



*The Dignity of Risk helps you Live your Dream*  
by Liz Phelan and Helen O'Regan  
Brothers of Charity Services



# The Dignity of Risk helps you Live your Dream

by Liz Phelan and Helen O'Regan

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# The Dignity of Risk helps you Live your Dream

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The Front Cover

Co-author Helen O'Regan and her friend Liz O'Donnell



## The Authors: Liz Phelan and Helen O'Regan



**Liz Phelan** was born in New York and having spent her formative years there moved to County Cork. Liz graduated with an Honours Degree in Applied Psychology from University College Cork before returning to New York where she worked in the Non-profit Sector with people with Disabilities for a decade. During this time Liz completed a Junior Fellowship programme with *United Way* of New

York City. This afforded her the opportunity to engage with a wide range of professionals working across the sector and to develop her skills in areas including change management and advocacy. On returning to Ireland in 2007 Liz commenced working with the Brothers of Charity Services Limerick Region. She has held a number of positions within the organisation most recently as the Head of Quality and Risk. She attained a Master's Degree in Healthcare Management from the Royal College of Surgeons in Ireland in 2013. Her experiences working with people with disabilities has led her to the firm belief that self-advocacy, a commitment to person-centredness and supporting people to take positive risks are at the very core of the Service's commitment to supporting people to live a life of their choosing.



**Helen O'Regan** was born in County Limerick.

Having lived in a congregated setting for much of her youth, Helen moved to a house in the community in her twenties. Since that time Helen has consistently pushed boundaries and advocated for ever increasing autonomy and independence. Helen's work extends far beyond self-advocacy as she relentlessly advocates not only for herself but also for others. Through

her participation in the *Inclusive Research Network* and collaboration as a guest lecturer for the Clinical Psychology Doctorate Programme in the University of Limerick Helen has influenced both current and future professionals in the field of Intellectual Disabilities.



## Foreword

The publication entitled *The Dignity of Risk helps you Live your Dream*, by Liz Phelan and Helen O'Regan is a welcome contribution to the literature in this field. Written in a deeply personal and inviting, rather than in an academic style, I found myself totally engaging with Liz and Helen as they told their story. Indeed their personable and gentle prose makes this booklet a lovely easy read.

In the space of a short number of pages the authors succeeded in giving me a real sense that I had come to know them, and that I was getting a real feeling for the extent of the risks that Helen had chosen to take. Every step of the way I was happy, even proud, that Helen was clearly identifying a risk and then taking the risk ... and I so wanted it to turn out well for her.

Risk and Risk Assessment has, for centuries, been considered essential to the safe provision of services for men and women who needed to be given support to live ordinary lives. Unfortunately, the response to the need to provide safe services, all too often, translated into attempts to ensure protection from the risks rather than to provide the necessary supports to the person to evaluate those risks and seek appropriate means to face and resolve them. Sadly, as a consequence, many of the institutional places of safety created with the best of goodwill and involving major investment had tragic outcomes which still have residual impact into our own times.

The exemplary and professional relationship which we find in Liz and Helen's *The Dignity of Risk helps you Live your Dream*, bears witness in the first instance to Helen's resilience and Liz's support; as well as to the support of her family, her friends, the many staff who assisted her, and those people in the community who contributed in various ways to building her powerful confidence and strength of character.

There has been a gradual unfolding, over the past 50 years or so, of a new emphasis on the provision of person-centred supports and on putting



the wishes, hopes and dreams of the persons supported at the centre of all of our initiatives. The contribution of many committed people, associated with the Brothers of Charity Services and other like-minded bodies to this initiative has been a significant one. The publication of the booklet *The Dignity of Risk helps you Live your Dream* by Liz and Helen is a testimony to the success of the efforts that have gone before and that have contributed to making their beautiful story a reality.

