‘Interactional Guesstimating’: Family carers’ experiences supporting profoundly intellectually disabled persons in decision-making - a constructivist grounded theory

by
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Acknowledgments and Dedication

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On a personal note, the writing up of this was a solitary activity, and required diligence and withdrawal from some activities and family. To a wonderful hubby, who took up the slack, and kept the show on the road, for your uncomplaining and constant encouragement®, Thank You, xx. To my two beautiful daughters, your kindness, patience and support meant the world to me; you are always in my heart xx. Of course, to the Hayes and extended family, I thank you all for your back up throughout this research xx. Mam and Dad, this thesis dedicated to you with love xx.
Abstract
Family carers supporting persons, living with profound intellectual and multiple disabilities in decision-making is critical, yet receives little attention. This dissertation addresses this need from family carers’ personal experiences.

Background: Research shows us that family carers support approximately 80% of intellectually disabled people in their own homes and family care remains the predominant type of care and support for this group. The evidence base concerning the lives, contribution, health and wellbeing of family carers’ in addition to the persons they support, requires considerably strengthening. One such area is to understand how persons, living with profound intellectual and multiple disabilities, come to make informed decisions and how families support this activity.

Aim: This research used a constructivist grounded theory approach and explored family carers’ experiences of supporting persons, living with profound intellectual and multiple disabilities, in decision-making.

Methods: Following ethical approval, (March 2012) data were generated by: 1) Individual interviews with family carers (n=26) transcribed verbatim and 2) ‘A Carers Group’ (n=6) which met eight times over a twelve month period (January 2013-2014) facilitated through ‘dialogue and reflection’. 3) Field notes of meetings and carers’ diary recordings. Data Analysis consisted of initial, focused and theoretical coding of transcripts (Charmaz 2006) and memoing.

Results: ‘Interactional Guesstimating: Growing confidence with uncertainty’ co-constructed with family carers indicates that supporting profoundly disabled persons in decision-making is a relational and learned experience combining intensive commitment and engagement, acquiring interactive, subjective and dynamic components of ‘knowing the person’. Described within the lenses of rights, understanding disability and personal development intense and extensive interactions represents a cyclical process of ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering Activities’ required to support profoundly disabled people in decision making. Family carers’ use reflection and ‘questioning self’ to navigate these activities.

Conclusion: This grounded theory evokes what Gilligan and Attanucci call the ‘care perspective’, which organises the relationship between self and other in terms of care and attachment rather than solely justice and equality. We propose a model of supporting decision-making that moves understanding of support beyond the view of ‘communication of needs and wishes as matter of fact’ or a ‘matter of entitlement’. Moreover, this approach conceptualises supporting decision-making as asserting value and meaning associated with the uniqueness and ways of expression(s) of the profoundly disabled individual.
**Contribution to new Knowledge** To the best of our understanding, this is the first constructivist grounded theory of family carers’ experiences supporting persons, living with PIMD, in decision-making. This grounded theory highlights from personal experiences family carers’ success and challenges of the nebulous concept ‘supporting decision-making’. In proposing a model ‘Interactional Guesstimating’ to support people, living with a profound disability, in decision-making a progressive realisation as advocated in the ideology purported by the UN CRPD is proffered.
Glossary

An Bord Altranais agus Cnaimhseachais-The Irish Nursing and Midwifery Board of Ireland. This is a statutory body responsible for the regulation of the practice of nursing and midwifery in Ireland.

Department of Health: Department of Health (entitled Department of Health and Children from June 1997-June 2011 and Department of Health prior to June 1997).

Health Service Executive: Health Service Executive which is responsible for the provision of healthcare in the provision of health and personal social services to all people living in Ireland. The Executive was established by the Health Act, 2004 and came into official operation on January 1, 2005.

Family Carer (Irish Government 2012): A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty. The National Carers’ Strategy Recognised, Supported, Empowered’ (2012) pg. 8

Intellectual Disability (Schalock et al. 2010): Intellectual Disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before the age of 18. The following five assumptions are essential to the application of this definition:
1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors
3. Within an individual, limitations often coexist with strengths
4. An important purpose of describing limitations is to develop a profile of needed supports
5. With appropriate personalised supports over a sustained period, the life functioning of the person with intellectual disability generally will improve

National Intellectual Disability Database: was established in 1995 and has in excess of 25,500 registrations. The database is managed by the Health Research Board on behalf of the Department of Health and outlines the specialised health services currently used or needed by people with intellectual disability. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need.

World Health Organisation: The World Health Organisation is a specialised agency of the United Nations (UN) that acts as a coordinating authority on international public health. Established on the 7th April 1948 its headquarters are in Geneva, Switzerland.
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<thead>
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<th>Abbreviations</th>
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<td>ABA</td>
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<td>ABI</td>
<td>Acquired Bran Injury</td>
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<td>AR</td>
<td>Action Research</td>
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<td>Action Research Cycle</td>
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<td>CRS</td>
<td>Congenital Rubella Syndrome</td>
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<td>Department of Health</td>
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<td>DoHC</td>
<td>Department of Health and Children</td>
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<td>ECHR</td>
<td>European Convention of Human Rights</td>
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<td>ETF</td>
<td>Enteral tube feeding</td>
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<td>GT</td>
<td>Grounded Theory</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>IASSIDD</td>
<td>International Association of Scientific Study of Intellectual and Developmental Disability</td>
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<tr>
<td>IRMSS</td>
<td>International Research Methods Summer School (hosted by Mary Immaculate College UL)</td>
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<td>NIDD</td>
<td>National Intellectual Disability Database</td>
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<td>NI</td>
<td>Northern Ireland</td>
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<tr>
<td>NIHR</td>
<td>National Institute for Health Research</td>
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<td>NMBI</td>
<td>Nursing and Midwifery Board of Ireland</td>
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<td>PIMD</td>
<td>Profound Intellectual and Multiple Disabilities</td>
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<td>PPCT</td>
<td>Process-Person-Context-Time</td>
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<td>RoI</td>
<td>Republic of Ireland</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>World Health Organisation</td>
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Declaration

This is to certify that:

(i) the thesis comprises original work

(ii) due acknowledgement has been made in the text to all other material used

(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signed:

_______________________________________________
Ruth Ryan, RNID, RNT, BSc Nursing Studies, MSc (Advanced Nursing)
**Prologue**

A woman the same age and known to the researcher acquired a profound intellectual disability at the age of eight. In 1982, a young girl then, this woman experienced stomach pains. Diagnosed with acute appendicitis underwent an appendectomy under a routine anaesthetic from which she never ‘recovered’ enduring irreversible brain damage. Now residing in a nursing home this woman has several impairments resulting from the ‘adverse outcome’ of the operation, including visual impairments, hypersensitivity to noises, dysphagia, GORD, spasticity, epilepsy and immobility. Prior to her appendicitis and consequently operation, this woman attended school with the researcher. Due to make our holy communion together, she did not make the communion mass, I recall how we said a prayer for her recovery.

