Report of the Consultation Subgroup of the HSE Review Development Group considering feedback received from Stakeholder Groupings via Focus Group engagement .

HSE Safeguarding Vulnerable Persons at Risk of Abuse – Report of the Consultation Focus Groups

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Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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1.0 Introduction

The HSE is committed to safeguarding people who may be vulnerable from abuse. The HSE launched its safeguarding policy - "***Safeguarding Vulnerable Persons at Risk of Abuse - National Policy and Procedures***[i]***"*** in December, 2014 which is now subject to a review process. The policy has been operational in all CHO areas since 2015 and key operational strengths, as well as challenges, have emerged. The terms of reference for this review covers all aspects of the current policy and its operation, including scope, prevention, definitions and procedural systems.

The Review Development Group was established in January 2017 and comprises of membership across the various sectors involved in adult safeguarding. A key component of the work of the Review Development Group is to consult widely both on the current safeguarding system, in addition to giving due consideration to future models of service delivery. This report analyses the information gathered from phase 1 of the review, with emphasis on the as-is situation, in relation to adult safeguarding in an Irish context.

This review has been undertaken on a phased basis. The first phase concentrated on how the policy is experienced and working in practice for current users of the policy. The second phase had a two pronged approach; one focused on written submissions from interested parties and stake holders and the other incorporated face to face consultation via focus groups meetings for more specific feedback and consultation.

2.0 Methodology

Formal requests were issued to the following organisations to take part in the focus groups (Table 1).

The format devised for the focus group focused on

1. Setting the scene: Presentation from the NSO on Review Process to Date (Appendix 1)
2. Engage discussion on any additional messages that were not covered in the

presentation that attendees felt were important

3. Key topic areas were then discussed in rotation (Workshop Questions outlined in appendix 2)
    a. Who do we want to protect and from what?
    b. What are the considerations regarding the implementation or not of a reporting threshold?
    c. What is the preferred model of safeguarding service delivery (HSE)
    d. What is the opinion of the group of the current oversight function provided by the HSE Safeguarding and Protection Teams.
4. This Report features the direct feedback from service users, older persons and persons with a Disability. In undertaking direct consultation with potential persons who may come into contact with the policy the service user engagement set out to consider
    a. Views on term “vulnerable”
    b. Views on current way of responding to abuse and neglect
    c. What changes or improvements would be in a policy
    d. Awareness of a safeguarding policy and what should be included

The section on the views of the Service Users and the facilitating organisations are presented in this document as submitted without any further analysis. This was to limit any potential reporting bias.

3.0 Results:

3.1 Profile of Focus Group Attendees

A total of 33 focus groups were undertaken within this process- a full listing is provided in table 1. There were 26 directly facilitated by the National Safeguarding Office with key stakeholders including HSE divisions, funded agencies, professional bodies and Trade Unions. The content of these focus groups will be documented within section 3.

In addition a further 7 focus groups comprising of Service Users/relatives/ advocates were consulted as part of this process. Approximately 33% of the focus group participants were comprised of service users. This engagement was primarily conducted independent of the HSE by the key advocacy and representative

agencies of Inclusion Ireland, Deaf Hear, Sage and the Alzheimer's Society of Ireland. The feedback from these consultations is documented in section 4.

Table 1 Summary of Focus Group Engagement

CHO 4 – Kerry & Cork	HSE	21/09/2017
South - Cork	Funded Agencies	21/09/2017
CHO 6	HSE	26/09/2017
CHO 7	HSE	27/09/2017
INMO, PNA and SIPTU	Nursing Unions	02/10/2017
IMPACT	Impact Union	02/10/2017
Dublin Area	Funded Agencies	03/10/2017
Dublin Areas	Funded Agencies	03/10/2017
CHO 8	HSE	17/10/2017
Midlands	Funded Agencies	17/10/2017
General	Medical Representative Bodies	01/11/2017
National Dublin AM session	Relatives and families	02/11/2017
National Dublin PM session	Relatives and families	02/11/2017
CHO5	HSE	06/11/2017
CHO 1	HSE	08/11/2017
West – Sligo	Funded Agencies	09/11/2017
CHO2	HSE	13/11/2017
CHO 3	HSE	15/11/2017
CHO9	HSE	23/11/2017
National	IASW & IASCW	27/11/2017
National	Acute Sector with Hospital Groupings	07/12/2017

National	Disability Federation of Ireland	29/11/2017
National	Disability Federation of Ireland	11/12/2017
CHO 2 and 3	HSE	04/12/2017
National	Deaf Hear and Deaf Village	27/03/2018
National	Sage	Q3 2017
National	Sage	Q3 2017
National	Sage	Q3 2017
National	Alzheimer Society of Ireland	Q3 2017
National	Alzheimer Society of Ireland	Q3 2017
National	Inclusion Ireland	01/11/2017
National	Inclusion Ireland	14/11/2017

3.1 Opening Remarks

Following the presentation attendees were invited to provide any additional comments that they had regarding the “as is” situation the following provides a summary of responses.

1. There needs to be greater streamlining of processes around documentation including greater clarity and alignment with NIMS and HIQA
2. The policy needs to be cross divisional so that current challenges with individuals with dual diagnosis can be resolved
3. The training requirement will be considerable for the expansion of the policy on a cross divisional basis with particular reference to the needs of the acute sector. Additionally there is a requirement for the training to be role specific.
4. It is important to consider what is working for example the D.O. structure and build on this in the revised policy
5. Greater clarity is required around consent and capacity.
6. There is still confusion regarding the existence of the elder abuse service particularly as there is documentation still on the internet
7. There is confusion regarding safeguarding and Trust in Care processes
8. There needs to be clarity around on roles and responsibilities, particularly the “lead role”.

9. Greater clarity is also required around roles and responsibilities in relation to self neglect.
10. There is a requirement for a health wide policy not just HSE
11. There is a requirement for a practice handbook
12. There needs to be learning from the Tusla experience
13. Resourcing of care plans is a key issue
14. Requirement for legislation is key to facilitate interagency working at a minimum and to facilitate professionals to intervene where there is identified risk
15. Challenges faced with implementation in the community setting within a family home
16. Peer-to-peer abuse is a huge issue.
17. Need for clarity in relation to engagement with An Garda Síochána
18. Timescales for response are challenging
19. Consideration needed for those who live in supported arrangement that do not fall under the remit of HIQA.
20. Requirement for an easy read document accessible to all.
21. Challenges faced depending on the risk appetite of the professional for example some may manage the risk for longer and delay intervention which can cause tension with other professional groupings
22. There is a wide variation in the provision of social work service across the country which is going to impact the successful implementation of any meaningful national safeguarding service.
23. Staff must feel protected and entitled to due process with a right to appeal
24. The right to not have concern reported

3.2 Topic 1: Defining those in Need of Protection

Challenges with Language

The general consensus was that the term “vulnerable” needs to change to reflect a position that is not as “stigmatising, labelling or patronising” and serves to empower rather than disempower the adult at risk. Many contributors spoke of the fact that service users do not like the term “vulnerable person” as it refers to a person’s own impairment rather than the context of the abuse.

Suggested alternatives need to be person centred, contextual and easy to understand with examples including the following

- Person who needs additional support
- An adult at risk- which is much broader (and which would have implications for practice)
- Adult in need of protection
- Adult who is unable to protect themselves from others
- Person at risk of harm and abuse

Additionally, the definition needs to have a requirement for a care and welfare focus while there was an acknowledgement of the challenges faced in the absence of mandated actions.

There was however some hesitation expressed by some that if we change wording that there could be a retrograde step for the service as there is a clear understanding by staff at the moment as to who the policy relates to. There was a sense from managers that while “we are still embedding change and culture “it is too soon to change terminology.”

Consider Adult at Risk/ Adult at Risk of Harm

Changing to the term “adult at risk” was seen as beneficial in that it is more operational but there was recognition that there are significant implications as this is much broader that the current definition.

The general consensus is that people are struggling with the concept that anyone with intellectual disability is vulnerable despite having the ability to make decisions.

It was pointed out that people can be vulnerable, but not at risk of abuse.

Some were more in favour of an expanded policy that would include adults at risk of harm thus including service users with safeguarding concerns such as the homeless, victims of domestic violence and people who self-harm. However others felt there was no point in expanding the remit given the resource limitations in the implementation of the current policy.

> "what is the point in spreading the service so thin that no one can get a genuine service"

There was a concern expressed about expanding the remit of the policy into the acute sector.

It was felt that people who need protection are those who have little support in their lives, often residing in the community and this needs to be focused on. Specifically, it was pointed out that those people who do not come to the attention of the HSE are isolated. There was a strong feeling expressed that there is a gap in service provision for those with safeguarding concerns in the community, due to lack of resources in primary care. There needs to be greater awareness of the reporting system for people who don't have agency/organisation to support them.

It was felt that in theory the policy should cover all adults at risk and could therefore cover all citizens at different periods of time in their lives. However there was a general feeling that this policy was never intended for the general population and we need to allocate resources efficiently and target those most in need particularly where there is a high risk.

Some contributors felt that the term "adult in need of protection" was better but that it was important to specify what they need protection from and within this debate we need to contextualize the capacity of the individual. In dealing with this it was noted that it is important not to burden the vulnerable person with having to prove their vulnerability in the screening process.

Contributors noted the importance of giving consideration around will and preference so that there is an appropriate differentiation between safeguarding and poor choice.

In addition, the following points were made;

- Ability to guard yourself is key and that you consent to the support
- Restriction of capacity\should be based on context- it needs to be meaningful
- Having the right to make a bad decision was a key theme- some felt that the use of the term “risk of harm” could potentially lead professionals to being risk adverse and the potential implications in populations such as those with autism
- Critical to recognise the autonomy of the individual
- Importance of confidentiality

Self Neglect

The self-neglect theme was particularly strong amongst HSE employees and there were divergent views on where it should lie and who should hold the ultimate responsibility. There was a strong sense that opinion on the topic of self-neglect was determined by the work location/ profession of the person expressing the opinion.

Contributors felt that self-neglect is a complex issue requiring multi professional and often multi agency response and these cases can often be resource intensive.
While some felt that primary care is a natural home for self-neglect others e.g. PHN were strongly advocating for its inclusion within the revised safeguarding policy and thus be managed by the Safeguarding Teams. Leading on from this there was a lot of discussion on the management of elder abuse within the elder abuse service. Specifically the consultants of Old Age Psychiatry that were engaged with felt that older people who are under the care of psychiatry of old age services should be included within the revised policy

The issue of mandated interagency collaboration was raised as a mechanism to enhance working relationships whose success is often dependent on individual relationship building rather than a mandated purpose.

Summary: Scope of Policy

Resources are key in determining the scope of any policy and this was a common theme permeating the discussions. Discussions focused on what is aspirational versus what is practical. Those individuals that are covered by the policy need to have their rights respected so that a person centred service delivery is achieved that promotes people's rights to autonomy and self-determination.

Shortcomings have been expressed with the current definition as the basis of inclusion/exclusion for people with disabilities relates to whether they or are not in receipt of services. Furthermore, contributors felt that there can be subjective decision making under the current definition that needs to resolved in the review.

The key word is around protection and the potential requirement for this to be enhanced by law i.e. the determination of who needs a protection assessment, and whether or not this is a mandated action.

The essence of the debate is the discussion of the term adult at risk of harm versus adult at risk of abuse. While adult at risk of harm is more inclusive and creates less divisions within services it may extend to people that do not want to be included e.g. homeless.

