

2025 CORK

THE ROLE OF INDEPENDENT GROUP ADVOCACY IN DECONGREGATION



SHEP
Advocacy Programme
Support for those Struggling to be Heard



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INTRODUCTION

The aim of this review is to provide an account of independent advocacy support provided to people living in one institution in the hope that it will provide:

- a record of work;
 - a sense of the challenges;
 - potential methods for development;
 - feedback from residents;
 - feedback from other parties;
- and in order to inform independent advocacy work going forward.

In 2011, the policy document 'Time to Move On From Congregated Settings' was published informing the plans to close institutional settings where disabled people had been living, some for many years.

This policy, alongside the introduction of HIQA Inspections of Residential Services for People with Disabilities (introduced in 2013) instigated the closure of The Institution that this report documents. 'The Institution' will be the name used to refer to The Institution at the centre of this report and for the purpose of this report. **Identifying details will not be disclosed in order to protect the anonymity of the people involved.**

HIQA's first inspection of The Institution was carried out in 2016 following concerns raised by the then Management Committee including concerns about 'financial irregularities'.

'..while some evidence of good practice was found, all five outcomes inspected against were found to be in major non-compliance with regulations and standards.'
(P4. HIQA Inspection September 2016).

Upon completion of the inspection and the concerns raised by HIQA, the Religious Order as the service provider and owner of the property immediately withdrew their service provision, and the Management Committee then stepped down.

The HSE then took interim responsibility for the service provision with the Religious Order giving a date (March 2019) when they required the return of the property.



01 AIM AND INTENTION OF THE SHEP INDEPENDENT ADVOCACY SERVICE

The SHEP Independent Advocacy Service (SIAS) had been aware of The Institution and the women who were living there and had been making efforts to offer independent group advocacy facilitation to the women with little success. (All fifty residents were women and we refer to them in this way rather than residents for the purposes of this report). We understood that many of the women had been living in institutions all of their lives or for many years including experience of being born into Mother and Baby Homes and time in Industrial Schools and Magdalene Laundries. We were very concerned that this group of women, identified as disabled, were amongst the most marginalised in our experiences of working with disabled people.

SIAS had previously offered this service in three other institutions that were going through the process of de-congregation and were practised in the facilitation of group advocacy specifically.

'It is a service that is desperately needed in Ireland and should continue to be funded and supported. '

(Feedback from Regional Service Provider Manager)



02 ROLE AND REMIT OF SIAS

A service agreement was established with the HSE setting out SIAS's role and functions, and budget for the work. (See appendix one). The service agreement set out to deliver a group advocacy model of facilitation with additional one to one supports provided to local issues, with more complex advocacy support needs being referred to the National Advocacy Service For People With Disabilities and Sage. This service agreement was reviewed and renewed annually for a period of seven years, transferring to another service provider in 2021.

The key working principles laid down in the service agreement by SIAS and some challenges faced in operating these principles included :

1) The independence of the advocacy service was paramount. Whilst it could be argued that direct funding from the HSE in the interim and then from the service provider once established, would not allow for full independence, in the seven years of

operation, there were no attempts that we were aware of to silence or control SIAS. However, there was one occasion where we needed to argue our position with regard to funding in order to support the women through to finally moving out and this coincided with our reporting a number of concerns to HIQA.

'Having independent advocacy ensured that (the service provider) was held accountable. The advocates provided an external check on (the service provider's) practices, ensuring that the women's rights were genuinely prioritised. '

(Feedback from staff member)



2) Agreeing resources that allowed for group advocacy meetings including private spaces, access to dedicated link worker(s) and support from staff to ensure people could access the meetings.

This was difficult at times with some spaces not being very private, some women being brought to the meetings without being asked if they wanted to be there or activities clashing with advocacy meetings rather than space being held for them.

3) Access to one to one advocacy support. Additional support was made available by SIAS as time went on with more complex advocacy matters being referred to the National Advocacy Service or Sage Advocacy Service. Our experience in relation to this was that the national advocacy services were overstretched and unable to prioritise a service for the women.

2.1 ONE TO ONE ADVOCACY

Whilst the service agreement was to facilitate group advocacy, it was inevitable that our work would also

include some one to one advocacy work. This was because we had established relationships with the women and so we prioritised our resources within the SHEP Advocacy Programme to accommodate this support as best we could.

The one to one advocacy work ranged from:

- Immediate support to speak with a member of staff about an issue e.g. medication, access to activities, community etc.
- Individual experiences around staff responding with dignity and respect.
- More complex matters around making a will, access to redress and revisiting decisions made about the de-congregation process that hadn't allowed for due transition support.

The advocacy supports given ranged from weeks to months to years and were an additional piece outside of the service level agreement that was much needed.



03 ASSIGNING ADVOCATES TO THE ROLE

SIAS consists of a panel of SHEP trained independent advocates who are supported and supervised by SIAS Advocacy Co-Ordinator's. The advocates are contracted to undertake advocacy work, are Garda vetted and are required to comply with all SIAS policies and procedures.

At the outset, it became apparent that there were two venues within the institution that required group advocacy. Additional advocacy resources were required to accommodate these advocacy needs and resources were allocated accordingly.

'When I was asking questions they answered them for me. They made it clearer. They gave me the answers.'

(Feedback from one of the women)



04 DEVELOPING RELATIONSHIPS WITH THE WOMEN

Developing relationships was the initial core work of the advocates. The opportunity to have a group space with people outside of the service to discuss all matters they wished to raise in the context of human rights-based practice was a new experience for the women. When we first met with them, there was a powerful sense of unrest, fear, upheaval and worry as the women were aware that the Religious Order had left abruptly and that there was a date assigned to them as all having to leave by, March 2019. Their community had already been disrupted in their eyes, with some women being separated from each other and moved to nursing homes with little time to afford inclusion and person-led support.