*Brother Alfred Hassett f.c.*

*Chairperson of the Board, Brothers of Charity Services Ireland*

## **Introduction**

The Brothers of Charity Services Ireland has a long and proud history of supporting people to live lives of their choosing. Core to the Ethos of the Brothers of Charity Services Ireland is the commitment to, '*working with people with an intellectual disability to claim their rightful place as valued citizens*' (Brothers of Charity, 2001). Processes such as Person Centred Planning have been introduced to ensure that each and every person is heard and supported in terms of their own vision for their own lives. Structures like the National Advocacy Council ensure that people supported are involved in decision making not only in their day to day lives but also at the most senior level of the organisation (Power & Flynn, 2021).

Great strides have been made in terms of supporting people to live more independently and to participate meaningfully in their community. People supported by the services have moved from congregated settings to independent living; from sheltered workshops to paid employment; and from a Brothers of Charity Services' bus to public transport. These types of moves towards greater independence and autonomy have resulted in an increased quality of life and have facilitated people supported by the services to gain their rightful place in the community in which they live.



## Increasing Regulation

As society in general and disability services in particular become increasingly regulated, there is a requirement to have evidence to demonstrate that services are doing everything they can to ensure that people supported by the services are safe and secure. There is a risk, however, that in seeking evidence to ensure that people supported are safe and secure we could inadvertently limit freedom of choice and place limits on people's opportunities and life experiences. This is where the risk assessment process comes into play particularly within disability services such as the Brothers of Charity. The concept of '*The Dignity of Risk*' is not new. It was first articulated in a 1972 article by Robert Perske (Perske, 1972). Perske cautioned that when we protect people from a reasonable level of risk taking, it has a detrimental impact on both '*their sense of human dignity and their personal development*'.

### Perske's 1972 *Dignity of Risk*

#### Abstract re-visited

In Denmark and Sweden, there is a growing interest in granting supported persons their fair and prudent share of risk-taking in their daily living. Denying supported persons' exposure to normal risks commensurate with their functioning tends to have a deleterious effect on both their sense of human dignity and their personal development. In addition, the removal of all risk diminishes the supported person in the eyes of others. It is shown how appropriate and reasonable risk-taking can and should be worked into the daily living experiences of supported persons in America.

The first of eight "*Guiding Principles*" of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) is '*Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.*'



When the UNCRPD was adopted on the 13th December 2006 it received the highest number of signatories in history to a UN Convention on its opening day. Clearly, there is a will to support dignity, autonomy and freedom for people with disabilities. The challenge for service providers then is to meet regulatory requirements while ensuring that the supports put in place for people enhance rather than restrict their rights.

### **The eight UNCRPD Guiding Principles**

These eight Principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) challenge us to take action to advance the rights of Supported Persons to achieve their inclusion as full citizens.

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
2. Non-discrimination.
3. Full and effective participation and inclusion in society.
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity.
6. Accessibility.
7. Equality between men and women.
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.



## The Role of Risk Assessment

The primary tool available to services to demonstrate evidence that people are safe and secure in the context of possible risks is the risk assessment process. Risk assessment is about being aware of the potential risks associated with an activity and identifying the actions or mitigations recommended to make sure that the likelihood of negative outcomes is minimised in so far as is reasonably practicable.

The risk management policy and procedures in the Brothers of Charity Services Ireland (Brothers of Charity Services, 2020) were developed mindful of the guiding principles of the UNCRPD and with the presumption of capacity at its core. The '*right to take reasonable risks*' is set out in the Brothers of Charity Services Ethos Document *Going Forward Together* (2001). Operating on the basis of the presumption of capacity means that as a Service we assume that every individual has the capacity to make decisions for themselves unless the opposite is shown. This means that we recognise the right to make decisions for oneself, including decisions that others might deem to be risky or unwise. With this value base in mind the risk assessment process is used as an enabler rather than a restrictor. By implementing the risk assessment process, the Brothers of Charity Services Ireland can show evidence that people are safe while also ensuring that the people supported have freedom of choice and that opportunities and life experiences are not restricted by an abundance of caution.

The question posed is not '*Is it safe for this person to engage in the activity that they want to engage in?*' but rather '*How can we make it as safe as possible for the person to engage in the activity that they want to engage in?*' By looking at risk assessment through the lens of supporting people to make things happen, risk assessment becomes another tool available to us to support people to take positive risks and achieve their own personal outcomes.



