



Advocacy: Nothing about Us without Us
in the
Brothers of Charity Services
By Claire Power & Siobhán Flynn



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by Claire Power and Sinéad Flynn

Peter Triest Publications

Kilcornan House

Clarinbridge

Co Galway, Ireland

H91 K2E9

e-mail: petertriest.publ@bocsi.ie

ISBN 978-1-8382723-3-3

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In the Brothers of Charity Services, management teams want to hear the voices of the people we support; we want to know their lived experience of being supported by our Services; we want to know how to improve what we do and how we do it. We trust that the Advocacy structure we have in place supports people to have their say and that this structure provides opportunities for people supported to meet with management at different levels throughout the Services. The structure ensures that managers meet with advocates to seek solutions, to resolve problems and concerns, and to create new possibilities and opportunities.

Mary Carty, Services Manager South East Region

Series Editor: Patrick McGinley

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Contents

- 2 Authors: Claire Power and Siobhán Flynn
 - 3 Foreword: Professor Mary McCarron PhD, Trinity College Dublin
 - 4 Introduction: Claire Power
 - 6 The Structure of Advocacy in the Brothers of Charity Services,
Mary Carty
 - 8 Jackie Sampson advocates with an External Body
 - 9 Pat Flaherty describes an Advocacy Success Story: Accessibility in Gort
 - 13 Self-Advocate Claire Nagle tackles the term “Service User”
 - 15 The Role of the Advocacy Supporter, Sarah Meek
 - 17 Advocacy from the perspective of Supporter Emily Walsh
 - 18 Advocacy Supporter Ann Holden describes the “*What’s Different
About You?*” Project
 - 21 The Caritas-Beechlawm Advocates meet several External Bodies
 - 24 Michael O’Toole worked with other groups to make Information
more Accessible
 - 25 Seven Important Advocacy Targets for the 2020’s, Siobhán Flynn
 - 27 References
 - 28 Acknowledgements
-

The Front Cover: Claire Power,
Chairperson of the Brothers of Charity Services National Advocacy Council

My motto for all my advocacy work is, Believe and
you can achieve, don’t ever be afraid to speak up,
you can make a difference and bring about change.

Give it a go.

Pat Flaherty



The Authors: Claire Power & Siobhán Flynn



Claire Power was born in Kilkenny where she completed her school education. During this time she lived in a large house with fourteen other children. Once finished school, Claire moved to Waterford City and attended a number of day services in the Brothers of Charity Services Southeast. She lived in a number of different community houses throughout the years and currently lives, with some support, sharing with a family member in their lovely home in Waterford. For the past number of years Claire has been involved in advocacy within the Services and has developed her skills as an advocate not only for herself but also for all the people supported by the Services. In 2015 Claire became a student of Waterford Institute of Technology on a part-time basis and successfully completed a two-year certificate in “Skills for Independent Living”. Claire is an avid fan of Liverpool Football Club and she loves watching films and listening to all kinds of music.

Siobhán Flynn was born in Waterford City. In 1996 she moved to



Dublin where she initially worked in St Luke’s Hospital before embarking on a Community Care course with St. Michael’s House. Siobhán spent nearly 10 years working in St Michael’s House in day services with adults with an intellectual disability. During this time she also graduated with an honours degree in Applied Social Studies with the Open Training College. In 2007 she moved back to her home county and has worked for The Brothers of Charity Services since 2008. Siobhán gained a Certificate in Training with the National University of Ireland Galway in 2010. Her current role is Learning, Development and Advocacy Officer. Her role as advocacy officer is to support the people within the Service to stand up for their rights both within the Services and in their everyday lives. Most recently she has returned to education and is studying for a Certificate in Management with the University of Limerick. She loves to travel, all kinds of sport and loves her county of Waterford.



Foreword

Professor Mary McCarron PhD, Trinity College Dublin

On reading this book I am reminded of the power of having a voice. For too long, the voice of people with an intellectual disability in Ireland was silent. But, with this book, the authors have shone a light on the power of advocacy, and the many ways that advocacy has given voice to the people with intellectual disability who are supported by the Brothers of Charity Services.

This is something that I strive to achieve in my research at Trinity College Dublin, particularly through the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) and the Trinity Centre for Ageing and Intellectual Disability. Inclusion is our core value, and by including people with intellectual disability in all aspects of our work we hope that their true voices emerge.

The inspirational stories throughout this book demonstrate how powerful advocacy can be and how much can be achieved when people with intellectual disability make their voices heard. Groups such as the National Advocacy Council of the Brothers of Charity Services and the other advocacy groups highlighted throughout the book are critical to enabling these voices.

The book also highlights the critical role that services and support staff have in empowering people with intellectual disability to make their voices heard in every aspect of their lives – *and in listening to those voices.*

This book serves as a reminder of the importance of listening to people, especially to those quiet voices that can sometimes get lost in the rush of service delivery and the demands of everyday life. It is especially welcome at this time, after we have endured so much as a society living with COVID-19 during the past year.



I commend the authors, Claire Power and Siobhán Flynn, for their vision and for producing a wonderful and inspiring book, and indeed I look forward to seeing the other books in the planned Series throughout the year.