The women had witnessed significant change, were fearful of what was going to happen next and pre-occupied with trying to work out who would go to live with who, what they would need and what they could

take in terms of possessions. There was a general sense of panic and worry with this being the theme of their concerns for the seven years we were beside them. Alongside these concerns, we also soon became aware of the women's resilience, patience, kindness and humour.

The women were initially suspicious of us and we took time to be with them to show them that we were there only for them, to support them to be heard and included in what was a complex and confusing time. We put up posters with our photographs, shared information sheets about the purpose of advocacy meetings and tried to ensure we were raising awareness about group advocacy and our roles.

Over the years, the women did connect with our responsibilities to 'find out about the houses' and not only to find out but to find ways for the women to be heard and included. The advocacy support also allowed for supporting the women's human rights in their day to day lives as well as plans for their future.

YOUR VOICE MATTERS

E.g. We worked together in the advocacy group meetings on a 'resident's charter of rights' and the women presented this to staff in a workshop. One to one and collective issues with staff around privacy, dignity and respect and informed consent were also supported.

Because of the continuity of advocates over seven years, SHEP was able to establish positive relationships with the majority of the women.

There were regular attendees at advocacy meetings which were large in number at the outset but got smaller as people moved, with a core group of 23 women remaining prior to the final closure of The Institution. Of those 23 women, 18 regularly attended advocacy meetings and a small number of women made regular approaches to the advocates outside of the meetings. The advocates made efforts to say hello to women who did not attend meetings and ensure they were aware of the potential to attend. When meetings were held with managers, all of the women attended with some choosing to stay at the back

of the room and observe.

Below are some quotes from feedback from the women. We asked the Internal Service Advocacy Officer within The Institution to facilitate this feedback. The communication and all feedback responses are available under appendix three.

'I remember that alright. Things were being kept quiet. She made sure we knew about the things that were being kept quiet.'

'They did a lot of hard work with us to be fair. They were fighting for our rights all the time. The two of them are very nice to be fair. They'd fight hard to get the things we wanted. They'd fight hard to get what was owed us.'

'They listened to us.'



05 ESTABLISHING & MAINTAINING A ROLE WITH STAFF

We did not formally facilitate a process with all staff but identified link staff who we would communicate with and this was primarily through the Director of Nursing.

Relationships with staff evolved over time. Whilst some remained cautious and wary of us, others sought us out when they were concerned about a matter or an individual and through doing so, allowed us to approach people and invite conversation to establish whether there was anything we could do to help. Keeping the balance between independence and professional communication is a challenge and requires careful consideration of our own behaviour and responses to staff. Our priority always to ensure that we were seen to be independent, meeting staff in the presence of the women and always attending to what the women were asking for as a first priority. Also remembering the simple yet often lost

ways of communicating, not using 'she' in the presence of the person but being fully inclusive. Staff were also invited to give anonymised feedback. Please see appendix four for all details.

Below are some quotes from frontline staff.

'Not only have you advocated on behalf of the residents but you have supported and encouraged them to be self-advocates going forward.'

'(The advocates) were a crucial support to our residents. The transition process was very difficult for our ladies. It was a very anxious time for all. There was a lot of uncertainty about where the ladies would live, who they would live with. Many of our residents were reluctant to leave (the institution).'

'It was not just words, there was real action and results. This was essential to our ladies who already felt they were being forced out of (the institution) and their choices were not being considered.'



06 COMMUNICATION WITH MANAGEMENT

6.1 Advocates

The advocates communicated regularly with the Director of Nursing as the formal link person, primarily through email so that responses could be brought to the advocacy meetings, and at times, through update meetings as we arrived at the building. There were times when it was challenging to uphold the principle of sharing all information with the women. There was one occasion where we delayed sharing information whilst efforts were made by managers to ensure that the women were informed. This can be an advocacy challenge that is worth further exploration beyond this report.

6.2 The Women and Advocates

Regular meetings were held with lead managers and the Director of Nursing over the years. All the women were invited and the advocates took the position of staying beside the women and not chairing or facilitating any of

the meetings. Our sense as advocates was that the women appreciated the opportunities to speak directly with managers and raise their concerns.

However, there was some frustration in having meetings when there was no progress to report so the women decided they only wanted to meet with managers when there was something to report to them or they had concerns they wanted to raise.

6.3 A Note on the impact of Changing Managerial Roles on the Advocacy Process.

Managerial roles were inconsistent both when the HSE was holding interim responsibility and when the Service Provider took over. In 2022, a level of consistency was found that assisted the women in understanding who was making decisions and held responsibility for all elements of the transition. The movement of managers was always difficult for the women and the advocates and it was helpful in the last two years to have some stability of management to develop communication.

It is important to note here that HSE management changed three times whilst the Religious Order and the HSE were addressing issues through the High Court. At this time little was done to progress what the women were asking about, namely 'the houses'. The delays due to no permanent responsibility being held by a service provider until the Service Provider took over in 2021 meant that trying to ensure the voices of the women were heard in this context was difficult. The Director of Nursing did play a critical role and was always open to respond quickly and with intention.

Below is one quote from her feedback which indicates the critical importance of independence. Her full feedback can be found in appendix four.

'The advocates informed me of the concerns raised by the women and gave me an opportunity to address them.

They were aware of the limitations I operated under and took matters further up the hierarchy when I indicated my inability to address an issue.'