After this, our lives separated, until I came to my ‘nursing’ career in my early 20’s. The following reflective journal entry describes the influence of my personal experience, which I explored in more depth triggered at the beginning of this research.

---

*Background; as I grew up I heard my mother speak of the tragedy that this girl endured. As I commenced this study, I overlooked the significance of this sentiment. Initially a bit of a shock to meet after these years but it was the reality of how different our lives were that surprised me. I have experience of education, travel, meeting new people, trying new foods, a good job, friends, likes, hobbies, and acquaintances. Good health, marriage, travel, work, children have brought me much pleasure in my life (no particular order), and immediately I was taken aback with the difference in our lives. I enjoyed our meetings and felt a bond with the woman that I did not share with other residents of the home, nor openly discussed with other colleagues.*
This woman presented with many impairments and her care regarded as high dependency, in that she required assistance in most activities of living. A particular concern was the management of ‘GORD’ the dispensing of ‘Gaviscon’ to action against ‘heartburn’ in reducing the number of reflux episodes. While indigestion was apparent expressed by this woman in facial gestures and bodily movements noticeable ten to 15 minutes after eating, this woman was not keen on taking the Gaviscon, as it was a pungent liquorice odour and taste. By not keen I mean she would close her mouth, clench her teeth when through her sense of smell identified it brought close to her mouth. It was more than a reflex. One day and by accident, the usual bottle of Gaviscon ‘Original Aniseed’ was empty and the replacement was Gaviscon Peppermint Liquid. Explaining verbally that the Gaviscon was different, I placed the mint flavour firstly under her nose and she immediately turned and opened her mouth to take the medicine. This was surprising as she refused the original Gaviscon. Initially I thought wow; you like it, and she smiled. I asked do you want more and she opened her mouth, I gave her another spoon. I was overjoyed at her smile, her swallow with ease and comfort with taking the peppermint version considering her challenges with dysphagia and her dislike for the original version. I took from this encounter that the peppermint medication was a preference to the original and requested other support staff members to order the peppermint version in future based upon this woman’s preference. It was an uplifting moment and I was truly happy and could see from her smile and facial demeanour she was too.

**Follow-up:** I was disappointed/annoyed during following weeks when the peppermint was not available and more attempts to acquire the preference of this lady was not as important to other support staff. I was disappointed in what may appear a ‘small thing’ but knowing that it could make a difference in someone’s life, obviously more than just the flavour, but to her ability to make choices and have her choice acknowledged, to be respected. **Conclusion:** the peppermint version had significance

Journal Reflections 0:1 Seeing the significance

This reflection formed the genesis for the proceeding study. Reflecting on this incident and other similar incidents in residential and ‘community residential’ settings made me question the actions of those who support people living in these homes. I never fully understood why the peppermint version was not a priority for other support staff. Did they see it as important? In my eyes, this reflection alludes to accepting a person’s autonomy by acting on her individual preference.
Yet, the woman in this incident has a personal care plan stating how ‘person-centred’ care and support ensures her autonomy be supported and respected at all times, I began to question the essence of this support? In addition, questioning the nature of residential living. This simply question started a journey of legal, ethical and philosophical debate contributing further to this area of study from the practical and real-world perspectives of those who offer support.

Supporting persons with disabilities in decision-making is receiving social, political and legal recognition with major re-configuration of services and practices with a wave of enthusiasm and hyperbole unprecedented in history: primarily in response to the United Nations Convention on the Rights of Persons with Disabilities (2006) vision. This dissertation furthers understanding of what actions and activities family carers undertake to make decision-making support available to people with profound intellectual disability, in addition to the challenges and complexities experienced by family carers in providing such support.

These findings aim to serve family carers in addition to the person they support. This dissertation proffers the term ‘Interactional Guesstimating’ to reflect a process in which utilising knowledge of acquaintance, personalising activities and interceding actions aid in determining intentionality within supporting persons with profound intellectual and multiple disabilities in decision-making. A complex and challenging endeavour, drawing from the study’s data three main categories, Sensing a Union, Framing Representation and Steering Affairs characterising supporter activities. Firstly, family carers’ commitment to such an intensive relationship over time, with extensive responsibilities is recognised. Appreciating the role and associated challenges for family carers’ recommendations for policy and practice are proffered. Secondly, presenting a model ‘Interactional Guesstimating’ may aid focusing practices and policy ensuring people with profound disability receive appropriate support in decision-making, a clear obligation of the Republic of Ireland under the UN-CRPD, the research now described in detail.
1 Chapter One Introduction and Background to Research

This chapter at a glance …

- Presents the motivation for this research
- Introduces readers to the research aim, objectives and process
- Summarizes the contribution of the dissertation
- Explains the structure and overview of the remaining chapters in the dissertation

This PhD dissertation summarises research that ‘explored family carers’ experiences of supporting persons, living with profound intellectual and multiple disabilities (PIMD), in decision making’ in the Republic of Ireland (RoI) from 2012-2018. This research was set against a backdrop of services and health and social care policies experiencing a great deal of change at the beginning of this century. Among the most important changes are the radical overhaul of service provision and legislation promoting the personal identity and autonomy of disabled persons, in addition to the resources and supports required to promote and sustain disabled individuals to make informed decisions.