Professor Mary McCarron, Trinity College Dublin

Introduction

My name is Claire Power and I am the current Chairperson of the National Advocacy Council of the Brothers of Charity Services Ireland. This is my second year of a 3-year term as Chairperson. The members of the National Advocacy Council work together to plan strategies to try and solve issues that have not been resolved at regional level. The Council also meets directly with the National Leadership Team of the Brothers of Charity Services and we work closely with them on how the Service can ensure that the Rights of all people supported are protected - and, most importantly, that we are never forgotten when decisions are being made that may have an impact on our lives. As Chairperson of the Council I am very fortunate to work closely with the representatives on the Council from our four Regions and I have gained great understanding of how our role on the Council can really help the lives of people supported by the Services.

Every year the National Advocacy Council hosts a National Advocacy Conference including a Conference Dinner and dance - a great evening very much looked forward to by everyone. This Conference has been held every year for the past 22 years and it continues to grow from strength to strength both in interest and influence. It is a great opportunity for all four Regions to promote advocacy to our peers, the staff who support us and importantly, the National Leadership Team.

I am delighted to work closely with representatives from the Council on this Booklet, *Advocacy: Nothing about US without US*. I hope you enjoy reading about the story of advocacy within the Services and some of the major achievements throughout the different regions for us as



advocates. We continue to work actively towards a better understanding of advocacy for all - you will quickly see evidence of the extent of this if you glance at the photographs in our Booklet. Just look at some of the people we are proud to have been in touch with recently including EU Commissioner for Financial Services, Mairead McGuinness MEP and Minister of State for Disability, Deputy Anne Rabbitte TD. All the time we seek to promote the Rights of all people who need support, on our journey to be treated as equal members of our communities around the country. We have a lot of achievements to date, but we have a lot more to do as you will see in our Booklet.

The first Brothers of Charity Services National Advocacy Conference was held in Galway in November 1998. On that historic occasion the National CEO Winifred O’Hanrahan warmly congratulated advocates Anne Mahon, Christina Burke, Joe McGrath and others who were among the new group of National Advocacy leaders.

The first meeting of the National Advocacy Council took place at the Woodstock Hotel, Ennis in May 1999. The Galway CEO described this first CEO / NAC meeting as “*a power shift*” and “*a sea change*” in how services would be run in the future. Advocates talked for the first time about “*having a say in how Services are run*”. These changes were a significant part of the continuing change from a “Medical Model” to a “Social Model” where people availing of support take much greater control of their lives and are supported to create their own presence in, and contribution to, their community.



The Structure of Advocacy in the Brothers of Charity Services, Mary Carty

In the Brothers of Charity Services, management teams want to hear the voices of the people we support; we want to know their lived experience of being supported by our Services; we want to know how to improve what we do and how we do it. We trust that the Advocacy structure we have in place supports people to have their say and that this structure provides opportunities for people supported to meet with management at different levels throughout the Services. The structure ensures that managers meet with advocates to seek solutions, to resolve problems and concerns, and to create new possibilities and opportunities.

Self-advocacy - Everyone has the right to be heard and supported to advocate on his or her own behalf. An example arose when two people in a house wanted to get a few hens - but a third person didn't want hens. The local group asked to meet with the manager about this. The solution reached was that the hens would come to the house but that work was needed beforehand to get a coop and a "run" ready for them; and the third person didn't have to have any involvement in preparing or looking after the hens at all. Everyone's opinion was listened to and they were happy with the outcome.

Local Advocacy Group - There is an advocacy group in every day and residential setting in the Services to discuss issues, concerns, and opportunities at a local level. For example planning the Christmas Party revealed that some people wanted a band and others wanted a disco, and the venue had to be agreed. The manager met the local group and set up a "field team" which went to different hotels with a questionnaire and came back to the local advocacy group with the information. Then a vote was taken and the solution reached namely, the hotel was agreed, and there would be a disco after the band on the night. People were listened to, they made the decision and were happy with the outcome.



Regional Advocacy Group - There is an advocacy group in every region of the Services to bring together representatives from each local group to discuss issues that cannot be resolved at local level, and that may affect a number of people across the region. The regional group meet with members of the regional management team and the Director of Services at least quarterly. For example during Covid-19, everyone in the country was restricted in line with Government guidelines but when shops, hairdressers, restaurants and so on reopened for the wider community, some people who lived in supported houses were ‘not allowed’ to go to these places on their own as they had before the lockdown. Naturally, people felt they were being unfairly restricted and treated differently to others in the community. The solution reached was that people needed to be supported to learn how to social distance, to wear masks, socialise and go shopping in these times of Covid. That was the only real way people could learn to be back out and about in the community. The managers were restricting people’s movements with the best of intentions but they were restricting the rights of people. The solution acknowledged that people supported have the same right to access all amenities in the community during the pandemic as everyone else and needed to be supported to do this safely (see Phelan & O’Regan, 2021).

National Advocacy Group - There is a National Advocacy group which brings together representatives from each regional group, to discuss issues that may affect a number of people across the country. The group meet members of the National Leadership Team and Chief Executive twice a year. A National issue of concern is that people we support want to be involved in recruiting the staff who will be supporting them. This has been difficult to implement in some places for various reasons but a solution was reached that ways will be found to ensure that people can participate in the staff selection process. The National Leadership Team agree, and all regions have to find ways to make this happen.

As managers, we have to LISTEN to what people are saying; we have to HEAR what is being said and we have to ACT with INTEGRITY, leading by example and WALKING THE TALK.



Advocacy - *Jackie Sampson* advocates with an External Body

Jackie is a friendly, outgoing young man who loves socialising and spending time with others. Jackie lives in Newcastle West in Co Limerick. The house that he lives in is supported by staff 24 hours a day but Jackie really wanted a chance to attend a Day Centre where he could meet up with friends from other parts of the Services. In 2016 Jackie looked for support from the Regional Advocacy Council to help him advocate for a day service placement.