(Director of Nursing)



Responses from the Service Provider Regional Manager with responsibility for the transition process included:

"SHEP is a vital element in supporting those marginalised by the label of their disability. In supporting the voice of the person – they hold the system and all stakeholders to account. Ensuring a rights-based approach in line with the UNCRPD. They are committed to working in positive solution-based pathways which is both helpful and supportive for the best outcome for the individual. '

'The utilisation of SHEP as an independent advocacy service was an essential element in the de-congregation process as it fulfilled the aims of its role. SHEP staff enabled and ensured the women's voice remained central to the process by supporting them to have their voice heard and by continuing to articulate/promote their voice."

(Service Provider Regional Manager)



07 SOME SIGNIFICANT ACTIVITIES

The priority for the women throughout our time with them remained 'the houses' and whilst this was core to our work, there were many other matters that arose. Below are some examples that were responded to.

1. Access to Independent Advocacy: Gaining Access to The institution as independent Advocates.

There is as yet no statutory right of access to independent advocacy. SIAS had established a level of expertise and experience within other institutions in the arena of de-congregation and independently facilitated group advocacy. Therefore when the institution was finally inspected by HIQA, it was possible to find a way to access the service supported by HSE representatives who we had been liaising with.

2. Capacity Building

Establishing a process of communication that included the women and being

witness to that development and the capacity of the women themselves to self-advocate in many instances was an important part of the process. However, it is important to note that the protection of the group also allowed for anonymity when there was fear of reprisals for causing trouble.

3. Financial Irregularities

Throughout the seven years, the matter of 'financial irregularities' identified in the first HIQA report remained outstanding until 2023, when the women had moved out. The advocacy work involved in keeping this matter live and it being brought to a conclusion was arduous. Appendix two shows a timeline of events, that was eventually taken to the Confidential Recipient (Grainne Cunningham) in order to try and conclude the matter. The matter was concluded in the summer of 2023 with all of the women being given a written apology, a meeting with a manager supported by independent advocacy and a record of their accounts to show discrepancies and rectifications. In her feedback for this review the Confidential Recipient said:

'It was a pleasure to work collaboratively with (the SHEP advocate). She did an excellent job of advocating for the women in (the institution), ensured their voice was heard, and stayed the course to reach resolution to their benefit.'

4. HIQA Inspections & Developing Relationships

We worked with the women on the role and purpose of HIQA and understanding what inspections were about. This culminated in the first invitation by HIQA to a group of residents to have tea and cake (made by HIQA staff) in the HIQA offices, once they had moved to their new homes. The intention was to celebrate and to encourage the women to feel more comfortable with HIQA and the inspectors. This was welcomed and appreciated by all.

HIQA practice now includes sending easy to read documents with information about the current inspector to people's homes before an inspection is due. As yet, HIQA Inspection reports do not come in easy to read format, something we have asked for over the years.

5. Empowerment

The women were supported to invite managers to meetings, agree the matters they wanted to raise and space to self-advocate and speak as representatives. This, together with confidential spaces and time with

independent advocates enhanced their sense of their own empowerment.

6. Food and Rights

Interest in food and diet among the women led to a session with a dietician.

7. Bullying

We also looked at policies e.g. on bullying and made representations for changes.

8. Contracts of Care and informed Consent

This was a major piece of work ensuring that this was not a paper exercise and that the women were supported to understand the contents and be aware of their rights with regard to consent. On sharing our concerns with HIQA, staff were instructed to repeat the work with clear evidence of how the women had been included and supported in the new contracts of care process.

9. Living Environment and Rights

This related to the ongoing concerns about the general decline of the physical building with concerns about fire safety, water leaks with mushrooms growing on one bathroom wall and general decline with the building no longer being fit for purpose and not being maintained.

10. Charter of Rights

Throughout a number of meetings, the women spent time working on a Charter of Rights which provided a space for discussion, allowing for conversations about rights restrictions in many instances, both historical and current. This work culminated in the Charter of Rights being launched by the women

with staff at an event that aimed to be celebratory for all.

11. Money and Rights

We worked together on topics such as rights and money, access to money, managing money, financial abuse and we established contact with a bank manager.

12. Medication and Rights

We worked together on the topic of rights and medication. This included informed consent, access to reviews, use of PRN medication, access to information and being treated with dignity and respect.

13. Internal Advocacy Officer

In January 2023, the Service Provider recruited to the vacant post of internal Advocacy Officer with the advocate being allocated to prioritise the needs of the women. This happened alongside SIAS communicating with HIQA about a number of concerns that had arisen. There was concern within SIAS at this time that the service level agreement would not be continued as it came up for renewal. However concerted efforts were made by SIAS to ensure that the independent advocacy provided to the women was maintained alongside the Internal Advocacy Officer.

The experience of communicating with the internal advocate proved helpful to the women as this was an additional level of advocacy support. It also proved helpful to us as independent advocates as she was open to our role and saw the benefits of the our situation as independent.

This is a critical piece to consider in that we can all understand and practice the principles of advocacy but the positioning of the role is key.

Working with each other whilst maintaining boundaries as necessary can offer a helpful model. The internal advocate has access to more information than we may be able to access but may be limited by internal hierarchies and internal regulations and expectations.

By keeping communication open with the independent advocates, we worked alongside each other to serve the women.

In her feedback, the internal advocate stated:

‘Independent advocates are not bound by (the Service Provider’s) organisational policies, priorities or potential conflicts of interest that I might face as an internal Advocacy Officer. This allowed them to represent the women without bias or pressure..... They made sure that the women’s views and wishes were represented accurately. It was important to have independent support in order to build trust and confidence among the women, especially during a time of uncertainty.’