The current state of knowledge in disability and supporting decision-making research consists of multitude dimensions, the most abundant mass of literature stemming from disability and law. Policy has been influential in this knowledge generation, with nationally and internationally, a drive and commitment to incorporate a rights based approach to support disabled persons to ‘live a full and ordinary life’ (Department of Justice Equality and Law Reform 2004; UN 2006; Department of Health 2009; Quinn 2009; Devi et al. 2011; HSE 2011; HSE 2012). Families in Ireland, similar to other countries, are the main providers of support for people with Intellectual Disabilities (ID) (Chadwick et al. 2013). In the following dissertation, the author will provide a series of arguments on how this study contributes to a significantly less explored realm in family carers’ research, namely to: their experiences of supporting persons, living with PIMD, in decision-making.
The challenges of responding to the expression of will and preference for people with profound intellectual disability is well documented in the literature (Carnaby 2004; Hogg 2007; Emerson 2009; Power 2009; Bellamy et al. 2010; Hostyn et al. 2011). The expression of preference, choice and self-determination for this group are rarely straightforward (Quinn 1997; Turnbull and Turnbull 2000; Petek et al. 2003; Redmond and Richardson 2003; Chou et al. 2011) requiring full time support demanding dedicated time, commitment and attention (HSE 2011; Cairns et al. 2014; Whiting 2014). This dissertation focuses on the support element within relationships. To date, this has proven to be limited with the majority of studies focusing on people with milder and less severe learning difficulties or from health care and paid supporter perspectives (Browning et al. 2014; Knox et al. 2015).

What is recognised is that little knowledge about how supporting decision-making processes operate or outcomes of processes exist (The Office of the Public Advocate 2014). Evidence to suggest the extent it can remedy the problems posed by surrogate decision-making processes is not clear (Devi et al. 2011) and indeed concerns with the potential to disempower people have been suggested (Flynn and Arstein-Kerslake 2014b). Therefore specific research agendas to develop evidence base and guide future policy are required (Kohn and Blumenthal 2014).

This research aimed to be inclusive cognisance of the philosophies and demands within disability and family carer organisations for ‘voice’ and ‘inclusiveness’ in terms of conducting research, therefore, an inductive mode of enquiry deemed to encompass the philosophies of inclusive research, and demonstrate an understanding of openness to hearing family carers’ voice was chosen. For this, a constructivist interpretive grounded theory (GT) approach provided the opportunity to engage ‘in and with’ dialogue and enabled family carers to discuss their concerns, success and challenges in supporting persons, living with PIMD, in decision-making.
As a part time study which commenced in January 2012 the research spanned over six years. The approach of GT adopted in this study informed by the paradigm of constructivism reflects the worldview of the researcher as part of the study rather than apart from it. Within this paradigm, data accrued through an eclectic approach valued contributions within the literature, interviews, and writings of family caregivers, in addition to observations and memoing. Data has provided insight into their experiences, and following analysis addressed the research aim ‘to explore family carers experiences of supporting persons, living with PIMD, in decision-making’, the main contribution of the dissertation.

A reflective stance was a feature of this research with acknowledgement from the researcher of the co-construction outlook influencing the design, collection and analysis of the data. Epistemologically, this reflexivity was important in devising the research approach, which specifically aimed to accommodate the sense of research as a shared experience, shaped by both researcher and participants (Charmaz 2006).

1.1 Motivation for this research

Interest in supporting persons, living with PIMD, and their family carers formed the genesis of the study. While choosing to focus on family carers supporting persons, living with PIMD, the author’s nursing practice in residential and community residential services with disabled people and their families resulted in frustration and dissatisfaction with existing practices viewed as marginalising and questioning the conceptual base for supporting disabled people and their families.

Challenges and opportunities are part of life not so unique to this group, but challenges with support and personalised support interventions were often difficult for a myriad of reasons. Some parents were admirably in their commitment to developing approaches in designing personalised interventions, evidenced by their commitment, energy, enthusiasm and humour, in realising these supports.
I choose an abstract from a radio interview to demonstrate the emotive and personal nature of research in this area. ‘All in the Mind-Intellectual Disability Communicating across the Divide’ (Klotz 2004b; Klotz 2004a) a story of how one’s family life was shaped and transformed via support. Jani Klotz, anthropologist, was one of seven children and three of her oldest siblings were intellectually disabled. Jani, Maryla and Joseph Klotz record this radio interview in 2004 on Australian ABC radio interviewed by Natasha Mitchell;

‘Natasha Mitchell: Hello, I'm Natasha and good to have your company for ‘All in the Mind’ this week, in what is our new weekend slot here on Saturday afternoons. Severe intellectual disability can make communicating confronting and awkward, especially if you're not familiar which each other. But today we're attempting to communicate across the divide and to search for an intimacy outside of language. It's a story of a family whose resilience is just astonishing.

Maryla: Yeees.

Jani: Do you want to say hello?

Maryla: Yeees.

Joseph (Joe): Hello.

Maryla: Hello

Jani: Hello Maryla.

Maryla: Hello

Jani: Are you looking for your bits and pieces?

Jani Klotz (Reading): I remember our last day together living as a whole family. We all dressed up in our good clothes and went down to the local park to take some photographs and play on the swings and roundabout. I was in my favourite burgundy and white summer dress with large flowers printed all over it. My hair was tied back and I had my good white buckle shoes on. We all looked really smart and formal as though it was Christmas and we were having photographs taken to send to my grandparents in England. The sadness in the faces in the photographs however is palpable. We knew that the family was breaking up and that Maryla and Steven were leaving to go to an institution, a mental hospital, a mad house.

Maryla: Mummy, mummy...that spoon is on the plate.
Joseph (Joe): The spoon is on the plate, yes.

Natasha Mitchell: Anthropologist Dr Jani Klotz was born into an extraordinary family. She was the 5th of the seven children, and her three older siblings Ursula, Stephen and Maryla were all intellectually disabled. Another brother Joe also had epilepsy as child. Ursula died at 5 from pneumonia and Stephen at 17 after an epileptic seizure. And if that wasn't enough one of Jani's other brothers unexpectedly passed away in his early 20s with a brain tumour. It's difficult to imagine how one family has coped with this much loss.

But Maryla, now aged 43 is doing well and she lives in a residential care facility with regular excursions back to the family hearth. And, after a lifetime of stares and whispers from strangers Jani Klotz, or Jane Jani as you'll hear Maryla call her, decided to turn your life experience into a PhD in anthropology. Her work presents a powerful and deeply personal critique of the way we view the lives and minds of those born with intellectual disabilities’.

‘Those born with intellectual disabilities’ a reminder of how we are sensitised to see disability as an inherent condition, situated within an individual. Yet the isolation, the detachment from family and societal response to ‘Those born with intellectual disabilities’ all plays its part in forming our understandings of peoples experiences of disablement. A family’s existence and demise described in this interview, with this practice continuing to exist in some countries.