The Regional Advocacy Council met with the Senior Management Team but were told that there was not enough money to provide a day service for Jackie. The Senior Management team advised that they must work within the budget set by the HSE.

This gave the advocacy council an idea! They decided it was time to speak directly to the people in the HSE who make decisions about funding. They invited the Head of Social Care for their Community Health Organisation (CHO 3) to their Regional Advocacy Meeting and one of the Regional Advocacy Council Members, Bernie, supported Jackie to tell his story. The Head of Social Care explained what an impact it made to hear directly from people supported by the services. He said, *“Meeting with the Advocacy Council brought the human face to stories”*. He realised from the meeting just how important a day service was to Jackie and agreed to fund a service two days a week. This was a huge moment for the Advocacy Council. It showed how speaking up and sharing stories can really impact positively on Quality of Life. Since then the Regional Advocacy Council meets regularly with HSE officials to share their stories and make sure that their voices are heard.



Pat Flaherty enhances road safety in Gort

Pat Flaherty describes an Advocacy Success Story: Accessibility in Gort

In 2007 I was introduced to the Gort Advocacy group. I wasn't sure if it was for me but I decided to go to one meeting to see and hear what it was all about. I always had issues accessing places and figured if I joined a group I would get to talk about my issues. I liked the idea of making a difference and improving accessibility for all.

At the meeting I got the chance to speak about the problems I was experiencing in my town of Gort, Co Galway. I got a lot of support as others at the meeting had experienced the same challenge that I had faced. We all wanted to feel equal and be more independent in moving around our town.

As a group we were very excited to take on an accessibility project, that was *about us for us* and for others in our town. We named the project "*Accessibility in Gort and its impact on people's lives*". We put together a document and backed it up with photographs. We highlighted issues with footpaths, parking, crossing the road, traffic lights, the 2-way system outside our Centre, and access to buildings.

We used quotes from people on our advocacy group to strengthen our document so people could hear at first-hand the voices of people living with a disability.

For me, I had the opportunity to highlight the issue I had with the traffic lights, the "Green Man" would stay on for only 10 seconds which allowed me get only half way across the road - I needed 20 seconds to get across safely. I got to highlight the accessibility issues I had with my bank, my favourite restaurant and the building where I had been offered a job.



Significant Success

As a group of advocates we met with local councillors who listened and made the changes needed. We got a ramp into the library, we got much safer parking in the town, funding was made available to make buildings accessible and I got the traffic lights issue sorted.

I found I really enjoyed doing this work and decided to continue going to meetings as I felt I could do more. I decided to take on a campaign to make the narrow roadway outside my Day Centre a one-way system. I decided this time to get a petition going. I got 700 signatures and gave it to Joe Byrne, a local councillor that I had got to know. The County Council changed it to a one-way system as a result of my petition, and now the roadway is safer for everyone. It felt great to get thanks from my neighbours, friends and locals for the work I did.

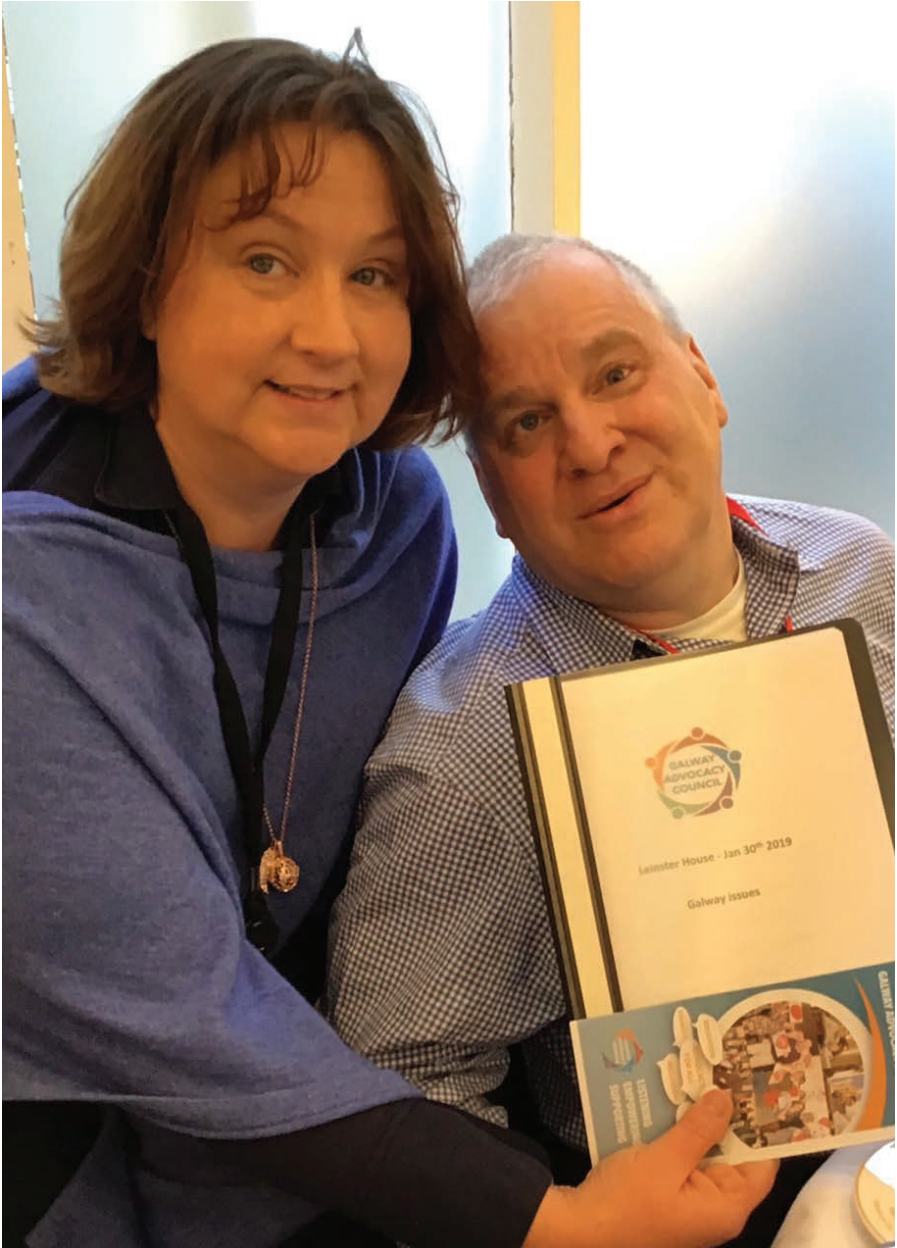
In 2018 I was elected by my peers to be the Galway Advocacy Council's Chairperson. As a result I am now involved in consultation with Brothers of Charity Services Senior Management, external organisations, TDs and even with Minister Anne Rabbitte TD.