(Full feedback in Appendix Four)



08 SOME DIFFICULT MOMENTS

The time span over seven years was very difficult for the women.

Describing it as 'moment' doesn't suffice. We would often hear some of the women saying 'we are never going to get out of here', 'there's no point in talking about it any more, it's not going to happen'

The women were in the place of watching and waiting, with some women feeling that they would never get out, others saying they would only believe it when it happened and a minority who said they did not want to go, that this was their home.

A transition process was established over time by those responsible as staff members. However, the community that the women had established together became fragmented with people trying to find their way through this complex process, struggling with rejection if they were not 'picked' by other women to live with them and women potentially saying they wanted to live on their own because no-one wanted to share with them.

Relationships were strained. The management changes as already described were very difficult for the women. Trying to understand why the Religious Order had left, who was responsible for what, the difference between the HSE and HIQA were just some of the challenges for them.

Judge Aingil Ní Chondúin, in a district court hearing in 2017 on the matter of the running of the institution said:

'Someone has to come in and run it. Charity doesn't come into it any more. This is about vulnerable people and how we look after them... go to the high courts if you like and spend a fortune on costs if you like. Off with you. You have 24 hours to do something about this. Take your courage in your hands and sign on the dotted line. You can do anything by agreement.'

[Irish examiner March 28th 2017.](#)

As we know, this didn't happen and the women continued to try and find their way through these years in a building that really was decaying around them and a community that was struggling.

The advocacy meetings provided a space to raise their worries, to talk through concerns, to try and find responses and to try and be included and central to what was happening in their own lives.

The first deadline of March 2019 for the return of the property was extended to December 2023. As this second date approached it was clear this deadline had to be met as HIQA would not re-register The Institution. There was an expectation that the premises would be vacant and returned to the Religious Order.

The Institution finally closed in December 2023. Some of the women finally moved into their own homes with eight women moving to a 'temporary accommodation' whilst further houses were sought. As I write, one of the women who played a central role in the advocacy meetings, never missing a meeting, passed away three months after moving to temporary accommodation. We wish to acknowledge her vital contribution and involvement in the process. She is missed and there is a sense of sadness that her time in what she identified as her new home, was so short.

The remaining seven women continue to live in this accommodation with them saying that they are happy there and do not want to move again. They are in a smaller purpose built accommodation in a central location in the community. Our final task as we move into the last quarter of 2025 is to ensure that all efforts have been undertaken to support these women



to have every opportunity to consider another move and what this might look like.

We continued to visit the women through 2024, as they settled into their new homes and by Christmas 2024 there was a sense that they were settling into their new lives whilst they continued to self-advocate and advocate as groups especially regarding promises made that had not yet come to fruition.

'With SHEP, they built up genuine relationships where they felt comfortable to consider their options.'

(Feedback from frontline staff member)



9 PRACTICE NOTES FOR INDEPENDENT ADVOCACY

Aising from our experiences supporting the women through this decongregation process we have compiled some practical practice notes for Independent Advocacy Services undertaking similar work going forward.

9.1 Resources

This service has been operational for 7 years. Consistency and time was needed in order to develop relationships with the women and ensure their will and preference could be established and supported. Effectively resourcing this type of work is key in our experience.

9.2 The Group Advocacy Model

Group Advocacy enables space for empowerment, collective action and security when the fear of reprisal is of concern. It is not a common model in Ireland at this time but when access to one to one support is limited and fear is present, this collective/group model can be an important one.

9.3 Internal Advocacy Officer

Having the boundaried support of an internal advocacy officer is a model that warrants further development. Access to one to one independent advocacy support remains difficult due to limited resources nationally. The model described in this report offers an additional means of enhancing the voices of marginalised groups within a human rights based practice.

9.4 Supporting Staff

To implement cultural change is a key part of any transition. While this will not fall to the remit of an independent advocacy service, it is a key part of discussions with any service provider when beginning the process.

9.5 HIQA Inspections

More support for people with disabilities is needed to understand HIQA inspection processes. This may include questioning and challenging HIQA procedures from a human rights based perspective.



10 A NOTE ON THE HISTORICAL SIGNIFICANCE OF CAPTURING THE EXPERIENCES AND THE LOST VOICES OF THOSE WHO LIVED IN INSTITUTIONS

The women with their vast experiences of institutionalisation are not our history. Their voices are easily lost amongst the bureaucracy of change, the ongoing potential to pathologise individual responses to very complex and difficult conditions of life and the potential excuse of limited resources.

The history of institutions is no longer in the shadows in Ireland but the voices of those who lived in them are often lost in our telling of the stories. And we need them to be ever present so we can fully ensure that their lives now and the lives of all those who continue to live in an institution or supported living, never experience the silence of the past.

It is intended that this report and the work captured therein plays some small part in making sure we capture and record the ongoing legacy of institutional living for many in Ireland to this day.

CONCLUSION

Over the seven years, our involvement as independent advocates with this group of women meant we established strong and trusting relationships. We witnessed:

- loss of their community, friendships and long term staff that they had friendships with.
- conflicts between each other as they tried to navigate the changes.
- fear of what was happening, of the future, of how they were going to manage, of all the details that went into a massive change in their lives.
- hope of a life that they had wanted and waited for over many years.
- friendships being maintained, support given to each other being critical to the women in managing the every day and the longer term.
- voices that were strong, resilient, assertive, yet wary and cautious about speaking out and speaking up at times.