## Foreseeable Risk

### Risk Assessment - a key process

Risk Management is embedded in management practice at all levels of the organisation. The risk policy encourages appropriate positive risk taking and risk assessment where required. Risk assessment is a key process and should be used as an aid in identifying the hazards and factors that lead to or contribute to service users' wellbeing being compromised. A planned strategy of mitigation with preventative measures to reduce the risk probability and impact in areas of concern will have a positive outcome for service users and safe working environment for staff.

David Harkins, Sheena Arthur & Karen Sweeney,  
Scottish Autism (2015)

Furthermore, the risk management policy and procedure recognises that a risk assessment is required only in the context of a foreseeable risk. To this end, the first and most critical step in the risk assessment process is around considering if a risk assessment is in fact warranted. Risk is an inherent part of life and efforts to eliminate risk inevitably impact on quality of life.

The people supported by the Services participate in a wide range of activities in their homes, communities and holidays. From cooking to gardening, dancing to skiing, angling to mountain climbing, people across the services have done it all. Many people have participated in these activities successfully and without the requirement for an individual risk assessment. Where a person supported by the Services can participate in these activities on the same basis as anyone else in the community no risk assessment is required, the presumption of capacity applies and the person can enjoy their chosen activity. Where a person needs extra support to be safe while engaging in an activity then risk assessment comes into play. The questions to consider become, *What does the person want to do*, and *How can they be supported to do this, while managing the associated risk?*



## **Risk Assessment enhancing Helen's Life**

In order to illustrate the positive impact that the risk assessment process has on the lives of people being supported by our Services, I have worked to share her story with my co-author Helen, a woman who has been supported by services since she was a young girl. I first met Helen in 2008 through our mutual involvement with the Brothers of Charity Services Limerick *Regional Advocacy Council*.

In trying to capture the potential for risk assessment to support positive outcomes for people, Helen immediately came to mind. I am grateful that Helen has afforded me the opportunity to work with her to jointly share her story as an illustration of how positive risk taking and using the risk assessment process can result in enhanced independence and improve overall quality of life.

Helen moved to a congregated setting for people with disabilities as a young girl. When she became an adult she moved to a house in the community with a number of other women with intellectual disability. While the move from a congregated setting to a community house was a big step and a positive one, Helen continued to be supported by staff in almost all areas of her life. Helen recalls being allowed to go for a walk on her own 'once or twice' during this time but most of the time staff were with her and her peers. Staff made the dinner, provided transport and made many of the day to day choices.

One of the most difficult choices that was made on Helen's behalf was for her to move to a different house in the community. This move was due to financial cut-backs in services, and after over 25 years of having her own bedroom Helen found herself in a situation where she was sharing a bedroom with another woman. This was a really difficult time for Helen who missed her privacy. Helen advocated very strongly for herself. She did not want to share a bedroom. She wanted to have increased independence, choice and control over her own life. There were many new skills that Helen needed to learn including walking to the local shop on her own, cooking her own meals, and managing her own household. Where concerns were raised that Helen's safety might be at risk the risk assessment process provided a tool for looking at the risks involved in the activity and working with Helen to figure out ways to support safety while ensuring that Helen could continue to work towards the independence that she wished for.



## Apartment Living

In 2012 Helen moved to her current home – an apartment in one of the many lovely suburbs of Limerick. Helen shared this apartment for many years with her good friend Liz O'Donnell and has many fond memories of their time living together including watching matches, going out for meals and visiting the local beauty salon. When she moved to her apartment, Helen was living without full-time staff support for the first time in many years. She had a key to her own front door and choice in terms of her day to day life. When chatting with Helen about this move she described it as the 'Best Choice' she has ever made.

With the increased confidence that Helen found in successfully living independently she wanted to do even more things independently. After a car accident many years ago there was a real fear that Helen would be unsafe if she were supported to access public transport independently. However, not using public transport was really limiting for Helen's freedom and for her ability to access her community independently. A bus stop near Helen's apartment provides a link to nearby Limerick City Centre and being able to use the bus independently would open up many more opportunities for community involvement.