My motto for all my advocacy work to date is, "*Believe and you can achieve, don't ever be afraid to speak up, you can make a difference and bring about change.*" Give it a go.

In February 2021 the Galway and Roscommon Regional Advocacy Team launched their own Video, *Information on Covid 19 Vaccine*. This video deals with the Covid-19 vaccination expected to become available in February. In the video, supported persons and some staff describe its purpose, the process of being vaccinated, possible side effects, and the choice which supported persons will be invited to make as to whether or not to accept the vaccine. It's well worth viewing, and considering - "Have you seen a better video anywhere on this important topic?"

Well done Pat Flaherty, Lorraine Mahon, Aoife Hegarty, Sarah Regan, Jackie Moran, Marian Spellman, Martin Dooher, Emily Walsh, Catherine Finnerty and Marina Moore.

<https://spark.adobe.com/video/3z2ZWYpAb0m6O>



Anne Rabbitte TD, Minister of State and Pat Flaberty



Fiona Coffey Brothers of Charity, John Dolan DFI, Noirin Clancy Inclusion Ireland in support of Pat Flaherty



Self-Advocate *Claire Nagle* tackles the term “Service User”

The use of the term “Service User” is still a cause of real concern throughout the Brothers of Charity Services Ireland, including in Co Clare. We all thought it was gone but unfortunately some of the staff are still using it as are some family members of individuals who are supported in the Service. This term is not something we should be known by.

When I was introduced as a “Service User” I was mortified and hurt. I didn’t like it and I found it very offensive. I don’t think it’s fair for individuals who are supported in the organisation be known as “Service Users”. The name came up because people didn’t know what generic term to use for each individual that’s supported by the Service. But we shouldn’t be called “Service Users” just because we use the Service. Outside of the organisation people use services all the time; for example people use the service of a hairdresser or a beautician, of the post office, of restaurants and service stations but they aren’t referred to as “Service Users”.

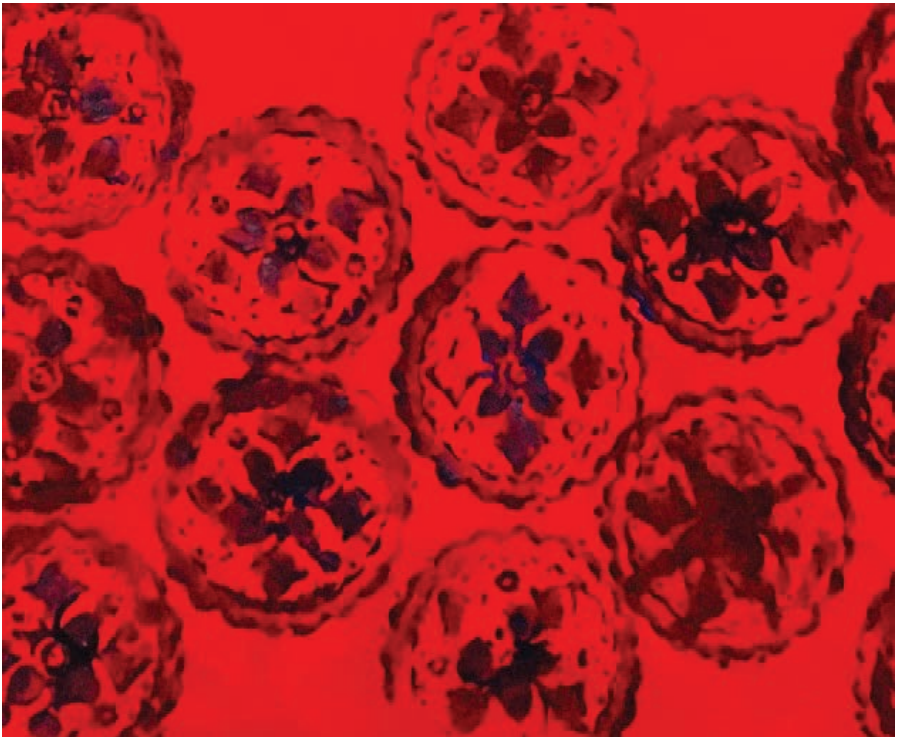
My point is that those of us using the Brothers of Charity Services are no different to other people outside of the Brothers of Charity Services. We are all human and equal and nothing else... we are not just Service Users. I myself don’t like the phrase. People being supported in the other regions don’t like it either. We do not like being known as a “Service User”. And we dislike hearing that word every time we hear it. When that word comes up in a conversation we go mad, we get so cross.