The implications for areas such as self-neglect. This discussion led on to more debate regarding whether self-neglect should be included or excluded from safeguarding and if it is to be included, who would manage these cases.

Determining the level of vulnerability and risk is integral to the safeguarding process as is knowing what is and is not an appropriate referral. Abuse is seen to be a more serious situation than harm

Key considerations

- Need to have empowering language with a care and welfare focus

- Definition of harm/protection is required- if the definition is too broad it becomes meaningless, too narrow excludes people
- Give due consideration to the fact that people may be temporarily vulnerable.
- The degree to which people have been engaged around their wishes. Safeguarding versus poor choice needs to be explored. Balancing rights and best interest principles in the context of both the Assisted Decision Making Capacity Act and the Mental Health Act.
- A cross divisional approach is required so that we don't miss individuals with multiple disabilities who are more at risk, and have potential to fall between the cracks when no one service takes responsibility
- It is about the denial of human rights- the voice of the person versus cultural roadblocks
- Need to focus on the protection of those who have little support in their lives and are community based.
- Not everyone that has a disability is vulnerable, can be able to advocate for themselves. Additionally others can be vulnerable and not 'at risk' e.g. asylum seekers/refugees. Context and situation specific.
- Capacity test meets 3 criteria- we need to define people in need of protection in the same way.
- Language matters.
- Consent/Capacity issues important
- A Safeguarding response is triggered by the situation that occurs as opposed to the diagnosis
- Further education and training is required for families who " want people protected from everything".

3.2 Threshold

There were divergent views regarding whether a reporting threshold should be introduced. As a general comment, issues around capacity and consent were mentioned as important factors in this discussion. One point was made that because

thresholds are very much about enforcement this had the potential to contradict the human rights principles which the policy seeks to uphold.

For those against its introduction reservations were expressed that it was premature to introduce thresholds at this stage. Comments made at the focus groups included; *"Implementing a zero tolerance approach has made a positive difference to the lives of service users. It is currently promoting a culture of respect and dignity, is clear for all to understand and some felt that it would be premature to implement a threshold."*

"We are not a level of safe cultural practice to be able to progress with the introduction of thresholds; it is more aspirational than practical."

"Zero tolerance policy has worked I would have an issue with the introduction of threshold…. every adult has right to live free from abuse"

As an alternative, the view was also expressed that the current position is "meaningless" and is "process driven".
People also pointed out that service provider can feel deskilled because of the "zero tolerance" approach as everything must be reported.

In relation to residential services some contributors felt that peer-to-peer abuse would benefit from implementing limited thresholds however, there was some reservation expressed that we must be careful to avoid a culture of acceptance or "assisting in the normalizing of abuse". There was an opinion expressed that once off, low level incidents should not be reported and the current system is a drain on limited resources given that some funded agencies have large social work departments and have greater resources that some of the SPTs.

In relation to community concerns many felt that zero tolerance within families would require a significant cultural change as there is a strong sense of entitlement evident in how the finances of both elderly parent and the finances of vulnerable adults is managed by family members. Some felt that a threshold is being applied already in the community.

Some people felt strongly that all concerns should be reported to the Designated Officer who would then apply professional judgment to assess what meets the threshold for referral to the Safeguarding and Protection Team. The respondents

envisioned that this model would require Designated Officer's in the community as well as services. It would be important to monitor lower level incidents and system would need to be in place to assess trends over time. Adequate resourcing of the DO role would be important in this type of model. On this theme, some people felt there is a need to assess each case in terms of intent versus harm with appropriate risk assessment tools. In relation to the introduction of a baseline threshold guide people felt that education and training would be essential.
There was caution expressed against using a rigid model such as the TUSLA thresholds, emphasizing that thresholds should guide but not dictate referrals.
It was felt that thresholds are helpful but concerns were expressed around being too prescriptive and not to move away from using professional knowledge. The context of the concern is also an important factor in assessing with a threshold.

In any model where thresholds are to be used, the need for good governance and clear accountability was mentioned as being necessary.

3.3. Model for Service Delivery

Model

The international evidence has illustrated that there is no definitive model for adult safeguarding delivery, ranging on a continuum from dispersed to highly specialized model. Indeed the oversight function of the current Irish adult safeguarding model is unique by international standards. The discussions within the focus groups identified varying strengths and weaknesses in the models presented. This often depended on the professional position or perspective of the representative in attendance. Current demands within services and the professional/ divisional perspective that an individual representative had a strong bearing on the views and responses given in the focus group sessions. Additionally operating models are conceptually challenging to fully comprehend within the limited timeframe of the focus group which posed an issue for some of the groups.
A strong sentiment was that the current model works best in the residential sector where there is a Designated Officer. Challenges are being faced in the community sector and especially where community residing cases are managed within by the services. From the discussions held there was no definitive model proposed

mirroring the international experience as outlined in the Rapid Realist Review. Some key themes have emerged in areas such as collaboration, training, resourcing and reporting requirements

Notwithstanding the above challenges a number of key themes and factors emerged from the focus group feedback:

1. **Multi- disciplinary working should not be lost and collaboration needs to be strong and mandated in an operating model**

- Strong views that model needs multi department and multi-disciplinary involvement with clear mandated collaboration / information sharing
- The communication theme emerged strongly and many felt that it was integral to the successful implementation of any policy. Therefore a number seeking a model that promotes greater direct interface between the services and a specialist team to enable more collaborative working. Where communication has been strong between the teams and funded agencies it has been viewed as positive leading to robust and challenging conversations that have benefited the service and the service user.
- Some contributors felt to that in a dispersed specialist model there is a need for strong multidisciplinary engagement and collaboration to counteract the "fear of dumping" that exists. Others expressed the view that the essence of "safeguarding being everybody's business is not currently experienced in practice
- Model needs greater consistency regarding liaising with An Garda Siochana and the local disability services as this varies currently across the country.

2. **Capacity and resourcing implications important for recommended model**

- There was concern expressed from some contributors that the current limited generic and local resources could drive the HSE towards a particular model such as a centralised model.

- The lack of social work positions and management structure in many primary care teams was also highlighted
- Concern that resource may not be adequately able to respond to legislative and regulatory implications, with some advocating a new Adult Safeguarding Agency separate from HSE
- Contributors felt that the safeguarding teams are not properly resourced at present, therefore the engagement with the services can be limited and in many cases the information that they have through paper lacks context which is a significant limitation in the oversight capabilities.
- Safeguarding plans need resourcing, especially with complex cases and at risk service users who need inputs such as emergency respite. Some have queried where the responsibility lies for accessing resources given that services are HSE funded.
- Models need support and be responsive as different CHO's could have different models/structures. Some CHO at an early stage and need to build up services
- Need for stronger clinical and operational leadership to manage demands and promote consistency

3. Oversight role and function needs to be clarified

- Many of the professionals at the focus groups sought a clearer and better understanding of the role with many voicing differing interface experiences
- A number of social work professionals in funded agencies and community teams expressed reservations about oversight role and function. Many queried the rationale to question their professional judgement whilst others welcomed this function however sought a more respectful, supportive and informed oversight interface with the HSE. This was especially expressed around areas such as peer to peer concerns, Garda notifications and agreeing safeguarding plans. Many funded services feel that the revised policy needs to enable them to take professional judgments with many favouring responsibility for holding a reporting threshold.

- Some of the points raised asked if operating model could incorporate an oversight function that is less procedural driven and has greater emphasis on productive and supportive learning.
- There were also views that the oversight function needs greater reform of the HSE commissioning model and Service agreements themselves need reform to place clearer safeguarding governance responsibility on funded agencies. Some concerns were expressed that current oversight is putting too much responsibility on a specialist safeguarding team
- Oversight role is large and complex .Concern was expressed about the challenges faced by Specialist teams doing oversight and community based work at the same time. This division of functions presents challenge and some felt that the current model is "top heavy" with stronger emphasis on oversight and quality assurance with a lack of case work involvement.

4. Operating model needs to be underpinned by a strong training and continuous professional development strategy

- Training is key and should be accessible through multiple mediums including online so that staff are prepared for real life safeguarding issues on the ground.
- There is a requirement for specific training for those undertaking specialist roles. There was a recommendation that the safeguarding teams need to access specialist training to develop a greater expertise in the ID sector and other roles.

Views on Generic Model

A number of attendees noted that whilst a Generic model would be desirable as the professional/social worker in a generic team would know the service users/ family, it does not lend itself to consistent practice. Such a model would need appropriate resources, support structures and a requirement for a very clear line of reporting to be in place. A key point raised was that a sole local response waters down responsibility – *"when it's everyone's job it's no one's job".*

A key point raised was the need for a cross divisional response model which is challenging for public health nurse who could be compromised by expectations of a generic model. PHNs representatives noted that have a personal relationship with families and it is important not to place too great an expectation on such a professional. An additional point raised from some in attendance was that some health professionals could end up doing safeguarding as a major part of their work time as a result.

Views on Dispersed- Specialist Models

Dispersed specialist was seen by some to lend itself to good practice by offering specialist support at local level .The advantages of having a dispersed model primarily focused on being "person centred" with those who have the greatest knowledge of the person being involved in managing the case. However others noted the success of this model is dependent on the appropriate allocation of resources.

Some of the participants expressed a preference for this model, as it provides the best outcome in making safeguarding part and parcel of what people do in their day to day working, yet having a link to a specialist function if and when it is required.

A number of contributors felt that "*safeguarding is everyone's responsibility*" and the Safeguarding specialist input needs to work at a local level and that there is reassurance in having someone locally who has an expertise to lead on it. Social Workers would not have all the responsibility but that they would lead on coordination and perhaps chair case conferences. Dispersed specialist should have stronger local accountability and responsibility but this needs to be clearly defined. There were concerns raised that in a dispersed model there would be a lack of uniformity in practice. This lack of consistency has been highlighted as a concern in the manner in which the teams currently operate. Others noted risk around role and responsibility confusion.

A number of representatives noted that focusing on service that know client best and could be more preventative and others pointed out strengths of the former elder abuse service with strong team work and inter agency collaboration. However concern was raised that it will not be able to grow and develop. Dispersed Specialist

could empower experts in the MDT but needs clear roles, good governance, and adequate professionally competent staff.

Some additional points raised:

- Some representatives related that Safeguarding Social Worker attached to primary care and mental health teams could be good fit for model
- While it might seem positive to the person who knows service user the best- this could compromise therapeutic role of the team
- In a dispersed model concern that local teams could end up doing safeguarding and lose out on being able to do other important work
- Could takes responsibility from all team- and could just focus on social worker
- Dispersed specialist could work similar to elder abuse service

Views on Centralised Models

The experience to date of having inconsistencies in the manner in which teams have dealt with concerns lead to some representatives promoting a centralised model with a specialist team. Some representative favoured a TUSLA like centralised referral model although others expressed reservations around this, and stated that this model does not necessarily work and the TUSLA “thresholds are set too high”.

A centralised model is seen by a number of representatives as impersonal and not person centred i.e. the person who knows the client best may not be involved in working the case. Some within mental health division expressed a concern with an expanded scope potentially “compromising a person’s therapeutic relationship with their client.” in some of the operating models.

Some representatives were of the view that centralised specialist builds on expertise/knowledge and clarifies lines of responsibility. Many s representatives noted that a centralised model would see trends and emerging issues and provide consistency in approach. Others noted that a specialist element may apply only in relation to complex cases such as ward ship application.