We also witnessed a cultural shift emerging across The Institution with staff. **This is a key area of transition that requires more support.** It remains a major concern in that service providers become so pre-occupied with the practicalities of the physical move, **that time and attention for staff to be supported to consider and implement required changes of practice were not available, as far we could witness.** This despite the fact that staff institutionalisation can hugely impact on the quality of life for the women.

This was also evident from the concerns some of the staff brought to us, saying at times, that the women were better informed than they were. The routes we created for the women to have voices meant that they in turn were better informed. It is not for the pages of this review to examine this in detail but it is of important note.



During these years, we were also witness to the commencement of the long awaited **Assisted Decision Making (Capacity) Act (ADM Act) 2015** which was signed into law in December 2015 and fully commenced in April 2023.

This law, which replaces the Marriage of Lunatics Act 1811 and the Lunacy Act 1871, is beginning to play it's part in the paradigm shift we are experiencing towards a culture of human rights based person led connections. It is playing a role in the move away from the culture of institutionalisation, 'best interests' and restrictive practices in all their guises, which are not only connected to physical spaces. We have a long way to go, but this change in the law gives support to all efforts in this transition.

It is helpful for all of us to keep the core principles of this legislation in our hearts and minds and they are:

- Presume every person has the capacity to make decisions about their life
- Support people as much as possible to make their own decisions
- Don't assume a person lacks capacity just because of an unwise decision
- Only take action where it is really necessary
- Any action should be the least restriction on a person's rights and freedoms
- Give effect to the person's wishes, values and beliefs
- Consider the views of other people
- Think about how urgent the action is
- Use information appropriately

The Statutory Office of the Director of the Decision Support Service was established under the ADM Act and provides a code of practice for Independent Advocacy.

Independent Advocacy is of critical importance in assisting in this paradigm shift. The debate about a statutory right of access to independent advocacy is ongoing in this jurisdiction. In the meantime, we hope that our efforts as a small independent advocacy project can continue to contribute to this debate, whilst doing what it has been doing for over twenty years; providing independent advocacy to people on the margins and excluded from their rights as citizens in the 21st century.

Deirdre Lillis
May 2025





ACKNOWLEDGEMENTS

We would like to extend our deepest gratitude to the women for trusting in us throughout a very difficult and lengthy process.

Thank you to all the SHEP advocates who worked so tirelessly during our time with the women.

Thank you to the HSE and the Service Provider for supporting and enabling the women's access to independent advocacy support.

And thank you to all those who have worked and continue to work to ensure that the voiceless have their say.

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APPENDIX.

Appendix One.

Sample Service Level Agreement.

This format was initiated with the HSE, adapted on an annual basis to continue with the agreed funding of the project that in turn passed over to the allocated Service Provider (CAS changed to SIAS in 2019.)

Proposal to Develop a Self-Advocacy Group at 'the institution' (2017)

Cork Advocacy Service (CAS) has been invited to develop and facilitate a self-advocacy group in 'the institution'. Access to one to one independent representative advocacy is through Sage and the National Advocacy Service (NAS). This additional advocacy support provided through CAS is intended to enhance access to advocacy through Group Advocacy.

CAS will work with NAS and Sage, ensuring that people are supported to access one to one independent advocacy when requested or considered required.

The National Policy & Procedures; Safeguarding Vulnerable Persons at Risk of Abuse launched by the Social Care Division, HSE in December 2014 states:

' Group advocacy is an important form of advocacy that has the potential to move self-advocacy to a higher level and it should be encouraged, supported and developed by service providers.'

(7.3.4. Advocacy)

The Health Information Equality Authority (HIQA) also encourages group advocacy through the development of Residents Meetings and Service User Forums.

CAS has experience of providing independent advocacy since the late 1990s. All contracted and volunteer advocates who work with CAS are trained at FETAC/QQI Level 6 and some have additional training in facilitation.

CAS has experience of facilitating Group Advocacy in other congregated settings in Cork. The independent facilitation of Group Advocacy can contribute to supporting the people who use the services of 'the institution' through:

- Supporting people to have a voice in decisions about their own lives including when 'a voice' may not be one that communicates through the spoken word.
- Supporting people to have a voice in the planning and delivery of services in their home. This will include developing a Charter of Rights for residents and incorporate other ideas for positive change identified by the group.
- Supporting people to be included in the plans for de-congregation.
- Supporting people to move towards full citizenship beyond the services of the institution
- Facilitating the Advocacy Group from the principles of Human Rights Based Practice.

This will be a new experience for people living at the institution. In order for this work to be supported the following actions will be taken:

1. Two independent advocacy facilitators will be identified and contracted to undertake this work for a 12 month initial period.
2. Link person or people will be identified by the institution to communicate with the Advocacy Group and advocacy facilitators.
3. Meetings with staff will be held to explain the role and intention of facilitating Group Advocacy.
4. Meeting with family members will be offered to explain the role and intention of facilitating Group Advocacy if required.
5. Meetings to begin in January 2017 and to happen once every two weeks.

Agreement would be required on the following:

- Advocacy Group meetings are confidential to those attending.
- There will be no staff in attendance unless the Advocacy Group have agreed and invited a particular person.
- The Advocacy Group meeting will have the right to decide who to invite as external speakers/guests.
- Attending the Advocacy Group is not compulsory.
- The advocates will keep a record of numbers attending the advocacy group meeting and a brief summary for the advocacy group's records. As part of the advocacy group's development, discussions will include what the group might wish to share with HIQA should they want to see the advocacy group records.
- Any issues that are to be taken forward with the agreement of the group will be put in writing for the link member of staff and a written response will be provided.

