existing social inequities. Disabled people are often denied financial or property control as a form of economic independence. Exclusions can often differ depending on societal assumptions about the specific disability. According to O'Donovan et al., (2020) the biggest indicator for choice availability in Ireland was type of residence, with type of disability not being very relevant. Many are assumed unable to manage finances adequately and will need to depend on others.

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:
Lead for Working Group

Date: 21/01/2021