The practice of non-admittance to residential institutions, based on the grounds of disability, is associated with the deinstitutionalisation movement that began in the late 1960’s and early 1970’s in Norway, Sweden, USA, Canada, Australia and Britain. Described as the most important change in policy and the pattern of service provision in ID in the last 50 years (Mansell 2006) notwithstanding significant challenges and barriers. The ‘changing landscapes of care’ (Power 2010) demonstrates the shift of direction consistent with community based and focussed care, described within the principles of normalisation theory (Wolfensberger, 1972), and social role valorisation theory (Wolfensberger, 1983).
Increasing input and parental desire to continue to care for their children at home, and consequential demands for tangible support services to facilitate this is a major driving force of ‘changing landscapes’ (Kearney and Griffin 2001; Redmond and Richardson 2003; Resch et al. 2010; Cairns et al. 2013). The value of recording and exploring family voices with a view to better understand the reality of supporting child and adults, living with PIMD, in decision making thus warranted.

### 1.2 Whom we are referring too

Family carers are the main source of support for people who require help to live in their own homes and research in this area is blooming in the past three decades (Twigg and Atkin 1994; Cummins 2001; McPherson et al. 2013). In this dissertation, we are referring to family carers supporting person, living with PIMD, and therefore it is important to acknowledge that the focus of the research is primarily on the family carer, yet the study domain is broader to reflect their families and the person they support. It is no longer acceptable to neglect the growing number of families caring and supporting their child or adult dependents with disabilities at home and the need to develop practices with family carers prominent (de Haas and Ryan 2016).

Chapter Two refers to the literature reviewed and demonstrates how the concept ‘family carer’ is generalised yet sophisticated, relatively new and emerging as a priority topic for the research funding agencies in most countries of the world; for example Horizon 2020. Espousing from ‘normative’ actions family carers and their roles are emerging as having major political, economic and personal impact that increasing recognition to these facets are now being addressed in the literature as opposed to original focus of ‘stress and coping’ and ‘adaptations’ perspectives, which all feature and form part of this dissertation.
Challenges for families with a child and adult dependent, living with PIMD, relate to little information available about the specific needs, supports and challenges that these groups of families face (Tadema and Vlaskamp 2010). There have been few attempts from the ROI examining the insights and experiences of Irish families supporting people, living with ID and PIMD. The relevance of this insight and experiential knowledge may vary from that reported in other countries due to cultural differences in addition to the reliance on voluntary, rather than statutory organisations, for the provision of services (Barron et al. 2006; Power 2010; Chadwick et al. 2013; McConkey et al. 2013).

To the best of our knowledge, no known previously published Irish studies that address the unique insights, understandings and experiences of family carers supporting persons, living with PIMD, in decision-making exists and this dissertation aims to address this gap.

1.2.1 Family Caregiving

In general, family caregivers are viewed as playing a key role in supporting sick and disabled people in their health, wellbeing and participation (Lafferty et al. 2016). Family caring literature focuses primarily on carers of older persons, family carers supporting persons living with dementia and newer insights addressing ‘young carers’ (Twigg and Atkin 1994, Department of Health 2012a, National Development Team for Inclusion 2016). Few studies have addressed the specific needs of family carers supporting the ID population (Lunsky et al. 2014), and indeed the needs of those living with PIMD (Mansell 2010; Family Carers Ireland 2016). The discourse recognises all family carers as a valuable resource for their family member/relative, community, services and governments (Twigg and Atkin 1994; Stalker 2003; Department of Health 2008; Cairns et al. 2013).
Legislation, policy and strategies aim to complement and enhance family carers’ roles in order to maximise their capacity to care for their family member/relative (Tadema and Vlaskamp 2010, Chou et al. 2011, James 2013). This is evident in the voluminous multidisciplinary perspectives in the literature primarily focusing on the study of family caregiving and its consequences for caregivers (Carnaby 2004; Gallagher et al. 2010; Mansell 2010; Gallagher and Whiteley 2012; Gallagher and Hannigan 2014). Yet some disability theorist suggest the word ‘carer’ ‘care’ and ‘caring for’ in the context of supporting persons with disabilities is haunted by the spectres of institutionalisation, medicalisation and paternalistic charities which characterises ‘caring for’ as a complex form of oppression systematically marginalising people with disabilities and therefore terms such as support, personal assistance are preferable (Kelly 2011).

Kelly’s review of ‘Making ‘care’ accessible’ (Kelly 2011) makes interesting reading. Her analysis of feminist scholars developing a political ethic of care urges us to see care as a civic virtue, and argues by simply replacing care with ‘support’ does not carry the same potential. Kelly aims to salvage care from its oppressive medical and charitable legacies through a discussion of personal assistance arguing care can be made accessible in policies and discussions of attendant services and in more general discussions. Like the built environment, care requires ‘retrofitting’ as in updating existing structures to fully include disability and family perspectives (Kelly 2011).

Part of the argument to replace care with support relates to the notion that policies that support family carers could be interpreted as reinforcing or perpetuating the oppression and dependency of person with disabilities. Therefore, tensions arise between policies to support carers and policies aimed at promoting choice and control for persons with disabilities (Moran et al. 2012). This can be due in part by the disjointed approach of government departments in addressing health and social policies, and disconnect between policy makers and different government departments. It is now timely to discuss the Irish governments approach to supporting care, carers and recipients of care.
1.2.2 Irish Carers Strategy Recognised, Supported Empowered

In the past twenty years, recognition of the contribution and distinct needs of carers is evolving in research and the literature. In Ireland, similar to other countries, our ageing population, medical advances in relation to disability and chronic illness will result in more people of all ages with longer term and complex care needs requiring care and being cared for in the community in the future (Department of Health 2012a).