"Concern was expressed that a centralised model becoming an emergency response and would lose local knowledge gained in the area. Other noted caution that centralised model would only address the most severe allegations and welfare

issues would be lost. Others noted fear that a centralised team may not be multi-disciplinary in composition

Some additional points raised:

- Centralised specialist are not community focused with large geographical spread and would lose local knowledge gained in the area
- Specialist teams can support front line response and then provide better co-ordination of complex cases
- Specialist service and Centralised system could lead to a more consistent approach to thresholds and assessment building on expertise/knowledge
- No reporting in community evening\weekend as central service closed
- Centralised model becomes emergency response and would only address the most severe allegations
- Centralised model clarifies responsibility and reporting line better
- Concern safeguarding teams can't do both oversight and specialist roles in this model
- Complex cases should\ could be specialist role and draw on specialist when needed
- Specialised team could let every other member of staff off the hook
- Reassurance in having someone who has an expertise to lead and co-ordinate
- Can be issues around consent with referral to specialist responses for adults with capacity
- Needs a specialist teams-but they could co work or take complex cases such as wardship
- Suggestion that different CHOs could use different models given differing structures and resources
- It was suggested that it is too early to have a specialist service- specialist teams could be a "dumping ground" need to have health care professionals across divisions involved and standardisation ensured
- Concern expressed that Primary Care role could be gone in specialist model with centralised safeguarding assessment and we then need to consider the provision of a welfare team.

4.0 Service User Engagement

4.1 Sage

Nothing about you / without you

sage
Support & Advocacy Service

Safeguarding Focus Groups

Sage would like to acknowledge the participants who kindly and generously contributed to the focus groups, and the organisations who facilitated participants' engagement and enabled Sage carry out this work.

1. Process & Format

Sage approached three organisations and services to assist Sage to facilitate focus groups as part of Sage's contribution to the HSE review of the *Safeguarding Vulnerable Adults at Risk of Abuse: national policy and procedures 2015*. The organisations and services engaged participants for the focus groups, and hosted Sage to facilitate the groups. An outline of the format for the Focus Groups is in Appendix 1. Each focus group was facilitated following the overall format, but differed from each other to accommodate the participants, venue, time allocated for each focus group and to incorporate learning from the facilitation of the previous focus group(s).

Three focus groups were held, two in the Dublin area and one in the South East area.

Focus Group 1

The group comprised of older people in residential care, respite and day services in the Dublin area. 11 people present, 2 men and 9 women. A person from the services the people are connected with was also in attendance. Approximately one hour for the focus group.

Focus Group 2

The focus group was with a large group of people and held in a large room, it was a part of a regular social event held in the Dublin area. The participants live in the community. Several people from the large group contributed to the focus group, some did not contribute possibly due to the size of the group. Time for the focus group format was short, due to time available and the size of the group. Prior to the focus group format commencing the facilitators spent time introducing themselves and explaining the focus group purpose individually and were available afterwards for any of the participants to speak with individually. The coordinators of the social group were also in attendance.

Focus Group 3

The group comprised of participants engaged with disability services in the South East area. 7 people were present, 1 woman and 6 men. All contributed at different levels. Participants were from a mixture of supported living, residential living, and living with family and independent living.

2. Analysis of Themes

Theme 1: Understanding Safeguarding

Safeguarding

Each of the groups responded to 'safeguarding' in the context of keeping safe, being safe, prevention, protection, and security. For Groups 1 & 2 responses related to personal security and safety, security and safety in their home and the importance of having contact with people, neighbours and friends. Group 3 referred to safeguarding in the context of health and safety. Group 1 responses referred to prevention in the context of preventing something happening. Group 3 was the only group to have responses that included the terms bullying, not being nice, and hurt. The participants in Group 3 referred to having done training in safeguarding, health and safety and self-advocacy.

The terms 'safe' and 'unsafe' were explored with Group 1, similar to the responses to 'safeguarding', responses related to safety and appropriate clothing, safety in their home environment, safety and the physical environment. When asked directly participants responded they have felt unsafe because of the actions of another person.

Vulnerable

Responding to the word 'vulnerable' the Groups described this is as not being aware, being taken in easily, not being able to object and say no to someone, somebody who is not strong or able to stand up for themselves. Groups 1 & 2 described being lonely, being 'on your own' and not being able to go out. Group 1 responded by referring to tradesmen, being let down by a person you rely on, and being deceived by someone to get money. In Group 2 the point was made about feeling vulnerable and uncomfortable by a group of teenagers in the community. When asked directly participants in Group 1 responded they felt vulnerable because of the actions of another person. Group 3 referred to a person in a wheelchair and people in institutions as being vulnerable.

Abuse

In responding to the word 'abuse' all of the groups referred to verbal abuse or somebody saying something to you, and physical abuse or harm. Groups 2 & 3 used the terms abuse of money and financial abuse respectively. Both Groups referred to taking or keeping a person's money without permission, for Group 2 this related to someone collecting a pension on someone's behalf and not passing it on to the owner, and for Group 3 this referred to keeping change from an errand. Group 2 also referred to someone pestering for a loan of money.

Group 1 responded in the context of abuse from a professional or service provider referring to how a person can be spoken to, treated or responded to when they need additional assistance. Group 2 referred to abuse of power, and Group 3 explored distinguishing between abuse, a mistake and unwanted but necessary physical contact in the context of a person receiving personal care or assistance from a professional. Groups 1 & 3 used terms of being interfered with and sexual abuse. Group 1 responded with reference to misuse of property, being robbed, and the physical environment in a bad area with bad traffic.

Theme 2: What would be helpful for you

Telling someone

In response to the questions exploring who people would tell if they experienced abuse all of the Groups referred to family members. In response to 'who would you tell', and 'who would you tell if a family member' was making a person unsafe the groups referred to the Gardaí. The importance of trust and a person who is trusted was mentioned several times, in the context of 'who would you tell' and 'who would you tell if a family member' was involved. Groups 1 & 3 referred to telling the GP or doctor. If a family member was making a person feel unsafe Group 1 responded that they would tell someone in the nursing home or in the Day Centre and Group 2 responded that they would tell a carer or another member of the family. Group 3 referred to telling cousins or uncles, a counsellor or a celebrity.

In exploring the theme of a family member was making a person feel unsafe, Groups 1 & 2 responses included that this would be very worrying, there was a concern that trust may not be kept within the family and members of the family may discuss the problem, that the person's story would be changed and it would 'grow legs'. It was discussed that the person would want help from the family, but there was a concern of bothering or being a burden to family, and that family might get 'fed up'.

In response to the question exploring 'who would you tell if a professional' was making you feel unsafe, Group 1 referred to not going back to the professional, changing GP for example, and that a person could go to the clergy.

In discussion on this theme Group 3 raised the question of what a person would do if they couldn't communicate or were afraid, and it was raised that a person may not have someone to trust.

Notifying and Consent

The concept of notifications of abuse and consent were explored with the groups, there was limited exploration with Group 2 due to time constraints. Groups 1 & 3 responded that seeking the permission of the person before notifying or making a report was important. This was stated in different ways in the discussions and related to trust, breaking trust and breaking confidence. Group 1 responded that the person was trusted and should not tell someone else (third party) if they were asked not to. Included in Group 1 responses is that each person is a person in their own right. Group 1 responded that it is important for the person to know everything that is happening if a notification/report is made, Group 3 discussed that it is important to communicate and discuss with the person (victim) why someone else has to be told, and that a report can be written if the person knows this, and trust is broken if something is reported without telling the person.

In the context of the theme of notifying and consent, Group 1 discussed who should be notified, again trust was an important factor and the group discussed a carer as a person who is trusted and important but that not all experiences of carers are good. The group responded that the GP, the Gardaí, someone in the office of the nursing home, or someone who could deal with it in an easy way are people that should be notified.

Groups 1 & 3 discussed reporting abuse, for both groups there was a concern about getting someone into trouble by making a complaint, and this might prevent making a complaint, along with being seen negatively for making a report about someone. Group 1 discussed that older people don't want trouble, don't want to cause trouble and just 'get on with it', that people are 'not able' for it. Not having a person to make you feel safe and comfortable was raised.

Group 3 discussed that a person who is trusted with information about an abuse has a choice to say nothing, but it was recognised that in order to do something about it and prevent something happening again or to someone else, they would have to tell someone who could do something about it or confront the abuser, and this was seen as a burden on the person. Group 3 contributed that not being able to articulate the problem, not being able to decipher if something is wrong can be frustrating and cause fear, a person may be afraid of being told to go away, not being believed and laughed at if they report abuse. From discussions on the theme Group 3 responded that hearing both sides was important.

Awareness of Safeguarding and Protection Team

In relation to awareness of the Safeguarding and Protection Teams, Group 1 responded that they did not know about the SPT, and Group 2 had a mixed response, it was observed by the facilitators that the majority had no awareness of the SPT when the name was mentioned.

Helpful

In exploring the theme the groups discussed what would be helpful and helpful to hear. Group 2 responded that a phone number to call is helpful. Group 1 responded that self-assurance, to have someone to share and listen to you, to know help is available, to give the person confidence, and to see a 'face'. During the session the group spoke about the personal security alarm positively, but were critical of the cost, and suggested a service that would call the person to check in would be helpful.

Group 3 responded that hearing and seeing action is important, and gave an example of what would be good to hear (see Responses table). During the session this group suggested the option of authorities meeting the person out of their natural environment as the person may be afraid of other people in their community/centre knowing. The group also raised the point that if somebody talks to the abuser this might be helpful. The point was made that it is not easy to tell someone when something is wrong, although we may think it is easy.

Theme 3: What would be a hindrance for you

In exploring the theme of what would be a hindrance or 'stop you' from telling someone about an abusive experience all of the groups responded in terms that fear, possible retaliation, repercussions, and what would happen to you (victim) are factors that would stop a person telling someone or reporting abuse. Groups 1 & 3 responded that fear of not being believed, being laughed at and told to go away are factors.

In the discussion with Group 1 it was raised that a person might think that something is wrong but they might not be sure, and this could cause a problem. This group also raised that telling someone about an abuse could start a row, and that the person (victim) may not be able to cope with that. It was contributed that the person's voice is not as strong now in older age, not as outspoken now and it is harder to challenge, that the person's voice is getting quieter.

Under this theme Group 2 raised embarrassment and not knowing what would happen with your information when given to an Authority as factors. Again the important role of the Gardaí were mentioned by this group. Group 3 contributed that being threatened by the abuser and intimidation are also factors that would stop a person disclosing an abuse.

Exploring the topic of engaging with authorities with Group 3, it was stated that it would be scary, strange and serious to be contacted by the authorities in relation to an allegation. The group discussed what it would be like to go to a Garda Station for example and the implications for the person if they were seen doing this, and what might be thought about the person as a result. In this context the group discussed an Authority coming to meet with the person in their own home, and this being seen by others. The group raised that this is from the perspective of the person themselves, and which would be the greater feeling for the person, people knowing that something may have happened to them or that somebody is trying to help them? This group discussed a difficulty if a person who is a victim of abuse is not able to understand the reason why an authority or another person should know about an allegation of abuse in order to help them, or to prevent harm to someone else. This group recognised that standing up for yourself is most important, but some people are not able to do this.

3. Facilitators' Observations

For each Focus Group the participants were given some useful contact numbers to take away which included the local Safeguarding and Protection Team contact number, and the relevant Sage contact

numbers for the area. To date the facilitators have not been contacted by the participants to discuss any issues arising from the focus group discussions.