The risk assessment process once again came into play in troubleshooting ways to support Helen to develop the skills to use public transport independently and as safely as possible. Gradually, Helen was supported to build the skills necessary to use the local bus. Helen says that being able to use the bus without staff makes things 'easier and quicker' for her and has increased her access to the community. In talking about all she has achieved through increased community access Helen mentioned that she has been part of a knitting group as well as a Fair Trade group for which she assumed the role of Treasurer. Accessing the community independently meant that Helen could meet a whole new group of people, try out new hobbies and develop new interests.



*Helen enjoying apartment living*



## Travelling Nationwide

As a member of the Brothers of Charity Services Limerick *Regional Advocacy Council* Helen has participated in many different consultation groups both within the Brothers of Charity Services and outside of the Services. As part of her advocacy work, Helen has been a member of the *Inclusive Research Network* since 2010. This is a group of researchers with intellectual disabilities who are supported by the National Federation of Voluntary Bodies, The University of Limerick, and Trinity College Dublin to conduct research into topics which are important to people with disabilities in Ireland. While Helen was initially supported to attend these meetings by staff from the Brothers of Charity Services as she grew in confidence and independence this support was withdrawn and Helen started attending *Inclusive Research Network* meetings in the University of Limerick independently on a regular basis. Her independence and participation in the *Inclusive Research Network* were challenged when the venue for meetings changed from the University of Limerick to Trinity College Dublin.

By this time Helen was experienced in accessing public transport in her local area but the trip to Trinity College would include a taxi drive, a train journey and a *Luas* transfer in a new city. Helen was determined to continue to participate in the Network and had no intention of letting the change in location stop her. By once again using the risk assessment a series of steps to support Helen to make the journey safely were agreed and a plan was put in place. Following that first trip to Dublin the Network met in other parts of the country and building on the skills she had already developed Helen attended meetings in a number of different locations. She has even stayed away overnight for a meeting that was too far to commute to and from in one day.



*Helen attended meetings in the University of Limerick*



## **The Process of the Risk Assessment of Helen's travel on Busses, Trains and Taxies**

The steps involved in supporting Helen to continue to participate in the *Inclusive Research Network* when the location of meetings changed from Limerick to Dublin may serve as a useful illustration of the risk assessment process.

The *first step* was to consider what was the exact nature of the risk. The main concern stemmed from the fact that Helen had not previously travelled outside of her local area independently and had not made a train-to-*Luas* transfer in the past.

In considering what supports Helen might need the *second step* was to consider what was already in place to support success (existing controls). For Helen, these included past experience of using taxis independently, past experience of using public transport for local journeys, an ability to use a mobile phone, and an understanding of the importance of calling someone when support was needed.

The *third step* was to think about what else would be helpful in supporting success for Helen. To this end Helen and her staff worked together to do a few things. A step by step guide of her journey with visuals was developed. Contact was made with the link person in Trinity College to explain that Helen was going to be making the trip to Dublin without staff support. This person agreed to be a local support on Helen's arrival in Dublin... a person she could phone if support was needed.

*Fourthly*, Helen worked with staff to troubleshoot different scenarios including what to do if the train was delayed, what to do if she missed the *Luas* connection, and what to do if the meeting ran late. Armed with this knowledge and with adequate funds to pay for a taxi for any given leg of the journey, if anything went awry, Helen set out with a friend and fellow member of the *Inclusive Research Network* for Dublin.

*Fifthly*, the risk assessment was reviewed and used over the first few months to check in to see how things were going; to consider if all of the necessary supports were in place; and to agree any additional supports.



*Helen gets up to speed with Limerick busses*



## The Impact of Covid-19

At the start of 2020 Helen, living independently with only minimal support from staff, was traveling to meetings around the country and was participating in a range of different community groups of her choosing. All of this was impacted with the onset of Covid-19 in March 2020. The country went into lockdown. People were told to stay at home except for essential journeys. In May 2020 as restrictions started easing for the wider community, service providers remained very concerned about the safety of people they supported and as a result Helen and other people supported by services did not experience the same easing of restrictions as the rest of the community. Helen was one of the first advocates to raise this as an issue.