In addition

The Cork Advocacy Service Co-ordinator will:

- Provide information sessions with staff and family members.
- Attend any planning and review meetings.
- Recruit contracted independent advocacy group facilitators.

- Attend Advocacy Group meetings as and when required,
- Support the development of the Advocacy Group and provide support and supervision to the Independent Advocacy Facilitators.
- Provide publicity materials e.g. posters, letters of invitation and any other method that assists residents to participate in the Advocacy Group if they wish to.

'The Institution' will provide:

- Link worker(s) who will liaise with, bring information and assist the Advocacy Group in finding responses as necessary.
- Venue – private room for meetings.
- Refreshments for meetings.

Appendix Two

Anonymised example of advocacy involvement with one issue to illustrate timeline and advocacy process which was then provided to the Confidential Recipient when support was sought. This related to an outstanding issue relating to an independent audit.

Timeline in preparation for meeting with Confidential Recipient on September 4th 2023

1. September 2016 – from HIQA report.

'HIQA received a letter from the Chairman of the Board outlining alleged financial irregularities in the centre.' Independent auditor appointed by the Religious Order.

'identified a significant shortfall in residents' private property accounts '

Second audit of resident finances commissioned by HSE.' Yet to be completed' (Ref HIQA report on visit carried out on 15th September 2016.)

As far as I am aware it is this audit that is still awaited and to which (HSE Disability Service Manager) refers to in the most recent of email correspondence.

2. Series of SHEP Advocacy correspondence with (accountants) to request updates on when audit to be completed and request that all women have a statement of their financial accounts.

No success. Just advised 'not completed'....

As we now know from (Disability Services Manager) (2023) the company who have since been instructed is

3. Correspondence with Religious Order.

Letter received 11th January 2018 following my attempts to get a response from (accountants)

'suggested inappropriate use of Residents' personal funds to pay for running costs ..'

Offered 'reassurances' ...'repaid'....but two outstanding...

Response from SHEP Advocacy sent February 2018:

Having shared contents of letter with the women, further questions raised and womens' serious concerns raised.

No further response to request for every resident to receive an individual response in relation to their personal account and current financial status following independent audits.

(Matters of responsibility between HSE and Religious Order were in the courts at this point.)

(Another HSE disability services manager) who was dealing with the matter in regional HSE office (was.....prior to) requested a copy of letter from Sr and consent was sought and given for me to do so.

May 2018 letter from Sr ...seeking necessary information from HSE (confusion around role of advocates) to conclude the matter re one living and one deceased . No mention of interest accrued.

So many gaps here for us as independent advocates with no rights of access to information.

4. Letter to HIQA raising the matter. March 2018

Letter to HIQA (and HSE Manager) raising the matter December 2018

January 2019 still chasing accountants and HSE.

5. June 2019

Ongoing correspondence with proposed Service Provider and HSE and meeting held on 8th July 2019 between the residents and HSE Manager and proposed Service provider CEO which included again raising concern about the outstanding independent audit.

6. September 2020

Mediation between Religious Order and HSE reaching a conclusion. (see HSE email 2nd September 2020 This is where 'historic issues' were then to be addressed including, as I understand it, the independent audit.

Still asking HSE 'whether the initial concerns about alleged financial irregularities have been addressed and whether the HSE is satisfied that all the womens' accounts and finances are in order'

7. October 2020

From HSE

'the HSE is currently working to conclude the matters relating to the financial audit of the residents' funds...this will take a number of weeks and will require support from an external party to conclude the audit.'

June 21 (15th) letter sent to ombudsman. No reply.

June 2021:

From HSE

'As indicated previously I have engaged an external company around the concluding of the audit. We are currently reviewing what stage they were at in 2016/17 and putting the plan in place around timelines for the next steps. I am sure you will understand, it is a complicated process given that these are not HSE records. Please assure the residents that we are working on same and I will revert as soon as possible. '

December 2021 -concern raised again with HIQA

May 2022. Letter to HSE

Response from another manager as left his post. June 22.

September 2023

The issue has remained outstanding with the matter being transferred to (another HSE manager) and ongoing emails to seek conclusion with most recent response being: '(Accountants) will start progressing this work next week. They have advised It hard to gauge the time required to complete the work but will work towards having it completed before month end and keep my office updated if there are any deviations from this.' (4.8.23)

August 2023 - Correspondence shared with CF and Ministers for Health and Disability

August 2023 - Question raised with Service Provider re this being a potential financial abuse safeguarding matter.

Summary of situation:

As independent advocates we have been informed that:

The independent audit is still outstanding with possible interest due to some women noting that some women have passed away in this time and some have moved to other accommodation. (HSE)

As far as we know. the women have not been advised in writing individually as to historical and current status of their personal accounts.

We have raised this matter on an ongoing basis with three HSE regional managers, with the CEO of the Service Provider and with HIQA inspectors. (Most recent correspondence advised that HIQA continue to pursue this matter with service provider.) We have also written to the ombudsman's office with no reply. We have been advised as on many occasions previously, that the matter is close to being concluded.

We have been advised that should the audit advise that monies are owing to any of the women, this will need to be reimbursed by the Religious Order. We have no idea how the women will be supported to do this should this be necessary.

No clear account of this matter has ever been given to the women as far as we know and no apology made.

This is only one of many matters that the advocates have supported the women with over the years and it is not one that the women raise regularly. They are far more concerned with leaving and finally getting a home of their own. However as witnesses to this issue and in the context of supporting the human rights of all the women, some of whom are not in a position to raise this matter themselves, we have sought to keep this issue live until all the women are advised that this matter has been addressed and an apology issued.