I was told that the word would often be used on the radio but I don’t ever hear it on the radio any more. What we would like to do is just get rid of it altogether, not just here in Co Clare but in all the other regions. In fact Co Clare has very nearly got rid of it and now we would ask Galway, Roscommon, Cork, Limerick, and the South East to get rid of it as well. We would like to say that we all wish to have that word gone once and for all.



A questionnaire survey was carried out and some people said they liked it, and some others said they didn't mind it, but several found it unacceptable. So what matters now is that the word is taken out of use. We would like an ultimatum that the term "Service User" is abandoned. We want a message to go to all the regions in Ireland saying that the word "Service User" goes. We want staff to be told not to use the term again - that we close it out for good.

I'm grateful for having the opportunity to express my opinion, the opinion of so many of us who avail of the support the Brothers of Charity Services. Let's get rid of this word and wait and see what the result is when the term "Service User" is gone. I look forward to that quite a lot.



Detail from 'The Room' by Joey Creighton, Waterford



*Supporter Sarah Meek and
Eliza Pentony*

The Role of the Advocacy Supporter, Sarah Meek

The role of the Advocacy Supporter is a diverse one and involves many different functions including,

1. developing easy-read information,
2. supporting people's engagement with those with whom they are advocating,
3. providing support for advocates making presentations and videos to tell important advocacy stories,
4. promoting the human face of issues, and
5. making sure supported people have all the tools required to participate in a meaningful way.

In the context of the Covid-19 pandemic the advocacy supporter has had to adapt the role and look at different ways of supporting people by "going virtual" - this has been a transformative time and has resulted in many people building new skills to engage in advocacy in a fresh way.

The pandemic has also meant that sometimes decisions about services and ultimately people's lives were being made at a fast pace and so the role of the supporter during this period was to keep people up to date as far as possible about changes to their services and asking the all-important question, "*How do you feel about this?*" Much of the supporter's role is to encourage discussion and ask questions about lived experience. It's about knowing that no one else has insight to the lived experience of people with disabilities better than they themselves.

For me, the role of the advocacy supporter is about working in the shadows - in the background. It's about taking the time to understand how much support a person needs or wants from you and respecting that position. It's about accepting that sometimes people don't need or want your support as much as you might think or assume. It's about empowering people to find strength in their own voices by quieting your own and by providing people with the relevant tools to build confidence in speaking up when fighting for justice or equality in their own lives.



In my opinion this role like many roles that involve supporting another human being requires constant self-reflection on how you are fulfilling this support function and equally, how the people you are supporting are feeling about you fulfilling this role. And it's important to be always considering ways in which this support could be improved upon, as the American civil rights activist singer and poet, Maya Angelou famously quoted, *Do the best you can until you know better. Then when you know better, do better.*



*Maya Angelou,
Civil Rights
activist, singer
and poet*



Flowers by Artist Caroline Burke



Advocacy from the perspective of supporter Emily Walsh

As part of my role in the Brothers of Charity Services I began working with Advocacy in early 2020. I joined a well established and hugely experienced group of Advocates and supporters. This was beneficial and daunting in equal measure. The ethos of promoting rights through Advocacy has always been very strong in Roscommon but I had never worked directly with the Regional or National Advocacy Councils before. I was met with a very passionate group of Advocates both Regional and National who were dedicated to promoting their own rights and the rights of others in the wider community, all sharing a strong sense of social justice. I found it really helpful in gaining a better understanding of what advocacy is about and how it works when Council members talked about issues they had worked on previously and how they went about their advocacy work.

Working with the Regional Advocacy Group I found that the best way to gain a clear understanding of Advocacy and how it should work was to let the Advocates themselves define the purpose of the group and what they hoped to achieve. They were able to clearly define what their support should look like and they were readily able to highlight the various skills of members within the group.

I have found working with Advocacy groups very inspiring and would encourage anyone with an interest to get involved. From my experience I would advise supporters not to presume they know the issues affecting people with a disability but to let the issues come directly from the people with a lived experience. Get to know the advocates well, find out all their various skills and encourage these skills. Supporting Advocates to take the lead is the most effective way to encourage the development of their confidence, wellbeing and trust. Above all else, talk less and listen more.



Actor Jeremy Irons



Mairead McGuinness MEP



Kathleen Lynch, former TD



Donal Linehan, Sports Star

Advocacy Supporter *Ann Holden* describes the “What’s Different About You?” Project

This project provided an opportunity for people with intellectual disability to celebrate difference and showcase their abilities. The project was drawn up by an advocacy group preparing to present at the annual National Service Users’ Conference. There are generally more than twenty video presentations prepared with great care, either to make a case for improving the wellbeing of supported persons or to show off the success of advocating for improvements to the life of an individual or a group of supported people. But this particular advocacy group in the Southern Services decided to present something entirely different from the traditional rights-lamenting or rights-celebrating presentations.



Michael Healy-Rae TD

Group facilitation established that advocates would like to illustrate their strengths in the community and pursue their dreams to interview well known people in sport, entertainment and politics and to film those interviews.