The general and specific needs of carers requires a strategic and co-ordinated approach which the strategy ‘The National Carers’ Strategy Recognised, Supported, Empowered’ (Department of Health 2012) aims to address. At its launch the then Junior Minister for Health and Disability Kathleen Lynch described the governmental strategic vision to support carers within this Strategy, Recognised, Supported Empowered’ as representing a significant milestone in the lives of family carers. The Strategy ‘Recognised, Supported Empowered’ (2012) has Four National Goals which are to:

- Recognise the value and contribution of Carers and promote their inclusion in decisions relating to the person they are caring for
- Support Carers to manage their physical, mental and emotional health and well-being
- Support Carers to care with confidence through the provision of adequate information, training, services and supports
- Empower Carers to participate as fully as possible in economic and social life

A key objective of the ROI government policy for older people, children and adults with an illness or a disability is to support them to live in dignity and independence in their own homes and communities for as long as possible. The strategy recognises that family carers are vital to the achievement of this objective and an acknowledgement of family carers’ contribution as the ‘backbone of care provision’ in Ireland described within (Department of Health 2012a). It is noted that the Strategy was published in a time of austerity, and it was understood that implementations of its actions within the term of the then Government would be on a cost-neutral basis.
In contrast to Moran et al.’s (2012) opinion of disjointed approaches to supporting persons with disabilities and their family carers, the National Carers’ Strategy espouses to be interconnected and does not exist in isolation but an integral part of the Government’s broader social inclusion. Its existence complements the National Disability Strategy (2004), A Vision for Change (2006), the National Housing Strategy for People with a Disability (2011-2016) and the forthcoming Children and Young People’s Policy Framework (2012-2017). The National Disability Strategy in Ireland (2004) is designed to build on existing policy and legislation and underpin the participation of people with disabilities in Irish society. Key elements supporting the Disability Strategy are:

- The Disability Act 2005
- The Education for Persons with Special Educational Needs (EPSEN) Act 2004
- Sectoral Plans for services (prepared by the following six Government Departments; Health, Social and Family Affairs, Environment, Heritage and Local Government, Transport, Communications, Marine and Natural Resources, and Enterprise, Trade and Employment
- The Citizens Information Act 2007
- A multi-annual investment programme worth €900 million targeted at high-priority disability support services (reduced in recent years)
- Assisted Decision Making (Capacity) Act 2015
- National Disability Inclusion Strategy 2017-2021

These policies are closely monitored in line with the delivery of efficiency and effective services (Department of Health 2012b). Combined with a strategic governmental approach many essential supports available for family carers provided by non-governmental ‘voluntary’ organisations, which represent the interests of carers at a local and national level, such as Carers Association, Parents and Friends Associations, National Parents and Siblings Alliance, Inclusion Ireland and Care Alliance Ireland. In addition to providing services (social services, training, information etc.), they advocate on behalf of family carers and play a central role in ensuring that their needs are articulated to those with responsibility for the development of policies that directly or indirectly impact on families and family carers in particular.
Internationally, ‘Eurocarers’ represents national carer groups to develop a European network representing family carers and their organisations. Eurocarers defines a family carer as a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework; 80% most often provided by family and friends. The contribution of these ‘informal’ carers clearly constitutes a great resource for our society, even if their role is not always recognised. ‘Eurocarers’, believes that recognition of the contribution and services of family carers is not sufficient and thus aims to advance the issue of ‘informal care’ at both national and EU levels by:

1. Raising awareness of the significant contribution made by carers to health and social care systems and the economy as a whole, and of the need to safeguard this contribution;
2. Ensuring that EU and national policies take account of carers, i.e. promote social inclusion of carers, the development of support services for carers, enable them to remain active in paid employment and maintain a social life.

Evidence suggests that an integrated approach, in partnership with families, identifies needs in which family carers access and avail of support (James 2013). However, the print version of ‘what is there’ is often different to the reality of experience of recipients (Power 2009) and this dissertation explores that reality which has proven to be complex and challenging.

Delivering a wide range of support services such as personal care, housekeeping, transportation, care and financial management as well as emotional support, and invasive clinical interventions family carers offer comprehensive and desirable option(s) for people in need of care (Brown et al. 2016). The number of family carers is expected to grow significantly due to de-institutionalisation, ageing populations, and changing family structures. The economic ‘value’ of this care, is noted. For example, an estimated 40 million American family caregivers provided an average of 18 hours of care per week, reflecting approximately $470 billion in unpaid caregiving contributions (Perez et al. 2018).
Closer to home, there are approximately 200,000 (4-5% of population) family carers in the ROI (Family Carers Ireland 2016). McPherson’s statistics on UK and other jurisdictions are as follows: 12% of the population in England (around 5 million people) are family carers and in the USA, 29% (65 million) are providing care for a chronically ill, disabled or aged family member or friend (McPherson et al. 2013). Attributing to this prevalence difference are classifications of family carers, in addition to awareness of status in the ROI only recently recognising carers in political and social terms in our first Carer Strategy in 2012. The Census, 2002, was the first census in the ROI to record data on the number of family carers in the ROI.

Census 2011 was the first in which family carers were asked to provide details on the number of hours spent caring weekly, and extended the question to young carers under the age of 15 (Family Carers Ireland 2016). Therefore, data in Ireland is at infancy stage, yet gathering. Census 2011 does indicate that 13% of the population had a disability, physical, sensory or intellectual, which equates to almost 600,000 people living with disabilities in the state. It is impossible to infer, however, what proportion of disabled people are reliant on family carers for everyday living.

The figures highlight that 6% of the population live with a disability connected with pain, breathing or another chronic illness or condition. Comparing the 2006 and 2011 census figures, a marked increase in the number of people aged 85 and older living with a disability (72.3%) and a dramatic increase in family carers in the 75 plus age group were recorded. The Irish Census 2016 identifies more female family carers than male. As of April 2016, females comprised 118,151 (60.5%) of the country’s 195,263 carers, while there were 77,112 male carers. There were 3,800 children aged under 15 providing care, accounting for 1.9% of all carers. Over half of all carers (52.7%) were in the 40 to 59 age group while the greatest proportion of carers was in the 50-54 age group, which accounted for 28,703 carers (14.7%). There was a 34.7% increase in carers aged 85 and over, where numbers rose from 1,318 to 1,776.
Carers provided a staggering 6,608,515 hours of care per week, an average of 38.7 hours per carer. This was an increase of 321,005 hours (5.1%) on 2011. In all, 83,754 carers (42.9%) reported providing up to two hours of unpaid care a day, which made up 8.3% of the total care hours provided. A smaller, yet significant number of 16,926 carers (8.7%) report providing full time 24 hour/seven day unpaid care, of which the family carers of this group would connect with, representing 43% of total care hours provided in the 2016 census. This has major significance and later identified in the findings and discussion chapter.

The next section describes challenges with identifying family carers supporting persons; living with ID, and the information available warranting further investigation within this population of carers.