Appendix 3

Responses received from residents via easy to read feedback form and with the support of the Internal Advocacy Officer.

15 responses received.

Responses from the women. (September 2024 when all had moved out)

1. Was it helpful to have (names of the advocates) coming in?

All said yes.

2.If you thought it was helpful can you tell us why?

- 'I'm very fond of them. They listened to us.'
- 'Oh it was yes, we used to talk about the place, we used to talk about moving in here.'
- 'We weren't getting the information back ever. They helped us with that. They gave us information. They helped us with the overpaying of the money. I was paying too much rent to the sisters. I didn't even know I was overpaying to the sisters. That was a good few years ago now. They helped us get that money back. I got my money back a few weeks ago.'
- 'When I was asking questions they answered them for me. They made it clearer. They gave me the answers.'
- 'I don't know. I can't think. They did a good job.'
- 'They told us where we were going. They talked to us about being in they houses. They said we have to be gone by Christmas. (Advocate) used to be saying to me 'I hope you'll be very happy.'
- 'I can't really remember their faces but I remember them coming in. They were very fond of me and (sister) especially. I knew they were honest.'
- 'They came to (institution). They were doing their jobs. Looking after us I suppose. Things are better now. They were good.'
- 'Because to learn our lessons. It was good when they were all talking except me.'
- 'I remember that alright. Things were being kept quiet. She made sure we knew about the thing that were being kept quiet.'
- It was very helpful. They were grand
- (advocates) are lovely. Tell them to come up another day. They were her the other week and they stayed about two hours. We had great chat and we were together. They were lovely girls.'
- 'They were very kind and everything and they listened to you. Tey came to visit me. I'd be still there only for them to be honest with you. (referring to nursing home.)'

3. Was there anything you didn't like about (names of the advocates coming in?

- 'No I didn't mind them really. They were nice.'
- 'I had no problem'
- 'No they were not bad. They were good.'

- 'No but sometimes I couldn't hear them with all the others talking.'
- 'No complaints about them.'
- 'No I didn't mind them coming in. They were very informative. They gave us the right information about what was happening.'
- 'No we used to love them coming in. They were telling us how things were going.'
- 'Ah no I wouldn't say a word against them. Sure they were very kind.'
- No x 7

4. Is there a thing else you want to say about the work (names of the advocates) did with you since 2017?

- 'They worked very hard. I liked that I could speak to them privately.'
- 'They did a lot of hard work with us to be fair. They were fighting for our rights all the time. The two of them are very nice to be fair. They'd fight hard to get the things we wanted. They'd fight hard to get what was owed us.'
- 'Myself and (advocate) are very great. I miss (institution) terrible. I miss it so much. I felt I had no choice. I didn't want to accept it. We're paying for cabs because we're not getting our own car. (A) said we shouldn't have to pay for taxis. I don't have a penny left over the taxis. '
- 'They are kind and lovable.'
- 'They work very hard. Give my love to them.'
- 'I was very delighted with the work they did.'
- 'They said there would be money owing to us but it mightn't be everyone. And they came here and they said it was the ones who worked in the laundry.'
- 'I would like them if anything went wrong with (sister) to come along to the removal.'
- 'It's all good and I'm happy since'.
- 'No, I don't know what else to say. Have I said enough? I don't know anything else.'
- 'Will they be coming to see me again? We had nice conversations. There was a couple of us down there and we had our own space to talk.'

Appendix Four:

Feedback from practitioners. August 2024

1.Feedback from the Director of Nursing:

What was helpful about the SHEP independent advocacy service ?

I was Director of Nursing from 2016 to 2022 and The SHEP Independent Advocacy Service was present with the women in the centre for most of my tenure. The service was very beneficial to me as I was reassured that the women could express their opinions and will and preference openly and secure in their anonymity without fear of upsetting my staff or myself. Issues could be discussed openly and confidentially with the advocates. The women in the institution appreciated having this service available to them and many looked forward to the meetings. Some also used the service to discuss and address personal issues that needed addressing outside of the remit of the centre. The advocates informed me of the concerns raised by the women and gave me an opportunity to address them. They were aware of the limitations I operated under and took matters further up the hierarchy when I indicated my inability to address an issue.

What was unhelpful about the SHEP Independent Advocacy Service?

I was not aware of anything unhelpful, in fact the service enabled me to address issues directly with some member of staff who needed to be reminded that we were working in the womens' home.

Towards the end of my time in the institution however I became aware that I had come to rely on the advocacy service to inform me of complaints the women might have. I feel I misused the service and should have given more focus to nourishing a culture where the women felt comfortable making complaints to the staff, myself or other members of the management team. This would perhaps have left more time for the Advocates to work with the women on their will and preference regarding the transition

.

Anything else you would like to say about the SHEP Independent Advocacy Service?

As carers we often assume clients will tell us when they are unhappy with a process or practice within the centre where we work. We forget there is an inherent power dynamic that makes it less likely that clients will make a complaint or express concerns. This is even more prevalent in long-term care settings when client and staff know each other for years or as in the case of the institution sometimes decades. A service such as the SHEP Independent Advocacy Service enables clients to raise issues and concerns confident that these will be raised anonymously with management. It returns a voice to clients of the service and enables individuals to realise or remember that they people with rights which should be respected.

2. Feedback from front line staff:

What was helpful?