The group invited Frameworks Films, a community film production company, to a meeting and the project was born, with the advocates themselves doing the actual interviewing and taking the role of operating the camera, sound recording and the clapper duties. The advocates identified the people they wished to interview and Jeremy Irons, Mairead McGuinness, Kathleen Lynch, Donal Linehan, Michael Healy-Rae and others agreed to be interviewed.

Methodology

- The advocacy supporter worked on the premise that people with intellectual disability are just as capable as everyone else in society if given the right support.
- A Consent process took place, comprising easy-read documents clearly stating consequences of saying yes or no.
- To avoid supporter influence, social work students facilitated the consent process.
- The supporters' role in this project was to ensure the supported interviewers had the right structures in place to maintain control of the project and carry out the roles they had identified for themselves.
- A person-centered approach and group work helped identify what interview prompts, or aids would facilitate each interviewer.
- Various methods were tested, the supporter met with each supported interviewer individually and assessed their needs through role play.
- Some interviewers choose to be supported with easy-read scripts, some used an Ipad while others used one-word cues.
- The interviewer who had nominated the celebrity decided on three questions and the group came up with another two questions.

Outcome

- The Project was a success, it was aired on *Irish Community TV* and got a great response, the film company recently indicated the aim to air the project on European TV.



- The Project showcased abilities and celebrated difference.
- The Project facilitated people with intellectual disabilities to come to really use their vocal skills.
- The Project facilitated people with intellectual disabilities to engage meaningfully in the community on shared interest topics.
- The Project served to debunk the dependency connotation which is too frequently associated with people with Intellectual disabilities.
- It placed people with intellectual disabilities on being of service to the community.
- The project enhanced skills development and dignity.

Conclusion

The project was a great success. The group have planned to do a follow-on project in 2021 and have identified for interview, rally drivers, community workers, GAA players and Corporate people from all walks of a life.

ADVOCACY

'The future of our services...will be directly related ..to our inventiveness in developing mechanisms, systems and structures which will allow the voices of those whom we serve...to be heard and really listened to by the decision-makers in our services, in our regions, and in the Country. Therein lies the dynamo and powerhouse for the future development of our services.'

(McGinley, 1992).



Noirin Clancy,
Inclusion
Ireland



Roscommon
Councillor Orla
Leyden



John Dolan
DFI



The National
Gallery



The *Caritas-Beechlawn* Advocates meet several External Bodies

Our group name is Caritas-Beechlawn, from Castlecoote and Hawthorn Drive, Roscommon. We have participated in the *Changing Places* campaign which seeks to provide toilet and changing room facilities for people who use wheelchairs.

Changing Places toilet facilities are different from standard accessible toilets. They provide extra equipment like a hoist and an adult sized changing bench. In the whole of Ireland in 2018 there were only 15 Changing Places toilet facilities, (www.changingplacesireland.ie).

We attended the launch of the Changing Places Campaign on 1st May 2018 at the *Irish Human Rights and Equality Commission* Building in Dublin. Our Group set out to raise awareness about Changing Places facilities. We started a campaign to get a Changing Places facility installed in our local area. We held monthly Advocacy meetings to plan our campaign. We invited Noirin Clancy, from Inclusion Ireland, to give a presentation about Changing Places. We invited Management and Staff to the presentation and we shared information at our weekly Advocacy meetings. We visited Changing Places facilities at IKEA and at The National Gallery of Ireland in Dublin. We met with the Customer Care Team at IKEA who offered support for our campaign.

We met with Councillor Joe Flaherty of Longford County Council. We made contact with Councillor Orla Leyden who advocated on our behalf and succeeded in getting a motion passed on Changing Places at a meeting of Roscommon County Council. We linked with Colm Kelly, Community Integration Officer, Co Roscommon.



*Denis
Naughten TD*



*Joe Flaherty TD
meets the
Advocacy
Group*

AN BILLE UM RANNPHÁIRTÍOCHT
PHOBAIL (MÍCHUMAS) (FORÁLACHA
ILGHNÉITHEACHA), 2019
COMMUNITY PARTICIPATION (DISABILITY)
(MISCELLANEOUS PROVISIONS) BILL 2019

If sanitary facilities are provided in a relevant publicly accessible building, an accessible change facility shall be provided for people within the building.

In this Part — ‘accessible change facility’ means a sanitary facility designed to meet the needs of people with severe and profound disabilities, which—

- (a) is at least 3 metres wide and 4 metres long,
- (b) has a ceiling height of not less than 2.4 metres,
- (c) includes a full room cover overhead ceiling track hoist system,
- (d) includes a peninsular toilet bowl with adequate space, being not less than one metre from either wall, on either side of the toilet bowl to allow for transfers or assistance,
- (e) has a height adjustable adult-sized changing bench, and
- (f) has a height adjustable washbasin.

Senator John Dolan invited the Group to a briefing of the Community Participation (Disability) (Miscellaneous Provisions) Bill 2019 which was held on 18th June 2019 in Leinster House, Dublin - followed by Afternoon Tea. The Group also supported the Bill by attending the public gallery of the Seanad on 19th June 2019. The aim of the 2019 Bill is to help make the lived environment more inclusive for people with disabilities. Part of the Bill requires relevant publically accessible



buildings to provide a Changing Places facility. People supported by our Services had earlier been influential in a change to another law on Valentine's Day, 2017 (Brodie, 2021).