1.2.3 Family Carers, supporting persons, living with ID

Family caregivers of persons, living with ID, are described as a unique set of caregivers (Mansell 2010, Lunsky et al. 2014) and arguably family caregivers of persons, living with PIMD are another group within this subset (Bellamy et al. 2010). Recognising that family carers play an important role supporting individuals, living with ID and PIMD, supporting development at all stages across the lifespan (Chou et al. 2011, Kelly and Kelly 2011), funders of services often desire ongoing involvement by family members yet they rarely collect data about family carers (Department of Health 2012a, Lunsky et al. 2014, Family Carers 2016).

Identifying family carers supporting persons, living with PIMD, is challenging as no definitive record of the number of people with ID exists, and nor does the census request specific categorisation of care recipient(s). A database referred to as the National Intellectual Disability Databases (NIDD) established in 1995, in the ROI, has in excess of 27,800 registrations as of 2014. The NIDD database managed by the Health Research Board (HRB) on behalf of the Department of Health (DoH) compiles information outlining the specialised services currently used or needed by people, living with an ID.
The database informs regional and national planning of services by providing information on trends in demographics, current service use and future service need. The database answers three main questions:

1. What is the demographic profile of people with intellectual disability in the ROI? What are their ages, gender and level of intellectual disability, and how have these changed over time
2. How many people with intellectual disability are receiving specialised health services and what services do they receive
3. How many people with intellectual disability are waiting for specialised health services, what service are they waiting for and when, in the next five years, do they need these services (Kelly and Kelly 2011)

The following figure describes the number of persons, living with ID and PIMD, in Ireland as of 2016 registered with the NIDD (Hourigan et al. 2017).

The NIDD data base for decision making in relation to the planning of specialised health personal and social services for people with intellectual, physical or sensory disabilities

Figure 1-1 NIDD 2017 Profile of Population registered
There were 28,275 people registered on the NIDD at the end of December 2016. Based on 2011 Census of Population figures, this represents a prevalence rate of 6.16 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported) was 2 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.59 per 1,000. As of 2016 NIDD recorded registrants, living with a PIMD, is relatively small (2.8% of males and 3.5% females) similar to other jurisdictions rates.

When considering the incidence of persons, living with PIMID, this data differs when compared to the figures related to the ‘Jack & Jill Foundation’. The ‘Jack and Jill Foundation’ is an Irish children’s charity set up in 1997 by Jonathan Irwin and his wife, and then Senator Mary Ann O’Brien based on their own experience of caring for their son Jack at home until he passed away in December 1997 aged 22 months. A parent led organisation this foundation advocates for support for children born with profound and complex needs, and their families. The aim of the foundation is to provide home respite care, early intervention and end of life supports in the ROI for all children who require it from birth to 4 years of age. The foundation's rationale for offering services to this age group was that some ID day services in the ROI are only offered to children aged 4 years and over (Redmond and Richardson 2003).

The foundation have supported over 2,000 children (from birth to 4 years old) living with brain damage who ‘suffer severe intellectual and physical trauma’. In all, an average of 105 children aged between 0-4 have received support each year from 1997-2016 a remarkably different number than that recorded on the NIDD of ‘9-11’ children between the age of 0-4 (http://jackandjill.ie/cycle/about-jack-jill/).
In addition, the NIDD reported that 2,060 people are accessing services from ID providers but not registered with the NIDD, as they were either awaiting consent or did not consent to having their information included in the national system (NIDD 2016). Therefore, it is important to consider data from the NIDD with some caution as it may under-estimate the number of children, adults and families experiencing living with PIMD, and by implication the number of families and supporters within this community. The next figure, describes the age profile of people living with ID, in Ireland between 1974-2017.

Since 2000 sustained number of adults, living with ID, in the ROI are registered on the NIDD

This figure illustrates the number of people aged 35 years and over with a moderate, severe or profound intellectual disability more than doubled since 1974 when the first census of this population occurred. This trend is similar to England evidenced in the work of Emerson conducted by the Centre for Disability Research in Lancaster University on behalf of the Department of Health (UK). Emerson’s report predicts, over the time period 2009-2026, needs and demands for improved health and social care services for children and adults with PIMD will be required (Emerson 2009).
Introduction and Background to Research

Figure 1.2 also indicates that family carers are supporting persons, living with ID, for longer periods than in the past. Implications of these trends suggest that identification of carers and supporters, circle of friends in addition to resources and service provision requires further considerations. While parents and siblings of those persons, living with ID, provide support well into adulthood this group of carers, tend not to be the focus of carer policy (Lunsky et al. 2014).

In addition, studies in Ireland and the UK (Mc Conkey 2005; Mc Conkey et al. 2010) find that families living in some geographic regions were more likely to receive differing types of services compared with other parts of the country. Building on these findings Power (2010) recognising the ‘changing landscapes of care’ demonstrates the shift of direction consistent with the decline in religious, voluntary roles in some areas resulting in a reality for many families that they feel they have no choice, no alternatives and are accepting of services what are on offer.

Upon submitting a ‘Request for Information Form’ to the NIDD in April 2012 requesting more detailed information regarding residential circumstances for persons, living with PIMD, I received the following information (via email) form the NIDD in May 2012:

<table>
<thead>
<tr>
<th>Main residential circumstance</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Setting</td>
<td>318</td>
<td>31.9</td>
</tr>
<tr>
<td>Community Group Homes</td>
<td>105</td>
<td>10.5</td>
</tr>
<tr>
<td>Residential Centres</td>
<td>426</td>
<td>42.7</td>
</tr>
<tr>
<td>Other full-time services</td>
<td>146</td>
<td>14.6</td>
</tr>
<tr>
<td>Insufficient Information</td>
<td>3</td>
<td>.3</td>
</tr>
<tr>
<td>Total</td>
<td>998</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Below is a breakdown of main residential circumstances for persons with a PIMD. As you can see 677 individuals (67.8%) were resident in full time residential services including, community group homes, residential centres and other full time residential services (these were mostly intensive placements for profound disabilities or challenging behaviours). The remaining 318 individuals were resident in a home setting.