- (The advocates) were a crucial support to our residents. The transition process was very difficult for our ladies. It was a very anxious time for all. There was a lot of uncertainty about where the ladies would live, who they would live with. Many of our residents were reluctant to leave (the institution).
- The advocates were always helpful and supportive to our residents.
- It gave the ladies a voice to air their concerns on a safe place
- The ladies were happy with getting help
- Yes it was helpful for our residents to receive support with moving to their new homes
- Supported a resident with personal information and advice given how to receive more supports.
- It was very helpful to have the support of the SHEP independent advocacy service during this time. The women reported that they felt that they were listened to and had their voices heard.
- Having (the advocates) support was also helpful for me too. Independent advocates are not bound by the service provider's organisational policies, priorities or potential conflicts of interest that I might face as an internal Advocacy Officer. This allowed them to represent the women without bias or pressure. Having independent advocacy ensured that.... was held accountable. the advocates provided an external check on practices, ensuring that the women's rights were genuinely prioritised. They made sure that the women's views and wishes were represented accurately. It was important to have independent support in order to build trust and confidence among the women, especially during a time of uncertainty.

What was unhelpful

- There was nothing unhelpful!

Anything else you would like to say

- It was very helpful to the ladies because their concerns were listened to and in some cases acted upon.
- They assured the ladies that everything would be ok
- Residents reported that they received a 'listening ear'.
- Residents reported that they were being listened to.
- Good advice and guidance given.
- It was traumatic for most residents to close (the institution). SHEP Independent advocacy made their transition easier. Thank you.
- (The advocates) took the time to listen to the ladies and follow up on what was discussed.

- Sometimes the ladies can get annoyed and frustrated when they keep reporting the same issues and feel they are not being heard. However the understanding with SHEP was that if something was possible to achieve it would be achieved and if not possible, it would be discussed and an alternative solution/compromise would be reached.
- Not only have you advocated on behalf of the residents but you have supported and encouraged them to be self- advocates going forward.
- Sincere gratitude by both residents and staff for the care and gentle approach you took in guiding us all through the transition process.
- I felt that the external, independent advocacy complimented the work I was doing as an internal Advocacy Officer. They made sure that everyone's rights were defended without any potential influence from the service provider's internal priorities and limitations. I knew the internal running of the organisation and was privy to what was going on within. The blended model of internal and external/independent advocacy worked well in this situation.
- I want to thank the advocates for all the support they gave to the women during the move. It really was a pleasure to work with you, and I felt that everyone was in safe hands!
- I look forward to working with you again in the future.

3. Feedback from Service Provider Regional Manager

What was helpful about the SHEP independent Advocacy Service?

The utilisation of SHEP as an independent advocacy service was an essential element in the de-congregation process as it fulfilled the aims of its role. SHEP staff enabled and ensured;

1. The women's voice remained central to the process by supporting them to have their voice heard and by continuing to articulate/promote their voice.
2. continued to support the women's voice to influence every stage of the de-congregation process and ensured their will and preference was included.
3. that the individuals were enabled to have control as much as possible over their lives going forward.
4. the wishes of the individual women were represented without judgement or the influence of personal opinion.

SHEP working in partnership with the women and the organisation has been a very positive process for all stakeholders. Feedback from the women has indicated they enjoyed and appreciated meeting with the SHEP team and found it helpful to have a safe space to talk about the process and what they wanted.

What was unhelpful about the SHEP Independent Advocacy Service?

Engagement was limited by resources and funding. More scope for individualised meetings and more access for the women to engage in more individualised pathways

would potentially have added to their experience and capturing their voice.

Anything else you would like to say about the SHEP Independent Advocacy Service?

SHEP is a vital element in supporting those marginalised by the label of their disability. In supporting the voice of the person – they hold the system and all stakeholders to account. Ensuring a rights-based approach in line with the UNCRPD. They are committed to working in positive solution-based pathways which is both helpful and supportive for the best outcome for the individual.

It is a service that is desperately needed in Ireland and should continue to be funded and supported.

4. Feedback from Confidential Recipient

What was helpful about the SHEP independent Advocacy Service ?

In my role as Confidential Recipient, I provided advice on how to progress the issues at hand. I found the SHEP advocate very committed to the service users and her empowerment and resolve was excellent.

What was unhelpful about the SHEP Independent Advocacy Service?

It was very good.

Anything else you would like to say about the SHEP Independent Advocacy Service.

It was a pleasure to work collaboratively with (the SHEP advocate). She did an excellent job of advocating for the women in the institution, ensured their voice was heard, and stayed the course to reach resolution to their benefit.

5. Feedback from HIQA Inspector

'it's good to see there is follow up.

Unfortunately I am unable to comment due to my brief as we were very involved in the regulating of these services and I must adhere to the functions within the act otherwise I am in breach.

However thank you'

6. Feedback from Internal Advocate

What was helpful about the SHEP independent Advocacy Service?

It was very helpful to have the support of the SHEP independent advocacy service during this time. The women reported that they felt that they were listened to and had their voices heard.

Having the advocate's support was also helpful for me too. Independent advocates are not bound by the service provider's organisational policies, priorities or potential conflicts of interest that I might face as an internal Advocacy Officer. This allowed them to represent the women without bias or pressure. Having independent advocacy ensured that the service provider was held accountable. The advocates provided an external check on the service providers' practices, ensuring that the women's rights were genuinely prioritised. They made sure that the women's views and wishes were represented accurately. It was important to have independent support in order to build trust and confidence among the women, especially during a time of uncertainty.

What was unhelpful about the SHEP Independent Advocacy Service?

There was nothing unhelpful!

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I want to thank the advocates for all the support they gave to the women during the move. It really was a pleasure to work with you, and I felt that everyone was in safe hands! I look forward to working with you again in the future.