Focus Group 1

- Capturing the vulnerabilities of the person is difficult in the focus group format
- House, personal and physical safety were the initial responses when exploring the term 'safeguarding'.
- Maintaining the integrity of the person's story is important
- The important and trusted role of a carer came across, along with the need for the person to be compatible with the carer.
- The people contributing in the group were vocal and would present as able to express themselves, but did state that they feel they are less outspoken and many expressed not being able to deal with confrontation/conflict which has an impact on if they will disclose or speak about an experience of abuse.

Focus Group 2

- The participants referred to security and safety when discussing the term 'safeguarding'. It was a challenge to engage participants in a discussion about abuse as understood in the HSE policy.
- Due to the large group it may have been difficult for people to share due to a fear of the group thinking they were referring to themselves.
- A participant spoke about a personal concern during the focus group format, one of the facilitators responded to this and followed up.
- Before the focus group format a participant spoke individually with one of the facilitators about an experience with a distant family member, the person expressed they didn't want to comment on another person, and didn't want to interfere.
- The group found it hard to respond to the question on what they would like to hear, and what they would like to happen if they experienced abuse beyond wanting someone to respond.

Focus Group 3

- The participants were open to talking about the topic, engaged, and some of the participants had completed training in safeguarding and in health and safety. It was observed that at some points these two concepts were conflated by the participants.
- Some of the participants had done or were doing self-advocacy training which was observed as being significant for the participants.
- The participants made some points about HIQA and paperwork demands, and the term 'alarm bells' was used when referring to HIQA.
- The participants discussed options a person may have and engaged in discussion on scenarios presented by the facilitators to give an example for the participants to explore the concept of consent. The examples included a situation where an abuse has occurred between two peers, and a situation where a person tells a peer about abuse, and a person tells someone working in a service about abuse.
- The facilitators used a PowerPoint presentation, it was not relied on as the group engaged well in discussion.

4. Theme Responses Table

Theme	Theme	Group 1	Group 2	Group 3
1	Safeguarding	• Keeping out of trouble • Keeping safe • Knowing what to do • Safeguarding – before something happens – prevention • Home and yourself • Dealing with tradesmen and people who call to the house • Don't open the door to strange people • Don't need safeguarding when people, neighbours and family, are near.	• Stay safe • Safe at home • Contact with people • Mobile phone • Security • Mobile monitor/alarm • To have a neighbour or someone to contact	• Protection • Protection from "health and safety" • Somebody giving out to you, bullying you • Not being nice to you or might want to hurt you in a number of ways
	Unsafe/Safe	• Not wearing proper shoes/boots – unsafe • Answering door to stranger • Being aware of where you are • Neighbours/ links security on re doors/windows • Physical environment – steps can be unsafe • Some participants responded that they have felt unsafe because of what another person does		
	Vulnerable	• Tradesmen and taking out money • Not aware • Expecting someone and feeling let down, relying on them	• Taken in very easy • You can't say no	• Someone with a disability, in a wheelchair • Somebody who's not strong, or not able to stand up for themselves. • People living in institutions

		• Someone saying something that isn't true to get money • Lonely – on your own • If you come from a big family and then you're on your own • Leave your light on to not be vulnerable • Some participants responded that they have felt vulnerable because of what another person does	• Some people might find it hard to object to some individual, can't say no, some people are vulnerable that way, people might want to cooperate • If you can't go out • People making me feel uncomfortable, groups of teenagers, when walking and feeling vulnerable	
	Abuse	• People interfering with you • Harming you • Ask a question and not answered properly, at the doctor for example, slow in answering you back can feel abusive • Misuse of other people's property – something growing in the garden – used against your consent • On the bus – conductor not happy if they have to help you • Saying something to you	• Verbal abuse • Physical abuse • Abuse of power and money • Old person on their pension and they're not getting it, someone taking their money	• Being called names or being made fun of • Being physically harmed, threats, cursing, a lack of care or understanding. • It is a wide ranging term. It could be physical, sexual, verbal, or financial. • Keeping another person's money without permission while carrying out an errand for them • Participants referred to health and safety training • It can be very difficult to distinguish between an honest workplace accident or mistake, or an example of abuse. There is a very fine line between what is and isn't right but are people aware of that? A lot of cases that have been coming up now, a lot of it is not real or not proper abuse… because anyone can be hurt accidentally.

		• Living in a bad area – traffic • People being robbed	• People pestering for a loan or for money • Someone collecting your money and not giving it to you	While you may not like some of the things that are done to or for you, they are often necessary and unavoidable due to the person's physical or mental disability or illness. For example having to be lifted into a chair, if a professional hurts you while lifting you, it is more than likely an honest mistake and so should not be seen as abuse. Although a person might not like being lifted, there is no other option but for someone to lift them. While someone might not like the lack of independence, or be uncomfortable with the physical contact involved, the help is necessary.
2	Who would you tell	• The guards • Someone close, a fried you trusted • Family • Someone you trust would be important	• Family • Person in post office, report it there	• Talking to someone and telling them your problem is important • A family member • Someone you trust • Ask the Gardaí • If you're not able to talk, or can't talk very well, or you're afraid, what then? • a celebrity • Cousins or uncles • a local counsellor • Important to have someone to talk to or to trust, as you don't always have someone you can have complete faith in • If you tell someone and they do nothing • Trust your friends, trust your instinct • Go to the doctor
	If family was making you feel unsafe	• Tells someone in the nursing home • Someone in your day centre • Trust is important • One person would tell the others – family tell others in the family • A tale grows legs in the telling • Important you could trust • For them to tell you what to do, to help me • Sometimes they'd get fed up if you go to them too often	• The Guards • That would be very worrying • Carer • Next of kin, other member of family	

		• Feel you're interfering with them • A good number of people are willing to help • If it's to do with family better off to tell the GP, keep it away from the family		
	If professional was making you feel unsafe	• Wouldn't go back, change doctors • Tell someone, the clergy	•	
	Notification & Consent	• Important to ask permission to notify • Important to know everything that is happening • I don't have someone to make me feel comfortable, to make me feel safe • Question on giving a present to a carer, if the present comes from the heart then why can't I give a present, not because I feel I have to give it. • No, the person you tell shouldn't tell another person • If you trusted the person tell them • Tell the GP • Each of us are a person in our own right, have our own troubles • Carer is a person you trust • Carers are important but some are not good • Don't want to get a person into trouble by making a complaint • Crime – phone the guards • Like the guards near, there's someone there	• It's good to know someone is out there. • Some people are frightened, to say anything	• In order to help and make an impact on the situation, someone else would need to be told. A person who has been told of someone else's problem has two choice; the person can keep it in and say nothing, or the person can do something about it. And the only way that the person can do something about it, unless they go directly to the abuser is to go to a higher person, which is fair enough. This is a very big burden for the person to carry as the same thing, or worse could happen again • Situations of abuse can be frustrating • The inability to sufficiently articulate a problem, or inability to decipher whether something is right or wrong can be a source of frustration and fear. The fear of being told to go away, or being told that they are imagining the problems, being laughed at. • For the person being told about the abuse to talk to a third party in order to get help that they had to get the permission of the person receiving the abuse first. And that to tell anyone else about the situation without their consent, or particularly in the case that they were told not to, they would be in trouble and they would be breaking confidence. • Person should get permission to tell somebody else, because the person being abused trusted them • It might be helpful to talk to/communicate with the victim that you are going to tell someone else because you have to tell someone else

		• The person you tell should tell someone in the office in the nursing home • The person you tell should tell someone who could deal with it – in an easy way • If you say not to tell anyone – they shouldn't tell anyone • Getting someone into trouble would probably stop you from telling someone • Example of grandson who was stealing money from a person, he didn't tell anyone in a service, only his peers. • All leads back to being vulnerable • Most elderly people don't like trouble – just get on with it – don't want part of the trouble • Not able for it • A neutral system should be involved • Wouldn't have anyone you could tell, there isn't someone I could trust, family would make a song and dance • There's [.....] or bit added on • Trust is important		• It is necessary that a record would be kept of any incident, no matter how small...even if you cut your finger, it has to be written in the book. • There is nothing wrong with writing a report if the victim is told that a report will be written. • You don't want to be seen as the "baddy" for reporting something • Reporting something can be breaking confidence. • If going to management without telling the person then trust is broken • Using an example a participant contributed that to some people certain issues might seem trivial but the same issues might be hurtful to others, it's not black and white • Important to hear both sides
	Awareness of SPT	• No	• Yes • No	
	What is helpful/helpful	• Help • Self-assurance	• A phone number	• I would like to hear and see action. I would like someone to say 'it's great that you're brave enough to tell me these things, but I

	to hear/helpful to do	• Someone to share it and listen to you • To know help is there • Everything that gives you confidence • Visit now and then to see a human being, put a face to the name		really must take this to somebody else, can I tell them or do you want me to go with you • Try to talk to the abuser as the problem might be rectifiable, and if not at least you can say you tried to fix the problem and you gave warnings. •
3	What is a hindrance/not helpful/stop a person telling	• Fear, not being believed, doubt • What would happen to you • You could think someone is doing something wrong but you might not be sure • Fear of what would happen – repercussions • Could start a row – not being able for it • You might not be sure – you could put your foot in it • Voice – not as outspoken as used to be, harder to challenge people now • Example of pendant alarm to make someone feel safe • Cost of phone service and personal alarm, should have a service that calls the person • Noone to tell	• Fear • Threatened by someone • Retaliation • People can be embarrassed about it • If complain to someone in authority, don't know what the person might do with your information • Everybody should have Garda number beside them, they're very good and will come out to you	• The person telling you not to for example "don't do it or I'll kill you". • Being afraid • Intimidated • Afraid of the person doing something worse • It would be strange, scary and serious if someone from a service contacted you looking to speak to you about abuse, looking for evidence, it would be a shock to get the phone call. • If someone sees you walking into the Garda Station what are they going to think, they might slag you afterwards, you might not want anyone knowing about this • If you haven't done anything you might think what are people going to think of me now, going to have a bad name • Are you going to be laughed at, told to go away you're only imaging this or is someone going to help you, they can either stop it or say come to me anytime… • Which is the greater feeling for the person, somebody knowing or somebody trying to help the person • Difficulty if the person who is the victim does not grasp that another person has to be told in order to help them, and to prevent something happening to someone else • Can get abused online • It's not easy to tell that something is wrong, although we think it is easy • The consequences • Great ad on television about domestic abuse • Standing up for yourself, that is number one • Some people can't stand up for themselves

4.2 Alzheimer Society of Ireland

Safeguarding Views & Perceptions

A total of 2 focus groups and 3 1:1 interviews were carried out with people with dementia and carers

Q: What does being safe mean to a person with dementia?

For participants with dementia, being safe means very practical issues in the home, such as turning off cookers, candles, being aware of the danger of falls and ensuring practical supports to live well. Being safe also means feeling "comfortable" and "confident" and feeling a sense of "security". This makes it somewhat easier to deal with a diagnosis of dementia.

Being safe means being able to live a life that is "free from harm" and having one's human rights protected and upheld. In a nursing home being safe means being respected as an individual and having one's privacy respected. Irrespective of how agitated the person with dementia is, the person should be respected. Very often care staff are not trained and do not understand that agitation may relate to needs that are not being met. If a carer does not understand this, the person with dementia may feel unsafe and the agitation or fear can escalate. People with dementia need to be understood in order to feel safe.