We invited the Manager from a local business to a presentation about Changing Places in the *Peter Triest Day Centre* in Roscommon. We asked if he would consider installing a Changing Places facility at his premises. We also met with Denis Naughten TD who advocated for us. We told him that Changing Places facilities are important to us and that we want the Government to make these facilities a priority. He advocated on our behalf with the business owners. We contacted MMS Medical Company which installs the equipment, they contacted the business owners too. The business owners agreed to include a new Changing Places facility in their plans for a building extension which was granted by Roscommon County Council.

We were delighted with the positive result and look forward to having a Changing Places facility in Roscommon town in the near future.

You can support the Make Changing Places Facilities Mandatory in Public Buildings Campaign by following this link and signing the petition. <https://my.uplift.ie/petitions/make-changing-places-toilet-facilities-mandatory-in-public-buildings-1>



The Changing Places Facilities



Advocate
Michael
O'Toole

Michael O'Toole worked with other groups to make Information more Accessible

My name is Michael O'Toole and I am a member of the South East Regional Advocacy Council. In 2012 I was Chair of the Regional Advocacy Council. During that year the Irish people were asked to vote on a referendum on the *Fiscal Stability Treaty*. When it came to discussing this treaty the Regional Advocacy Council in the South East found the information really hard to understand. Although every house in the country received a booklet explaining the treaty, it was not easy for us to understand it because it was a very complicated Treaty.

As a result of this we agreed to write to the Referendum Commission and ask them to make sure that the information they provide to people would be accessible to everyone. Not only would having information accessible and easy-to-read help people supported by the Brothers of Charity Services but it would also help others with an intellectual disability. And it would be helpful as well to the many people who have literacy problems and to the great number of people whose first language is not English.

The Secretariat of the Referendum Commission responded very quickly and told us that not only had we written to it regarding this issue but *Down Syndrome Ireland* had requested the same. It was suggested that we would link with each other and see how we could work together with the Commission and other stakeholders to try and find a way to make sure that when a referendum is called in Ireland the information about it is accessible to everyone. As with all referenda the timeframe for getting information out is very limited which meant that for this particular referendum very little work could be done in that timeframe. However, for other referenda in the years to follow, a working group which included myself, representatives from Down Syndrome Ireland, the Speech and Language Therapy department from Brothers of Charity Services Ireland, Cheeverstown House and St John of Gods have worked together to make sure that the information on the referenda are more accessible to everyone in Ireland.



Siobhán Flynn: Seven Important Advocacy Targets for the 2020s Staff Recruitment

For the past number of years, the National Advocacy Council has advocated to seek to ensure that people supported by the Brothers of Charity Services are part of the recruitment of staff who will be supporting them. Some regions have trained Supported People to participate on interview panels and some of those who were trained have been invited to have a role in the recruitment process. But, sadly, some regions have declined to find a role in their recruitment process for a Supported Person. The Brothers of Charity Advocacy Council believe that it is really important that the people supported by the Service are represented in the recruitment of staff in every Region.

Rights and Citizenship

In the early days of advocacy, a lot of internal issues were addressed such as ensuring that everyone had keys for their front doors, that everyone had the choice of having their own single bedrooms, and generally having more say in the daily routines of their homes, issues like being entitled to choose what time to go to bed at night. As the years have gone by more complex issues around Rights and Citizenship have arisen and how best to further expand support for these issues within the Service is something which will require to be ongoing.

Governance

As the Brothers of Charity Services Ireland is an organisation for supporting people with intellectual disabilities or autism it is worrisome that at present Supported Persons have no role in the Governance of the Organisation. One way to have a role in Governance would be to have a supported person invited to sit on the National Board of the Brothers of Charity Services Ireland. The National Advocacy Council is working closely with the National Chief Executive to explore the issues surrounding the role of supported persons in the Governance of the Brothers of Charity Services.



Policy Statements

The National Policy Action Group which is a subcommittee of the National Advocacy Council has worked over the past number of years to make the Policy Statements of the Brothers of Charity Services easy to read for everyone supported by the Services. We believe that we should have a direct involvement in the development of new policies from the beginning. This would ensure that the voice of people supported is heard from the very start.

Equal support for Advocacy in every Region

We believe that the level of support for advocacy within each region should be resourced equally. This would ensure that people within the Service continue to receive a consistent, high quality Advocacy service. While each region provides a range of different types of services to different numbers of people supported, the level of support for Advocacy should be the same throughout the regions. At present there are different levels of resources available to advocacy within each region and this is somewhat inequitable.

Planning Future Service Development

The National Advocacy Council will continue to build on its consultation and its current level of participation with external groups locally and nationally such as local and national government bodies. We believe we should have greater involvement in plans for future Service development and in decision-making in consultation with the funders of our Services.

Enhanced Staff Training

We would like to see more staff training in Advocacy to ensure consistent appreciation for and support of our Advocacy efforts across all areas. More training is needed for Advocates to learn about how to lobby government on their own behalf.

These seven issues will take time, effort and negotiation to resolve. The most important is the delivery of the Rights of people supported to all of the Rights identified by the United Nations Convention on the Rights of Persons with Disabilities, especially Rights such as the Right to Education and The Right to Employment.



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Detail from large tiling project (6 x 1 metres) a joint project between Supported Artists and Community School Pupils



Acknowledgements

Thank you to the current members of the National Advocacy Council who contributed to this Booklet: Claire Power & Claire Maher (South East); Pat Flaherty & Lorraine Mahon (Galway); Sean Donovan & Bernie Burke (Limerick); John Collins & Tom Mulqueen (Southern); Nora Healy & Killian O’Gara (Roscommon); and Claire Nagle & Lisa Acheson (Clare). Special thank you to former members of the National Advocacy Council who over the years have worked to make sure that advocacy is where it is today. Your work and dedication to Advocacy on our behalf is greatly appreciated.