Helen turned 60 in May and wanted to mark the occasion with a few close friends. Through the risk assessment process Helen was able to organise to meet a few friends outside, in a socially distanced way to mark her special day. Later on when non-essential services such as hairdressers, restaurants and beauticians opened, Helen again advocated for the right to access these services. Her work in raising this issue on behalf of people supported by services, contributed to the organisational discussion around how people could be supported to do the things they wanted to do in line with public health guidance while also managing safety concerns in the context of an ongoing pandemic. This resulted in the development of a guidance document, *Approach to supporting people in residential services as Ireland moves through the phases of easing Coronavirus COVID-19 restrictions* (Brothers of Charity Services Ireland, 2020.) This document was helpful in facilitating people to do things as safely as possible using risk assessment as a tool to consider each person individually and set out the supports required to assist them to do the things that they wanted to do. Through this process Helen has been able to visit family and friends, go to the hairdresser and enjoy meals out, all while managing the ongoing safety risk associated with Covid-19 to the greatest extent possible.



*Helen gets access to her Beauty Parlour as Covid-19 fades in Summer 2020*



## Helen visits her Boyfriend

Helen's determination to do the things that are important to her, resulted in a risk assessment being put in place in October 2020 to support her to visit her boyfriend of many years who had been enabled to move into a long term care facility in 2019 due to his changing needs. During most of the pandemic Helen was connecting with her boyfriend over Facetime or WhatsApp but in Helen's words, *This just wasn't the same.*

While a face to face visit involved some risk, Helen knew that a visit would lift her boyfriend's spirits and have a huge impact on his wellbeing. Through the use of infection control measures as set out in the risk assessment Helen was able to visit her boyfriend while ensuring that they both stayed safe. This was a huge achievement at such a difficult time and as Helen says, *'It brought a smile to his face'* just to see her.

In her day service and her residential service, her role as an advocate, and most recently in the context of the Covid-19 Pandemic, Helen has worked to increase her independence, choice and autonomy in all areas of her life over time. She has used risk assessment as a tool to ensure that supports are in place to achieve her goals and also providing assurance to her Circle of Support that she can take risks, in safe ways, to do the things that she wants to do.

A **circle of support** is a group of people that forms a community around a specific individual (focus person) with significant disabilities to assist him or her to achieve personal goals. It is one of many tools addressing life planning from a functional or strategic assessment approach known as person-centered planning. Person-centered planning replaces more traditional assessment approaches associated with the medical model of services. Circles view people as individuals and assist them to attain self-determination focusing upon empowerment and not dependence of the individual. It is capacity oriented and identifies strengths, preferences, likes, and dislikes of the individual. The circle will also identify support needs in order to achieve a particular goal.

The focus person leads the process and decides who will participate in the circle (Armstrong, 2011).



## The Risk Assessment Process as Evidence of Assuring Safety

Helen's story is just one example of how the risk assessment process allows the Brothers of Charity Services to ensure it has clear evidence that we are supporting safety and security while also ensuring that an individual's hopes and dreams for their own lives are to the fore. Each opportunity afforded to a person to try something new enables them to gain further experience and confidence in navigating their world and directing their own life. We can use the risk assessment process to demonstrate evidence that we are mindful of safety while always supporting people to live the life of their choosing to the greatest extent possible.

This is the ultimate aim of risk assessment in an organisation like the Brothers of Charity Services and ensures that we afford people we support *'The Dignity of Risk'*. As Paulo Coelho said, *'Be Brave, Take Risks, Nothing can Substitute Experience'* (Coelho, 2012).