Some participants described "touch" as important for feeling safe, for example, holding the person's hand. One participant described how her mother may not know where she is, but she knows that she's somewhere safe. "A safe environment" means to be somewhere that the person with dementia recognises, "it's somewhere familiar or somebody they can trust". Participants highlighted familiarity and structure as contributing to feeling safe, as one day care centre client explained, "everything happens in the same place, in the same way, and I'm with people I know and they understand me". Participants described the importance of using a non-threatening approach to make a person feel safe by smiling and being friendly.

In the focus group, carers felt that "education of the (family) carer is a critical issue" in enhancing safety. For example, one participant felt he was not adequately educated and did not recognise the signals that could lead to his wife having an

accident or fall. It was explained that family members should be allowed to call to the nursing home at random times to check on their loved one and ensure they are being well cared for.

Q: What does being unsafe mean to a person with dementia?

Participants described being unsafe as a feeling that is “frightening” and “uncomfortable”. For them it means “not being understood” and a lack of understanding of the condition from people around them can leave a person with dementia feel very unsafe. One participant felt that the number of people in a room and the tone of voice some people many use can be very distressing for a person with dementia and that many people will feel safer and more secure with one-to-one interaction. Adequate support and understanding were emphasised as crucial to feeling safe. Interestingly, participants with dementia tend to define ‘unsafe’ as a feeling rather than an action or behaviour, such as feeling scared, intimidated, uncomfortable, being ignored or not heard or listened to.

Participants discussed how the turnover of staff in nursing homes can be very frightening for a person with dementia. There was a discussion about the approach in acute and long-term care and participants felt that staff members need to be clear and reassuring before they start getting a person out of bed, washing or dressing them etc.

Participants agreed that people with dementia are very vulnerable and are at the mercy of people calling to the door or out in the community. One person gave an example of a woman with dementia who used to get her hair done once a week, but then began to forget she had it done and so went every day. Instead of trying to support her, the hairdresser let her pay €40 each. There were numerous examples given of people with dementia being “taken unfair advantage of financially” and certainly participants with dementia were aware of their vulnerability in this regard.

Q: Should the word vulnerable be used to describe people with dementia?

There was unanimous agreement that people with dementia are vulnerable, even prior to a diagnosis and certainly from the point of diagnosis. They are vulnerable when living on their own and also in nursing homes as people providing care are not always monitored. People with dementia may not be able to speak up, express need or ask not be treated in a certain way. Having limited capacity means one is vulnerable.

People with dementia are vulnerable particularly in terms of physical safety. Several carers described concerns around physical safety how their loved one put a hot kettle on a hot plate and the dangers this and other actions posed to the person themselves and their families. One participant spoke about how his wife wanted to go walking without him, but would get lost so he would follow her in his car to ensure she was safe, “the person themselves may have no awareness of their safety”.

Participants with dementia explained that not being treated as an equal citizen can leave them feeling vulnerable. They might be excluded from conversation and feel demeaned because of their condition.

Participants highlighted the lack of care assistants for vulnerable people, including people with dementia, in hospitals as a problem that must be addressed. A carer highlighted the practice in St Vincent’s Hospital of putting a pink ribbon on the end of the bed of a vulnerable person as a positive example. This would remind staff that the person needed extra support with eating etc.

Q: What makes a person with dementia feel safe/unsafe in their home or in the community/day centre?

Support from service providers can empower a person to live well, and this feel safe. Practical supports can make a person feel safe such as a panic button, using GPS when outdoors, having someone who can check in on them. Planning ahead is important, while one can, and the ‘Think Ahead’ document is very useful for people with dementia. Planning ahead requires certain awareness and skill.

Experiencing difficulties navigating or becoming lost can be very disconcerting and frightening for people with dementia. In addition, responses from other people to dementia can make one feel unsafe. Not feeling understood or being made feel awkward can make a person feel unsafe. The fear that one is perceived as “weird”, “strange” or to be avoided can also contribute to feeling unsafe, and the person with dementia may be fearful they will not be helped or supported if needed.

Q: In what other ways might a person with dementia be abused?

Participants gave numerous examples of how a person with dementia can experience abuse:

- A participant informed the group that a carer washed her husband with cold

water, even though hot water was available and it was only when she intervened that she stopped.

- People discussed the pressure staff members are under in nursing homes and that there may only be time to look after a person's basic needs with no time to interact. While participants recognised that the job of a professional carer can be very difficult they felt that a person should not be in that job or they should remove themselves from the situation if they are starting to feel annoyed.
- The tone of voice used by professional carers is very important. They may be under pressure and therefore very frustrated. One participant shared an experience where a carer had shouted at her husband with dementia, "sit down and have your tea". She had to explain to the carer that he would respond much better if she spoke to him gently.
- Participants highlighted their concern for people with dementia who do not have family members to advocate on their behalf.

Uninformed or negative perceptions of dementia can make this cohort more vulnerable, as participants explained. One noted that, "The person disappears and the disease defines them. They become a problem".

Another commented that it is upsetting that things have not improved for people with dementia – "food being shoved into [a person's] mouth with a dessert spoon, too fast…On the ground little things haven't changed". Another explained, "In acute hospitals a person with dementia is "always a problem patient and a mobile person with dementia is a nightmare".

Q: If a person with dementia was being abused who would they tell?

Participants with dementia reported they would tell someone they trust or someone they know well, such as a family member, friend or a Dementia Adviser. They agree that the trusted person should then tell someone else who could also help. However, in the context of a nursing home, reporting abuse might be more challenging. As participants with dementia pointed out, diminished cognitive abilities means the person with dementia may not recognised if they are being abused and may not be aware of it. While physical abuse might be visible, emotional abuse can be subtle. The person with dementia may be fearful of not being believed or that reporting abuse may compound the distress and make life more difficult.

Similarly, carers of people with dementia, explain that their specific condition and cognitive challenges means “they may not realise they’re being abused”. One participant explained that her mother had overpaid a number of workmen by significant amounts and instead of saying anything they had just cashed the cheques and taken her money. In that instance her mother didn’t realise that she was being abused. Another carer described how all her mother’s bank accounts were emptied and the family still are not sure exactly what happened. Someone else described how her husband was put on medication for aggression when he went into respite, even though she explained that he just needed time to settle into a new place. When he came home he began to have falls because he was over medicated and he then had to be weaned off that medication. Carers were of the view that the voice of a person with dementia is not taken seriously and when a person with dementia makes an allegation of abuse it may not be taken as seriously due to their condition.

Q: If a person with dementia reports abuse, what should happen next?

Participants offered the following suggestions about what should happen when a person with dementia reports abuse:

- “I would like to be recognised, heard, validated and acknowledged.”
- “Family members and people involved in my care should be informed immediately, including members of my multi-disciplinary team”.
- “I would like someone to check it out, and see what has happened, how a safe environment can be created for people with dementia like me, and also the care workers”.
- “The person with dementia should be removed from that environment immediately” and/or should be distanced for the particular member of care staff.
- “There should be an independent investigation”. Participants said that there should be an independent body like HIQA to investigate reports of abuse.
- Participants believe it should be investigated if such abuse has happened before, and to explore if care staff need further training in caring for dementia clients.
- People with dementia should be informed of progress of the investigation if the have the capacity to understand. But if it causes further distress then the person with dementia may not need to be informed. There is no ‘one size fits all’ and the specific needs of the person should be taken into account, and a

person-centred approach should be adopted.

- The service investigating possible claims of abuse should visit the person with dementia to give an update on the investigation. But again, this is dependent on the capacity of the person to understand and the stage of dementia.

The group discussed the difficulty people with dementia may have in reporting abuse, as a result of the condition. A participant called for a social worker in all hospitals and nursing homes who will monitor the treatment of people with dementia. Interestingly, a carer highlighted the fact that no one is checking whether her husband is being cared for properly at home. She believes that a social worker or someone should check in on families every once in a while. Another person said that every person with dementia should have access to a Public Health Nurse who visits regularly.

Q: What would make it difficult for a person with dementia to report abuse?

The specific nature of dementia and its symptoms can make it particularly challenging for the affected person to report possible abuse. Verbal difficulties mean "they can't tell people what they need or want".

A carer explained that when her mother was grinding her teeth she knew something was wrong. But this was the only signal as she did not have verbal skills anymore, and therefore "you have to take the signs and interpret them". Another participant highlighted the experience of her husband who is in long-term care. She explained that he does not cooperate with the staff to wash because he is frightened and they move too fast for him for he is unable to verbalise this, "I want him to be looked after to the highest possible standard, that's not too much to expect. The one thing that really does matter is respect and care for the person".

As above, fear of not being believed because of dementia, allegations being taken less seriously because of dementia are all factors. Perceived power imbalance between the person with dementia and service provider/care staff would also hinder a person from reporting abuse. Participants feel that abuse claims are not often taken seriously and properly addressed. People with dementia reported feeling fearful they will be "turfed out" of a service if they complain and often feel bad even about raising questions, "I would be afraid things would get worse, that I would be intimidated, and it would go on and on." Interestingly, participants from day care centres also noted they would feel guilty about reporting someone, especially if it was a family member.

Other Observations

- Participants agreed that education of staff is key and one commented that a lot of care is driven by personality. One carer will make heavy weather of something and another won't.
- Participants discussed the fear that informal carers have of accidents, falls and somebody walking alone and getting lost. Despite these fears, there was agreement that it is important not to overreact to incidents and go overboard with safeguarding measures.
- "Respect, dignity and love. If you have that approach other things will fall into place".

4.3 Inclusion Ireland

Consultation on Safeguarding Vulnerable Adults Tullamore Wednesday 1st November 2017.

This first consultation meeting in Tullamore was with a relatively small group of participants (7) with a good mix of male and female service users, from the local area, including one service user from Kilkenny. There were also two carers who attended the meeting with the consent of the service user they cared for. However, their presence neither impeded or undermined the participation of the service user they accompanied. Additionally there were 2 facilitators, Mary Lee and Petria Malone who outlined to the participants the reason for their attendance at this consultation, what would be discussed, how necessary and important their views were as they were the experts, as it was their views which would be passed to the National Safeguarding Committee for consideration. Petria also spent some time outlining the details of the policy document to establish that the participants had heard about it and that they understood what it meant for the service users themselves. She advised them that there were going to be a number of these consultations over the coming weeks, in a number of counties nationwide, with Tullamore leading the way as the first meeting. She reassured the group that their answers were entirely confidential, there were no right or wrong answers and that it was not a test. She reiterated that the reason for the meeting was to get their opinions, through the use of a number of different questions, which they would answer as a group with the additional aid of a power point presentation to ascertain how the policy of safeguarding was working for the group themselves in the 3 years since the policy was introduced.

Mary then did an overview of the list of questions with the participants and a lively and interactive discussion ensued.

What is the National Safeguarding of Vulnerable Persons at Risk of Abuse Policy?

The group were largely unsure as to what the policy was, only one male service user knew what it was. After the facilitators discussed it with the group and they were happy to know more about it. One service user then mentioned that they had seen

some information on it in their home environment.

What is Safeguarding ?

A couple of the service users offered their opinion on what it was. 'it is about being safe, everyone deserves to be safe, and to feel safe'. It is good that a policy is in place to keep us safe',(female service user)

Why is this consultation happening?

The group as a whole appeared aware that this consultation meeting was to enable them to give their opinions, which were very important, they were the experts in this area and that they were being listened to. Being listened to was an important aspect for them.

Q1. Is there a word to describe a person in need of help?