A special thank you to Dermot Darcy from the South East region. Dermot was very much involved in advocacy within the Services from the beginning. Always ready to voice his opinion on what was important to him and to everyone supported by the Services, Dermot worked closely with other representatives and management in making sure the rights of people supported by the services were always at the top of the agenda. Dermot continues to be very involved in advocacy in the South East. Thank you to Christina Burke former Chair of the National Advocacy Council. Still involved in advocacy locally in Galway, Christina is a member of the National Advocacy Council policy group and external groups including The National Platform of Self-Advocates, Inclusion Ireland and the Inclusive Research Network.

Thank you to all the Advocacy Supporters within the Brothers of Charity Services Ireland for your collaborative work with advocates past and present. We look forward to your continuing support over the coming years.

Finally we thank Series Editor Patrick McGinley for his advice and guidance at every stage and for the design and layout of *Advocacy - Nothing about Us without Us* in the Brothers of Charity Services.

Claire Power and Siobhán Flynn, February 2021



A Celebration of Quality in the Brothers of Charity Services Ireland

As Service Providers all of us who set out to provide supports to children and adults with special needs recognise that the Quality of the supports we offer is of the utmost importance. Sadly, and all too frequently, when we set out to measure Quality we generally end up measuring the lack of Quality. Our focus, whatever the measurement instrument, too often switches entirely from the 92% of what we do really well, to the 8% which we don't do very well. Of course that 8% needs systematic, corrective and time-lined attention. But we must not give it all of our attention, we cannot allow the 92% to be taken for granted... to fade gently away into the Celtic Twilight. We are pleased to recognise the many important areas where the people we support, staff, families, volunteers and local communities achieve the highest standards. We gratefully acknowledge the tremendous commitment of every member of staff who, working individually and as team members in co-operation with other stakeholders, achieve wonderful, sometimes amazing, outcomes. We are happy to celebrate together in 2021 the level of success we have achieved in implementing the Mission of the Brothers of Charity by: *“Providing quality services to support people who are in danger of being marginalised... and creating opportunities and choices that develop and maintain connected lives where all are cherished as valued and equal citizens in our communities.”*

Patrick McGinley, Series Editor

In this Series - Published by: Peter Triest Publications, Kilcornan, Clarinbridge, Co Galway. H91 K2E9

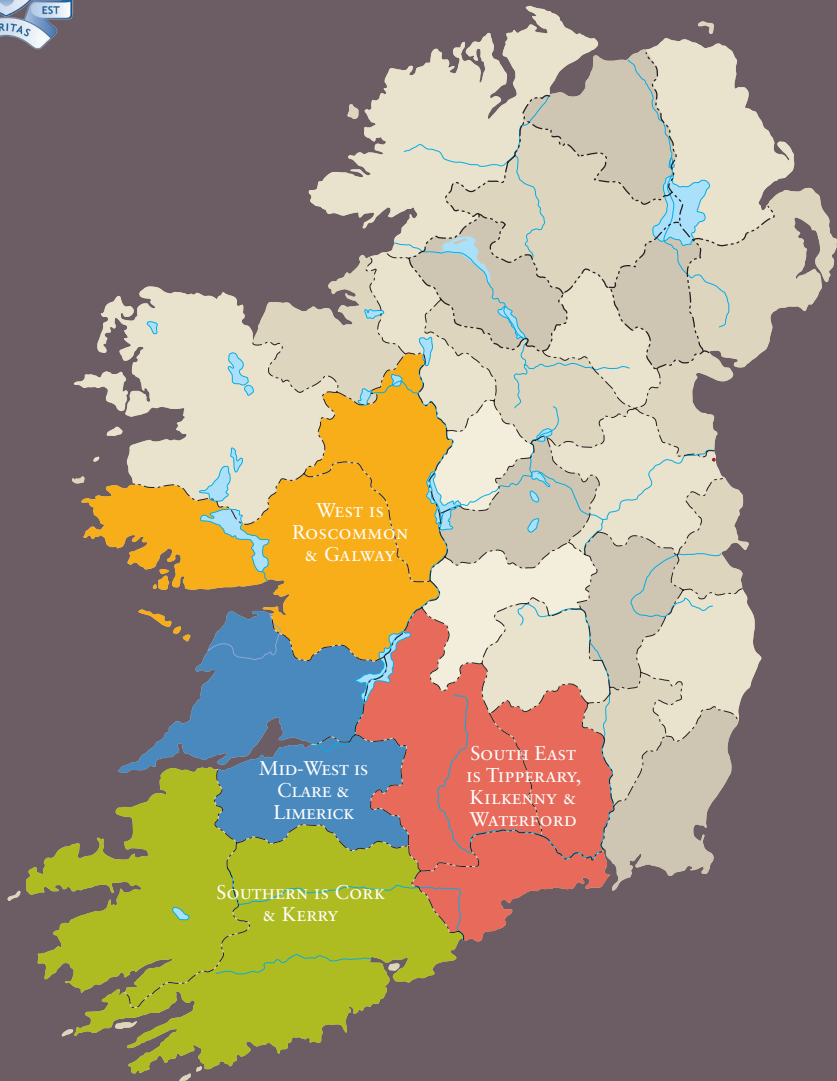
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Over 8,400 men, women and children received support from the Brothers of Charity Services Ireland in 2020, with over 4,300 employees (about 3,500 wte) making it the largest provider of support services for people with intellectual disability in Ireland.