Caraíosa Kelly, Research Analyst Disability Database Unit, Health Research Board, An Bord Taighde Slainte, Knockmaun House, 42-47 Lower Mount Street

Email 1:1 ‘Residential Circumstances of persons, living with PIMD’
As of the year 2012, the NIDD has records that identify 32% persons, living with PIMD residing in a home setting and 68% of persons, living with PIMD, reside in residential, community group homes or other full time services such as nursing homes. Noting the accuracy of the data in relation to 0-4 year old children, and exclusion of 2000 ID service users these figures were somewhat surprising. Following up on this inquiry in April 2016, the following information from the NIDD residential circumstances of those registered on the database from 2010-2014 current figures:

Table 1-1 NIDD Five Year Data Residential Circumstances

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people registered on the NIDD</th>
<th>Number of people with a profound level of intellectual disability</th>
<th>Main residential circumstance (profound disability only):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Home Setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>318 (31.9%)</td>
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<td></td>
<td></td>
<td></td>
<td>316 (32.1%)</td>
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<td></td>
<td></td>
<td></td>
<td>317 (32.9%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>311 (33.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>307 (33.7%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Community Group Homes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>105 (10.5%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>109 (11.1%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>127 (13.2%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>126 (13.5%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>128 (14.1%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Residential Centres</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>426 (42.7%)</td>
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<td></td>
<td></td>
<td></td>
<td>412 (41.9%)</td>
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<td></td>
<td></td>
<td>372 (38.6%)</td>
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<tr>
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<td></td>
<td></td>
<td>362 (38.8%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>344 (37.8%)</td>
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<td></td>
<td></td>
<td></td>
<td>Other full-time services</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>146 (14.6%)</td>
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<td></td>
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<td>144 (14.6%)</td>
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<td></td>
<td>146 (15.1%)</td>
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<td></td>
<td></td>
<td>135 (14.4%)</td>
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<td></td>
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<td></td>
<td>131 (14.4%)</td>
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<td></td>
<td></td>
<td>Insufficient Information</td>
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<td></td>
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<td></td>
<td>3 (0.3%)</td>
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<td></td>
<td></td>
<td>3 (0.3%)</td>
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<tr>
<td></td>
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<td></td>
<td>2 (0.2%)</td>
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<td></td>
<td>0 (0.0%)</td>
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<td>Total</td>
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<td></td>
<td></td>
<td></td>
<td>998 (100.0%)</td>
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<td></td>
<td></td>
<td></td>
<td>984 (100.0%)</td>
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<td>964 (100.0%)</td>
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<td>934 (100.0%)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>910 (100.0%)</td>
</tr>
</tbody>
</table>

Table 1:1 provides information to the residential circumstances of people, living with PIMD, from 2010-2014. While the population remains small approximately ⅓ of the group live in a home setting and this has remained constant within this five-year period.
Therefore, this implies that $\frac{2}{3}$ of this group of people live in residential or group home settings. Upon reflection, and noting the challenges with figures with the databases, it is nevertheless saddening to see such high figures in relation to residential settings and group homes, in light of the political and social agendas to support personalised home living. Noting the Census 2016 data, the number of carers (8.7%) report providing full time 24 hour-seven days a week unpaid care, of which the family carers of this group identify with, representing 43% of total care hours provided in the 2016 census (Central Statistics Office 2018). Therefore, the input and articulation of this small but significant group of carers has major significance.

This background and family carers’ prevalence and policy sets the scene to clarify the research approach and study domain, now addressed.

1.3 Research Approach

Constructivist principles that engaged family carers aimed to ensure that findings co-constructed with family carers, had credibility and resonance. This research began with a somewhat a-theoretical or bottom-up approach that focused on a constructivist interpretivist viewpoint aligned with grounded theory approaches. This inductive approach in research differs from traditional deductive approaches where a chosen theoretical perspective informs the research question or aim (discussed in Chapter Two Literature Reviewed).

The rationale for this lies in the epistemology of the methodology of the study, which is discussed in more depth in the Chapter 3, but important to mention albeit briefly at this stage. Grounded Theory approaches originally developed by Glaser and Strauss in the 1960s, aims to develop theory about phenomena inductively and through ‘emergence from the data’ in opposition to hypothesis-testing and the application of existing theories to new data, in that regard a theory ‘emerges’ from the data.
Grounded Theory represents a progressive and complex research approach in which identification and integration of ‘categories of meaning’ arise with data collection and data analysis occurring simultaneously. It is precisely this connexion that challenges researchers in addition to complexities of understanding grounded theory as both the process of category identification and integration (as method) and its product (as theory) (Gelling 2011).

In this study, grounded theory was valued as a research approach in which a theory as a depiction provides understanding for what is happening in the field and developed from the information collected systematically. This approach was deemed appropriate for this study which was not seeking cause and effect but rather explore with family carers their experiences and understandings to contribute to new insights.

Constructivist Grounded theory as a methodology explains the theory that emerges in the ‘voice’ of participants, in harmony with my beliefs which identified the need for ‘voice’ and ‘inclusiveness’ in terms of conducting research. As a result of an inductive approach, ‘Interactional Guesstimating: Growing confidence with uncertainty’ a constructive grounded theory of family carers experiences of supporting persons, living with PIMD, in decision-making was co-constructed with family carers.

### 1.3.1 Study aims and objectives

The aim of the study was to ‘explore family carers’ experiences of supporting persons, living with PIMD, in decision making’ with the main objectives of:

- Hear and listen to the stories of family caregivers
- Gain insight and understanding of the success and challenges that family caregivers have when supporting people with PIMD
- Engage in a participatory process with participants
- Consider the process of gaining this insight
- Develop a substantive theory
1.4 Study Domain

The study domain may initially appear complex and convoluted as its broad nature reflects the theoretical and practical aspects of individual family carers, the person they support, the support services they receive, in addition to social and political policies and influences that underpin and shape their lives. The domain of study is the union and intersection of 1) national and international emphasis on rights, 2) understanding the nature of disability and required supports, and 3) an evolving understanding of the role of familial support. Enquiry into the union and intersection of these three topics accentuates the study statement.

The first knowledge domain makes reference to the changing international and national emphasis on the rights of disabled people and those who support them, to live as full citizens, leading to significant change and progress in the engagement of disabled people and their families (UN 2006; Carnaby and Pawlyn 2009; Quinn 2009; Family Carers Ireland 2016). This thesis integrates a human rights perspective, noting the liberal political theory as incorporated into the international United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Meaning, that it accepts the individual as a rights holder and the state as having specific obligations to individuals. This dissertation concords with the view that human rights are conceptualised as ‘inalienable’ and ‘universal’ embracing natural law theories espousing a moral code that is all encompassing. The liberal concept of the individual as a rights holder is front and centre in human rights.