Mary then asked the group to outline what they called a person who needed help again through the use of power point pictures along with the question. One male service user suggested 'victim' which led others to suggest 'an injured person' they were not necessarily familiar with a specific word to describe a person in need of help but they understood the concept of what it meant.

Q2. Do you know where to go to or who to speak to if someone is hurting you?

There was plenty of discussion around this question with lots of ideas and answers. Some suggested their key worker, (male service user),' a parent', (female service user) 'the guards, another person in authority such as a manager, or a neighbour. 'someone that you can trust ' female(service user). 'someone in the same situation as you '(male 'service user) or in hospital. ' Tusla or HIQA' (female service user)

Q3. If you think you will be hurt by someone what can your family or staff members do to help you? 'Listen to me, believe me, treat me like an adult' (female service user.)' they can speak to management', get something done about it go to the An Gardai Siochana (male service user) or if they are worried see a social worker'(male service user).

Q4 . If someone helped you in the past when you were hurt what could they have done better?

They could pay more attention to what I am telling them', listen to me better '(female service user).

Q5. What is abuse? What are the different types of abuse?

The participant group were very aware of the different types and levels of abuse. They were well able to vocalise their ideas and opinions about abuse. It is 'everywhere ' (female service user) sexual abuse, financial abuse, cyber abuse, bullying, older people are abused' (male service user), shouting, stealing from people, spitting at people, name calling, taking advantage of people, grooming, 'children are abused' (male service user) not just sex but they can be neglected too, not fed properly or they cannot go to school' female serice user) one service user mentioned emotional or psychological abuse, again through the use of imagery via power point which helped them to verbalise the different types they saw on screen. 'coming into my room when I dont 'want them to', female service user) the facilitator explained that this was invasion of privacy another good example of abuse.

Q6 . Do you understand what the word vulnerable means?

Most of the participants were unfamiliar with the actual word. However one participant said 'a victim, or an injured person '(male service user) however they gave some good examples when they saw the power point pictures.

Q7 .Who is a vulnerable person?

People who are depending on others for support' (male service user) 'people who cannot speak up for themselves' (female service user). 'people who are alone'(male service user), people who have disabilities, people in hospital, (female service user), 'children', (male service user).

Q 8. Have you ever heard of the National Safeguarding Office?

Only two of the participants had heard of it and one male service user explained what it was to the group

Q9. What does this office do?

Is it is a contact place for people to contact if they need help? '(male service user)

Q10. Who is the national safeguarding policy to help?

The group believed that it 'was trying to help everyone who is any type of danger'(male service user). Disabled or elderly 'people being harassed,' (female service user'). ('it is for all of us' (male service user).

At the end of the consultation, by way of conclusion the facilitator Mary asked the group if they had learned anything or gained anything from the session. She emphasised the importance of their feedback.

One male service user said that 'it helped me to realise the importance of speaking up for myself'

'It's made me realise that everybody needs help at times' (female serivce user')

Consultation on Safeguarding Vulnerable Adults Sligo - Thursday16th November.

The Sligo Consultation on Safeguarding Vulnerable Adults was very well attended by 12 participants all from the Sligo area, with a 50-50 mix of male and female. There were two facilitators Barry Lynch and Noirin Clancy who were well known to the participants. After initial introductions Noirin began assisting the service users with the completion of their consent forms. all the service users were happy to participate. When the consent forms were finalised Barry began discussing with the service users the reason for their attendance at todays' meeting, to ascertain if they understood why they were present at today's meeting. They all confirmed they were aware. He outlined the reasons behind the meeting and explained to them that their participation at today's meeting was of key importance, they were the experts in this area, and that the HSE were keen to get their feedback and opinions, this was not a test, there were no right or wrong answers their experiences and ideas were most relevant. He advised them that the questions were quite short, and easy to answer, together with a power point presentation which would assist them with answering the questions the advised them that their answers were confidential and no names would be included in the final report. He also let them know that other meetings had

been held around the country to get information using the same format and list of questions.

Barry continued by asking the group if they knew what the National Safeguarding of Vulnerable Persons at risk of Abuse policy was and as with other meetings the service users were unaware of it so Barry explained to the service users that it was an HSE document that explains why it is important to protect people at risk of abuse. He also told them that it also explains who is responsible for protecting vulnerable people and how it should be reported.

Why is this consultation happening? The service users were aware why the consultation was happening and knew that their views and opinions were necessary especially to find out on how the Policy of Safeguarding has been working for service users the last 3 years. They were also aware that other meetings had been held nationwide.

Q1 Is there a word to describe a person in need of help?

The service users gave lots of examples of the different types of people who need help, 'people in a wheelchair, people on buses, crossing the road, a 'blind person', 'an elderly person' but no specific word was mentioned.

Q2 Do you know where to go or who to speak to if someone is hurting you?

The Sligo participants had lots of ideas on who to go to in such circumstances 'a manager in my service or higher up (female service user), a neighbour, a friend, or family, 'it depends on what's happened to you '(male service user), 'the guards' female service user)'my best friend' (female service user). ' a person in a position of authority (male service user), 'someone trustworthy '(female service user), 'the doctor' (male service user), 'a social worker' (male service user), 'there are lots of places and people to go to for help '(female service user).

Q3 If you think you will be hurt by someone what can staff or your family member do to help you?

'Take me to my room and spend time talking with me, or bring me to a staff member' (female service user) , 'then my family can sort things out with a manager, as some staff might not believe me, especially the younger ones they may not know you very well or they aren't well trained'(male service user).

Q4. If someone helped you in the past when you were hurt what could they do better?

'They could talk to me more,' calm me down' (female service user) count to 10 and if I am angry let me hit a punchbag or pillow to get anger out.' 'they didn't help me' I had to keep it in, 'I had no choice I had to do what I was told' (female service user).

'sometimes the ones who are longer term staff are better to talk to'(male service user).'better training would help newer staff. '(female service user') however in contrast a male service user commented 'younger staff might listen better as older staff often don't want to listen to you anymore'(male service user). 'It's just a job to them, they don't care '(the older ones' (male service user), it makes me angry. 'it can be hard to speak to newer staff' but they can call someone to speak to you, a family member perhaps'(female service user), or maybe just make a cup of tea and just listen to me'(female service user). 'problems should be sorted out in service, they shouldn't always involve family because if it is a small thing to sort out it can turn into a bigger thing than it was at the beginning'(male service user').

Q5 What is abuse?

The service users had lots of examples of the different types of abuse, 'people hitting you, shouting at you, name calling, hair pulling, threats', theft of belongings'(male service user).'elder abuse, 'physical abuse or emotional abuse, '(male service user). 'people can hurt you without touching you'(male service user) 'sexual abuse 'that's not good' (male service user)'being asked to keep things a secret '(it gives you a bad feeling' (female service user).'no means no'(female service user). 'There is also financial abuse', one female service user gave the example of being short changed in a local supermarket and demanding her correct change back and being happy to have done so. 'it happens in pubs too and restaurants as well, it's hurtful as you know they are doing it because you have a disability they think you are stupid.' female service user). Barry explained that there are different types of psychological abuse 'discrimination due to being different in some way' how you look, your sexual orientation, skin colour, race, religion, neglect, a lack of sufficient food, clothing, 'educational needs not being met are also types of abuse'(male service user). as well as institutional abuse e.g. in boarding schools, orphanages, 'priests and nuns can also abuse'(male service user).'not being allowed to have a relationship because you have a disability 'that's abuse too' (male service user). 'not being allowed into pubs,

or restaurants because you have a disability, you feel unwanted and embarrassed '(male service user) 'that's abuse too'. One female service user gave an example of being sick and unwell and no basin for her to use as she was getting sick, 'when it's not your house you have no say', e.g. lights over our beds are too bright keep asking for different lights but nothing is done.' 'it doesn't seem like home '(female service user) 'often the staff are too busy with paperwork to do things for you' (male service user)

Q6. Do you understand what the word vulnerable means?

The service users as a group were unaware of the word and what it meant however, when Noirin explained it's meaning to the group they were aware of what it meant just unfamiliar with the actual word

Q7 Who is a vulnerable person?

Some examples the group used were 'someone who cannot help themselves', e.g. children, autistic people, elderly people'. (female service user). 'being out in the dark at night makes us vulnerable '(male service user). 'it can depend where we are and in what circumstances'(female service user). 'people in wheelchairs are vulnerable too'(male service user).

Q8. Have you ever heard of the National Safeguarding Office?

Yes some of the group had heard of it in their place of residence, however the majority of the group had not. 'we should be told about these things' (male service user)'our homes or service should tell us about it' (male service user).

Q9 What does this office do?

As the group were not aware of what the office did Barry then outlined that it was there for service users/ their families, staff and carers to tell them how to safeguard service users and those who cannot protect themselves.

Q10. Who is the National Safeguarding Policy trying to help?

'It is for everybody' all of us'(male service user) or 'blind people, people who are ill or in hospital'(male service user).

Then the facilitators asked the group did they think there is too much safeguarding?

Are we overly careful? the group agreed that it was for their own good 'for the most part'(female service user). 'It's good to feel and be safe' (female service user). Lastly the facilitators asked the group what they had learned from today's session. Overall the feedback was positive, the service users felt they had been informed about important policies and places they could contact for help and advice, 'some things I hadn't known about or heard about in my life before' its been brilliant, getting to speak up and be listened to'(female service user)'people should be supported and helped to speak out, treat us like the adults we are'(male service user). 'let more people know about things so they can avail of them '(male service user).

Consultation on Safeguarding Vulnerable Adults Cork Tuesday 14th Nov 2017.

The Rochestown Park Consultation was well attended (9 participants) with a good mix of female and male service users. There were two facilitators, Julie Ireland and Susan Doyle.

Susan started the proceedings by asking everyone to introduce themselves.

Once the introductions were completed Susan opened a discussion on the consent forms and their role in the proceedings. She then introduced Julie, and also asked people if they needed help to fill out the consent forms. Once this was completed she advised the participants of their importance in attending this consultation. She stressed that their opinions were the key reason for this meeting, their opinions mattered as they were the experts and crucially there were no right or wrong answers. it was not a test, and all answers given were confidential. There would be no names attached to the answers in this report.

Julie went through the questionnaire with the service users using a power point presentation to assist them with answering the questions and also explained in detail whenever questions arose. Additionally she advised the group that if they missed answering a question they could speak about it later if they needed to.

What is the National Safeguarding of Vulnerable Persons at Risk of Abuse Policy?'

'We would love to know' (male service user).The group as a whole were not aware of any policy.

What is Safeguarding ?

After some further round table discussion one service user felt that '

' If it is making Ireland a safer place for those with disabilities or need support, it's for all of us'(female service user).

Why is this consultation happening?

'It is happening as the HSE want our opinions, we are the people who have to deal with stuff.' (male service user), the service users were happy to hear there were a number of consultations happening around the country.

Q1. Is there a word to describe a person in need of help?

'A person in a wheelchair' (male service user' 'someone who needs help, 'or they have a disability'. (female service user), or a deaf person. 'someone who cannot advocate for themselves' (male service user) A specific word was not mentioned. When the power point images were being shown one of the service users asked if they were real images ? were they actual incidents of people who had needed help, and the facilitator reassured her that they were actors in the photos.

Q2. Do you know where to go to or who to speak to if someone is hurting you?

In common with the Tullamore consultation group, suggestions ranged from members of family, 'a friend I can trust with secrets' female service user), key worker, staff, neighbour.

Q3. If you think you will be hurt by someone what can your family or staff members do to help you?