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## Acknowledgements

It is often the case when recounting achievements that it can appear as if they happened easily, without any great effort or support. This is rarely, if ever, a reflection of reality. Like so many people who set out to achieve ambitious goals Helen has had setbacks and struggles and has received support along the way to do the things that are meaningful to her. From family to friends, colleagues in the Inclusive Research Network to staff in the Brothers of Charity Services Limerick Region, Helen would like to acknowledge all of those who have supported her in various ways to live life her way.

A special word of thanks to the series editor, Patrick McGinley, for supporting us to share Helen's story as an illustration of what can be achieved when people are supported to do the things they want to do in their lives.



## 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.”*

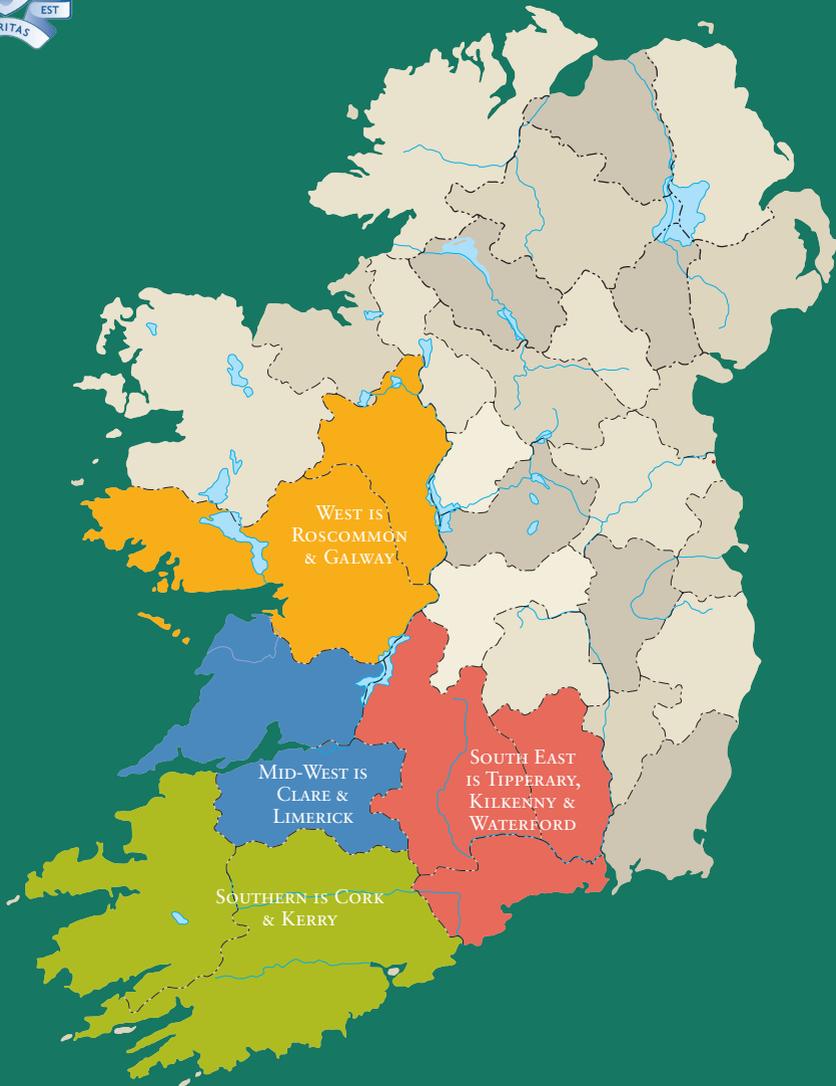
PMcG, Series Editor

In this Series

Hope, L. & Sexton, M. (2021). *Celebrating Fine Art and Great Artists in the Brothers of Charity Services*. Peter Triest Publications, Kilcornan, Clarinbridge, Co Galway.

Phelan, L. & O'Regan, H. (2021). *The Dignity of Risk helps you Live your Dream*. Peter Triest Publications, Kilcornan, Clarinbridge, Co Galway.

Power, C. & Flynn, S. (2021). *Advocacy - Nothing about Us without Us in the Brothers of Charity Services*. Peter Triest Publications, Kilcornan, Clarinbridge, Co Galway.



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.