The service users felt that their family should go to a person in authority e.g. Boss or manager, or the Gardaí,'as long as they back you up'(male service user)

Q4 . If someone helped you in the past when you were hurt what could they have done better?

'They could have reassured me, given me confidence '(female service user) 'explained things to me better', 'tried to understand me better '(male service user), 'ask me what the problem is and give me advice'. (female service user) 'or put me in contact with the correct professional who can help me' (male service user) 'show compassion' and /or understand where I am coming from '(female service user)

Q5. What is abuse? What are the different types of abuse?

The service users were very aware of this topic and gave many examples of abuse, such as pushing, spitting, being called names, 'not getting the things you need,' or are entitled to' (male service user), physical abuse, emotional or psychological abuse. 'there are always people who are not nice but stay close to the nicer ones' (male service user), sexual abuse '(female service user). 'or the 'silent treatment' (male service user) 'neglect, lack of food, shelter,' (female service user.) or institutional abuse, medical abuse, 'children or people in orphanages like in Romania' (male service user) who himself was adopted.

Q6. Do you understand what the word vulnerable means?

The service users had quite a few examples which showed their understanding of the term vulnerable.' a 'person who needs support is vulnerable (female service user'). 'A blind person,' (male service user).

Q7 .Who is a vulnerable person?

' People can be vulnerable even within a family' (female service user) Children, are vulnerable.' (male service user). Someone who doesn't understand what's going on around them' (female service user), 'an easy target', or 'an elderly person' (male service user).

Q 8. Have you ever heard of the National Safeguarding office?

In common with the other consultation meetings nationwide. The group as a whole had never heard of the National Safeguarding office. When the facilitator explained what it was the group felt confident once they now knew what their purpose was, they would investigate claims, or complaints, give feedback and communicate with service users and their families.

Q9. What does this office do ?

Once it had been explained to them they were confident the Safeguarding Office would would help them and they could contact the office if they needed help

Q10. Who is the national safeguarding policy to help ?

'we would love to know 'male service user) is it nationwide ? Or is it just in certain

areas? the facilitator explained it was nationwide. ' It's for everyone then'. (male service user).

At the end of the Cork meeting the service users said they felt more informed and aware of what the Safeguarding office did and what the policy document stood for, especially as they now knew it was there for them. They agreed as a group that knowledge was power, and that the Safeguarding Office 'should make it a priority to let more people know about its existence and who it was for.' (male service user). 'they need to advertise it more so more people know of it's existence' (female service user).

4.4 Deafhear and Deaf Village

DeafHear.ie
Services for Deaf & Hard of Hearing People

Review of the HSE Vulnerable Persons at Risk of Abuse Policy

Deaf Village Cabra 27th March

1. **What do think of the word "vulnerable person"? What word would you like to describe yourself or members of the Deaf Community when you may need any assistance or help?**

   Some contributors felt that the perm "vulnerable person" was apt and they preferred it to "unsafe". However others felt that the term is patronising and labelling and too broad and therefore would have reservations in its use going forward. It was suggested that language needs to be more positive and empowering.

   During the discussion isolation emerged as a big issue and how this links to vulnerability. Deaf people don't see themselves as disabled and would not consider they are vulnerable because of deafness but isolation leads to their increased vulnerability. "You need to be part of a community for example a campus". One participant provided an example of being in a hospital ward and the curtain being pulled –for a deaf person being unable to see or hear anything can create a heightened sense of isolation.

   Furthermore isolation in terms of living circumstances can lead to loneliness. There was a suggestion that all deaf people should qualify for a travel pass as a means of combatting this. Feeling safe was also important and one contributor mentioned the benefits of having Phone Watch and felt that this should be funded by the HSE

   There are implications if changes to terminology are implemented in the revised policy and this was discussed. Contributors query raised the issue that if "vulnerable" changes what will be the knock on effect for organisations. This lead on to a discussion on resource implications and the requirement to meet interpretation requirements for deaf people which are now a requirement for all public agencies

   The discussions lead on to discussing the word abuse. There was concern expressed regarding abuse in the context of over protective families and the

challenges faced in labelling their behaviour as abusive. It was felt that people within the deaf community may be afraid to report in a general context. There was a suggestion that more such be done to improve safeguarding for vulnerable adults including the provision of CCTV in all public areas in nursing homes.

2. **Do you know about the HSE Vulnerable Persons at Risk of Abuse Policy?**
   Two people had an awareness of the policy through the Catholic Institute for Deaf People. A general discussion too place on the need to focus on communicating the policy more effectively with the deaf population.

   Given the new legislative status of Irish Sign Language there is a requirement for all policies to be translated.

   The following recommendations were made

   - Be easy read
   - Review information provided by the Catholic Institute for Deaf People
   - Focus on social media- videos, facebook, vlog
   - Give due consideration to the fact that everything with deaf people is visual
   - Give due attention to the fact that written material is not provided in deaf peoples first language – contributors queried how this translates for deaf people

3. **Are you happy about the way professional staff and other people do things when they are worried about your safety?**

Deaf people need to know where to go if they have a concern. It is vitally important that information is disseminated that outlined who to go to and were there are supports in place such as access to an interpreter. So much depends on the social worker- their level of awareness, their attitude and their ability to build a relationship. Visual message is so important for those that have a hearing impairment particularly facial expressions and body language. Contributors felt strong that this could be pivotal on whether or not someone who is deaf chooses to open up. To develop and build on this competency it was felt that deaf awareness training should be promoted amongst social workers which is provided by the Irish Deaf Society and Deafhear.

Regarding awareness provided an example of the differences between the cultural identity of those that are born deaf versus those that become deaf later in life. There is a strong cultural identify that deaf people have from growing up deaf that people who become deaf do not have. As a result the participants felt that those people that lose their hearing can be more vulnerable than those born deaf.

4. Can you tell us what help or assistance you may need if you think someone might hurt or harm you? Do you know what to do if you are worried about someone harming or hurting you?

The type of help required would be dictate by the situation but “trust” was identified as a key element in where a person would seek help. Participants did not feel vulnerable at this moment in time but felt that they would be assertive and would seek help and support. Sources of support included Citizens Information and the Catholic Institute for Deaf People. Additionally the group felt that they would go to Social Workers if they had information on where to access one.

5. What would you like to see in a revised policy to protect adults from abuse?

Key themes that emerged were

- there was strong opinions regarding online abuse- with many having personal experiences of this and this needs to be considered
- The issue of sexual abuse was raised and contributors felt that this is an important issue particularly focus needs to directed at those that are isolated, as it was felt that because they cannot tell they are more vulnerable.
- Advocacy for deaf people is very important- some people who are deaf do not realise the power of advocacy for them and this needs to communicated to empower individuals
- Congregated settings work for deaf people for support and service delivery. Contributors felt that decongregation can lead to isolation and increase the vulnerabilities.
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4.5 Disability Federation of Ireland

Question 1: What do you think of the word vulnerable person? Do you think it is a correct word or should there be a change on how we describe adults who need protection from abuse or neglect?

- There was concern expressed that by taking away the word vulnerable it leaves the term too broad and might leave it meaningless.
- Where a person is in receipt of services from the HSE then the HSE has a general "duty of are" to that person. By extension, the Vulnerable Adults Policy should be inclusive of all those who come under this "duty of care"
- Human rights concerns were raised- considering the voice of the person versus the cultural roadblocks.
- Could asylum seekers be considered vulnerable adults, where do people fit that don't fit in this policy but might need the service?
- Some people felt that by labelling someone as "vulnerable" we are beginning to make decisions without the agreed consent of that person.
- What is abuse, anybody can be abused, and the most able bodied person can be vulnerable where an abuse of power takes place
- There was general concern that the word vulnerable is labelling
- Conversation needs to be open to anyone who feels they are being abuse
- Training for service users to recognise abuse everyone themselves
- Service needs a legislative basis and there were challenges discussed in relation to service users moving from child to adult services or indeed where no adult service is provided.
- Any adult can be the victim of an imbalance of power. What is most important in the first place is that the person is heard, valued and enabled

Q2 Do you know about the Vulnerable Person at Risk of Abuse Policy?

- There was awareness of the policy with some contributors stating that they had recently completed associated training
- There was a sense that people tend to become aware of the policy when they are about to engage with the service
- Some of the attendees were also aware of the Confidential Recipient Leigh Gath

Q3 Are you happy how the HSE and Professionals/other agencies do things now when they are worried about your Safety?

- There was reference also to the complaints policy of the service and its importance.
- There was a discussion on the importance of advocacy and contributors felt supported in speaking up
- Some contributors referenced “bullying” pointing out that the HSE could be party to this too- the experience of feeling abused by the system or at least the staff in the system. The culture of the organisation needs to change.
- Abuse is not always the big things- very often it’s the small things that build over time
- The issue of Garda vetting was raised
- Financial abuse is huge- noted by carers
- One client mentioned challenges he faced in accessing buildings which had addressed with a service but was unhappy with the response provided.
- It was pointed out that in relation to record keeping, the case notes reflect the interpretation of the professional. The service user is generally not aware of what is in the notes or invited to contribute to ensure an agreed case note
- Imbalance noted regarding record keeping, that case notes on record reflect what the professional interprets and the client is not invited to respond or disagree with.
- Concern was expressed regarding the level of oversight of plans with some stating that once developed there was little if no oversight of plans
- Some respondents pointed the importance of training of service users to recognise abuse themselves
- The importance of advocacy training and empowering people
- The stigma around disclosing an abuse needs to change this requires a change of culture and there needs to be engagement with consumers
- Some felt that the HSE has a number of get out of jail cards to exclude people from the safeguarding service.
- Concern was expressed on how difficult it is to navigate system and make a report
- It is important to feel heard and enabled- it’s everyone’s right, but person felt they don’t get heard that they are denied that right. This is a form of abuse.

How does this work at present, in the general sense?

- People report concerns and it took too long for it to be dealt with
- Policy has meant that a person gets a response when they would not have in the past however some contributors felt that the follow up was not great and most situations were not resolved.
- There was also concern that there is a delay in an issue being dealt with
- There was concern expressed of professionals doing the referring and not allowing the person the space to make a referral themselves
- Some people felt that the response to an abuse was dependent on having staff available
- Lack of knowledge by allied HSE and other professionals as the process for referral

- Disability service unregulated and therefore there can be different responses ton concerns raised.
- Staff may be vulnerable and find it difficult to challenge practice
- Concern expressed regarding individuals who live independently and HIQA have no input
- Key message needs to be that safeguarding is everyone's responsibility and that abuse is not okay
- In relation to the disclosure of an abuse, it was commented that listening and
- The culture needs to change
- Prompt response within the three days
- Non judgmental

What happens now if you are worried about someone harming or hurting you?

- The discussion very much focused on verbal and financial abuse and abuse experienced via social media.
- The message to staff from contributors was
    - Do not judge, provide reassurance
    - The policy needs to ensure that people feel supported so that they are more independent and empowered

What would you like to see in a Policy to Protect People from Abuse?

- The new policy needs to have strong references to references human rights principles.
- Information needs to be available in an easy to read version- so that language is clear and understandable for all
- Needs to be promoted using social media- linked to apps with due consideration for the following
    - Consider visually impaired- provide audio
    - Be free to download
    - Reader friendly with big print
    - Do an associated dvd- with reference to the work of the service users with the Brothers of Charity Service in Clare
- HSE should provide workshops in the revised policy to up skill staff and could be part of an ongoing training and advocacy programme
- Information for people who might receive a referral or a disclosure
- Information for people who are abused or even the referral on what happened in relation to the referral

4.6 Mental Health Service User Forum in One Community Health Area

HSE Safeguarding Vulnerable Persons at Risk of Abuse, Policy and Procedure

This policy is being reviewed and the HSE would like to hear the views of mental health service users and supporters

The HSE would like to find out your views on adults who may need protection from abuse.

1. Are you aware of the Safeguarding Vulnerable Adults Persons Policy?

Many not aware of this policy – However in preparation for the focus group many researched and read the FAQ's document published in 2014 that accompanied the policy document.

2. Are you happy how the HSE and professionals /other agencies do things now when they are worried about the safety of a 'vulnerable adult'?

Internal procedures at first glance seem ok but would like to see some data on how many cases have been reported and the outcomes.

3. What happens now if you are worried about someone harming or hurting you?

Until now many have been unsure as to how to proceed. More public awareness is required

4. Can you tell us what assistance you may need from staff and/or carers if you think someone might hurt or harm you/someone you support?

See response to Q6

5. What do think of the term 'vulnerable person'? Do you think it is the correct term or should there be a change on how we describe adults who need protection from abuse or neglect?

"Vulnerable person" is ok, only suitable alternative would be "person at risk" For example "Safeguarding Vulnerable Persons at Risk of Abuse - National Policy and

Procedures", could read " Safeguarding Persons at Risk of Abuse – National Policy and Procedures" It is simpler and easier to understand.

6. What would you like to see in a policy to protect people from abuse?

Establishment of National Safeguarding Office is good step forward but this Office needs to be promoted (knew nothing about it until I started to research for this questionnaire) as an "independent department" with a Freephone no. that can be used to report abuse. By giving too many options through which to report (seems like a good idea) but dilutes effectiveness as it creates confusion. One Department, one number keeps it simple.

If abuse is happening within an HSE institution, then impartiality becomes suspect and motivation to report is reduced / negated in fear of retaliation if the initial report has to be made directly to an HSE department.

The appointment of a Confidential Recipient is a step in the right direction but the appointee appears as an HSE employee. This role needs to be promoted as sitting under National Safeguarding Office.

Also, the Loc Call number needs to be a Freephone no. Dialling 1890 from a mobile can incur "premium rate charges" and may potentially deter someone from using the service.

7. How would you like to hear feedback in relation to this survey?

A summary report of findings

All present happy to join any future focus groups/ committees working on any amendments to this policy.

5.0 Appendices

Appendix 1: Presentation

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Learning and Development Seminar for Safeguarding Facilitators

Review of Safeguarding Vulnerable Persons at Risk of Abuse, Policy and Procedures

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National Safeguarding Office

Purpose of Review

1. **Review current operation**
2. **Consult and consider revisions**
3. **Redraft and propose revised policy**

Review Development Group

Chair: Martina Queally CO CHO6

Review Subgroups

Key Considerations

- Governance
- Risks
- Stakeholder considerations

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Purpose of Phase 1 of Review

- **Research international policy and legislation**
- **Draw up project plan and map out stakeholder groupings**
- **Survey staff views of current policy**
- **Carry out a governance led analysis of strengths and weakness of current policy**
- **Communicate work of the review development group**

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Phase 1: Findings

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Research Subgroup-Paradigm Shift

MOVE FROM	MOVE TO
• Best interests	• Human rights based approach
• Compliance/process driven case management	• Focused approach: assessing and managing risk
• Procedural driven Zero Tolerance	• Proportionality
• Interventionist	• Person centred: support people to improve or resolve their circumstances
• Service driven	• Needs led
• Risk adverse	• Shared responsibility for decisions holding risk

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Key Message from Literature Review

- We need to consider **how best to support service users-** to know their rights are and how to advocate for them? How to Measure this?
- **Adequate resourcing** is required in drawing up policy (and legislation)
- Needs to be a match between the breadth of **definitions and resource base**
- **Adequate training** across HSE and funded agencies is essential
- **Mandated /legislated interagency cooperation** between key agencies / professionals is essential : role of Safeguarding Committees

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Key Message from Literature Review

- **Consider change of language and terms –** vulnerable adult to adult at risk
- **Service-user participation**-wishes and preferred outcomes are discussed
- **No clear operational model recommended** specialist v mainstream
- No clear direction on inclusion or not of **self neglect**
- Need to **re-prioritise service provision** on the prevention/protection
- **Mandatory reporting conflict with** person centred/proportional responses

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Safeguarding Models

1. Dispersed-generic model

- Safeguarding is a core part of social work tasks for all SWs and as appropriate for other professionals i.e. assessment/intervention
- Safeg. specialist team- limited operational role. Involved in serious enquiries i.e. organisational abuse/Oversight/No casework assessment

2. Dispersed Specialist model

- Specialist team dispersed within operational teams (PC/MH etc)
- Specialists team has co-ord. role/ some level of assessment & protection planning- levels can vary
- Specialists teams work jointly with operational teams or have special workers based in teams

3. Centralised Specialist models

- Referral process into specialist teams where they may be managed and investigated depending on complexity and risk
- Key co-ordinating role

Thresholds and Language

•There are differences in the level of mistreatment that triggers state responses

•There are differing thresholds for reporting

•Scotland has a threshold based on harm, whilst England narrows response to abuse and neglect

• Who needs protecting? Vulnerable Adult.. Adult at risk of abuse... Adult at risk of harm

•Protecting from what... Person undertaking abusive behaviour... Context of harm as well as abuse.....Undue influence or pressure....self neglect

•Proceeds of intervention....Enquiry, assessment , investigation?

Section 2 - Governance Sub Group

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Headline Strengths	Headline Weaknesses
Advances the Human Rights principles and better outcomes for vulnerable person	Differing understanding around concepts, terminology and Language
Improved clarity and aids recognizing and reporting of abuse and neglect	Lack of threshold for reporting
Greater accountability and oversight Better Planning, recording and standardisation	Inadequate operational scope across HSE and Health Service
Having safeguarding team supports screening/ reporting process	Inconsistency in the operation and practice of safeguarding teams
	Lack of current capacity/resource
	Confusion on roles expectation in mental health services and Primary Care
	Operational scope across the HSE needs legislative basis

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Section 3 – Consultation Sub Group

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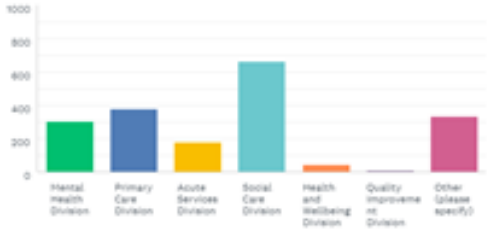
Survey Participants & Feedback

66% HSE, 30% HSE funded services- even CHO split



I understand purpose of policy (74%)

I am clear who it is intended to cover (67%)

Zero tolerance is easy to understand (74%)

Zero Tolerance has protected people using service from abuse 37%

The policy assists me in my roles and responsibilities in protecting service users (56%)

The policy helps my service to respond effectively to concerns of abuse 44%

Policy clearly states steps to take if I have a concern (57%)

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Qualitative Feedback

1. Need grater clarity and training on capacity/consent
2. Clarity on self neglect and Definitions
3. Support for staff and administrative burden
4. Training input
5. Clarity in the Community Referral Process
6. Management of Peer on Peer Interactions
7. Consistency of Safeguarding & Protection Teams
8. Requirement for a cross divisional approach

Decisions

- Consider vulnerable adult v's adult at risk concept?
- Should safeguarding be a specialist service or mainstream?
- Reporting threshold? Based on harm-abuse or neglect? Impact on model
- Which operating model? Include or not include self neglect?
- Breadth of policy ?inclusion of domestic violence, addiction and homelessness

Where to Next?

- Review models in an Irish context through focus groups and governance
- Gov. Group -to review role and function of the Safeguarding Committees
- Liaise with self neglect sub group-in relation to best fit within each of the models

Contribute to thinking on:

- **Thresholds Definitions and Language**

New Policy Requirement to Align with:

- **Revised Trust in Care Policy /Assisted Decision Making Act /Mental Health Act /Draft Safeguarding Bill**

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Decisions

Where to Next?

- Review operational models in an Irish context through focus groups and governance group
- What is best and most appropriate fit with each of the models
- Consider role and function of interagency collaboration and alignment with other key policies and legislation
- Liaise with sub group to be set up on self neglect

Contribute to thinking on:

- **Thresholds Definitions and Language**
- **Possible threshold in a revised policy**

New Policy Requirement to Align with:

- **Revised Trust in Care Policy /Assisted Decision Making Act /Mental Health Act /Future Draft Safeguarding Bill**

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Thank You

Any Questions?

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National Safeguarding Office

Appendix 2: Focus Group

Consultation Work plan

Introduction:

Welcome and thank you for your participation.

We will be looking at 3 areas relating to safeguarding on how they may change the policy in its current form.

Participants will consider the questions and work in groups with the facilitator to consider these questions and definitions.

An appendix is provided with further information on definitions and models.

Please be advised the definitions/terminology etc contained in this information sheet are for guidance only.

In order to ensure we can have an engaging and successful focus group

- One person speaks at a time
- No right and wrong answers
- If you do have something to say please do so- it's important to capture everybody's views
- There are no right and wrong answers just differing points of view. We are as interested in negative as well as positive comments and at times negative comments of what will not work are the most helpful
- We would appreciate if you would switch off mobile phones

Review Focus Group

SUBJECT **Facilitator(s):** **DATE**

[Policy Review]

OBJECTIVES

Materials Required	Sign in Sheets – Handout Presentation Overhead Projector Laptop Participants Information Sheets Focus Group Facilitators Workbook x3 Name Badge for Participants Name Badge for Facilitators
Workshop Plan	10:30 Introduction/Ground Rules  10:35 Presentation Outcome of Phase 1 of Review 10:55 Round Robin and questions for participants[1] 11:15 Focus Group rotation 1 11:45 - rotation 2 12:15 - rotation 3 13:45 Wrap Up and Summary 13:00 Finish

Discussion Topics

Group 1: Language/Terminology-definitions in relation to who needs protection in a revised policy?

[1] What was your view of the presentation?
Is there something of relevance from your service that wasn't included in the presentation?
Answers to be documented by facilitators

Defining those in need of protection? Vulnerable Adult / Adult at Risk?

A) How we define and clarify those who need protection in a revised policy? Should we change the language and terminology about who needs protection and from what do such adults require protection? (consider appendix sheet below as guide)
B) Should we replace "vulnerable person" concept with "adult at risk of abuse" or "adult at risk of harm" concept?
C) What would be the implications of any such changes to your service users and your service?
D) Should Self Neglect be included in the Definition?

Group 2: Threshold and Proposition Questions

Should we have a reporting threshold in the revised policy?

a) Should we have a thresholds which are led by professional judgement and based on when an individual becomes "in need of protection" or the presence of risk of harm/ abuse?
b) From your experience do you think this would be an appropriate move in the review of the policy?
c) If introduced what could this be based upon?

- Harm V's abuse/mistreatment

- Professional judgement/proportionality

Group 3: Operational Model

Specialist v Generic Models see Appendix 2 to consider options along a continuum.

a) Do you think the assessment and protection planning of Safeguarding concerns should be managed more centrally through specialist teams or should be managed more locally as part of local operational teams?
b) What would be the main barriers/challenges with these models?
c) Could we have a combination approach i.e.: Dispersed Specialist?