Nevertheless, challenges in such thought arise primarily in cases where the individual as rights holder has difficulty or cannot articulate their wishes, choices, will or preferences, at least in a conventional fashion and this study goes to the heart of these challenges.
The second knowledge domain that this study has drawn from is our understanding of ‘Profound Intellectual and Multiple Disability’. This term is used to describe severe learning difficulties and additional co-existing complex disabilities, such as sensory, mental health and physical health conditions (Munde and Vlaskamp 2010). This term aims to describe a person who communicates at pre- or protosymbolic level via facial expressions, sounds, movements, body posture or muscle tension (Vos et al. 2010) and utilises little verbal exchanges. Persons, living with PIMD, require support in activities of daily living, from personal hygiene, positioning and comfort, nutritional support, continence care, arranging activities and travel supports.

Associated complex physical needs or technology dependent, with a high prevalence of severe and complex epilepsy, nutritional difficulties and communication difficulties (Mencap 2001, Bellamy et al. 2010, Hostyn et al. 2011) affect the daily functioning and overall health and wellbeing experienced.

Increasing emphasis on ‘an ordinary life’ challenge those who support and care for persons, living with PIMD, akin to those who commission and manage the services they receive to think and act creatively, respectfully and meaningfully (Hogg 1999; Carnaby 2004; Mencap 2007; Goldbart and Caton 2010). Due to the ageing global population and advancing medical treatments, there are now many more people living longer with PIMD (Emerson 2009). However, little is known about families and direct care supporters that support this group of people, in fact the evidence base is uncertain and often ethically complex (Edwards 2008; Diekema and Fost 2010; Clarke et al. 2013).
These two domains interlink with the third element of the study ‘an evolving understanding of the role of familial support’. Most literature describes the burden and stress of caring dominated by psychological methodology (Twigg and Atkin 1994). In contrast to other forms of family caregiving, being the parent or carer of a child with an ID implies an ongoing responsibility beyond the attainment of age-related adulthood (Durà-Vilà et al. 2010; Pilnick et al. 2011). Research has examined families that undertake care for their disabled son daughter or sibling report physical and mental health difficulties (Gallagher and Hannigan 2014), emotional stress (Gallagher and Whiteley 2012), and financial hardship (Power 2009) resulting from their caregiving role. This group of caregivers are often noted for providing the greatest number of hours of care including personal care (e.g., bathing, dressing, positional supports,) are more likely to report stress and social isolation related to their caregiver ‘role’ (Gallagher et al. 2010).

Therefore, the overall study domain exposes nationally and international agendas in promoting family carers to engage in delivering personal support services and accessible interventions, to meet the complex health and social needs of people with PIMD. This study brings into focus an enquiry in which the intersection of these three topics formed the research statement now presented.

1.5 Study Statement
The research draws from knowledge domains in exploring, with family carers, their experiences of supporting persons, living with PIMD in decision-making. Recognising the interplay of the following domains ‘Becoming and being a family carer’ ‘Understanding PIMD’ and ‘Supporting decision-making’ recognised as mutually reinforcing concepts located within individual, social, and cultural environs as portrayed in the following figure (discussed in more depth in Chapter Two; Literature Reviewed)
This inductively derived conceptual framework provides the substantial theoretical and practical framework for the research undertaken for this PhD discussed herein.

Figure 1-3 Conceptual interplay as the study progressed

Now presented a summarisation of the significance of this research.

Firstly, family carers contribution ‘considered a backbone of care provision’ requires acknowledgement and understanding as identified in the National Carers Strategy, the first carer’s strategy in the Republic of Ireland (ROI) (Department of Health 2012a). This dissertation highlights the intensive and extensive functions and responsibilities that this group of family carers contribute to in their role supporting their sons and daughters not only in decision-making but also in activities of functioning and living.

Secondly, the expected ageing population and medical advances in relation to disability (Emerson 2009) and chronic illness will result in more people, of all ages, with longer term and complex care needs (Mansell 2010) requiring care and being cared for in the community in the future (Department of the Environment Community and Local Government 2011). A proactive approach to these projections requires knowledge and understanding of the family carers’ role and this dissertation goes to the heart of this understanding.
And finally, significant changes in health and social care service provision and legislation in the ROI, namely the re-configuration of local, relatively autonomous voluntary organisations to a more centralised equitable service provision has implications for all using these services. Integrating family carers’ experiences, judgements and expertise to inform this modernising agenda, respecting cultural and familial contexts, may contribute to effective implementation and positive outcomes.

Therefore, hearing and listening to family carers ‘voice’, contribution and opinions matters.

1.6 Thesis Contribution

Two main contributions in this dissertation are offered- the first contribution of the dissertation ‘Interactional Guesstimating: Growing confidence with uncertainty’, a constructivist grounded theory illuminates family carers’ physical, emotional and social experiences in constructing and making meaning of supporting another in decision-making. The constructivist grounded theory acknowledges contextual narratives and practical experiences, contributing to new knowledge. This contribution is summarised in Chapter Four founded in an ethic of care and commitment that recognises ‘personal involvedness’ of the supporter and challenges of this commitment.

Recognising the relational aspect to human living, ‘Interactional Guesstimating: Growing confidence with uncertainty’ reflects the acumen sensitivity and endeavours that family carers espouse and deliver in supporting persons, living with PIMD, in decision-making. Altruistic, motivational and transformative mechanisms experienced by family carers were components of ‘Interactional Guesstimating: Growing confidence with uncertainty’. Some examples of these components reflect family carers seeking information, resourcing and finding remuneration from significant others to negotiate physical, social, learning and living opportunities for their sons and daughters. Most notably, these activities transform parental status to that of healthcare worker, legal representative, health and social engagement secretary in addition to many other extended roles.
Described in more detail within the findings chapters of the dissertation, the grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ describes family carers main concern as ‘getting it right’ for their son or daughter. Overcoming this concern, family carers resolve ‘getting it right’ by engaging in three main activities ‘Sensing a Union’ ‘Framing Representation’ and ‘Steering Affairs’. These activities necessitate a relational ethic in which supporters through experience gain confidence over time and occurrence in offering support and ‘getting it right’.

The second contribution of the dissertation proffers a model of supporting decision-making based on family carers experiences, presented in the following figure:

![Interactional Guesstimating model of supporting persons, living with PIMD, in decision-making](image)

‘Interactional Guesstimating’ model of supporting persons, living with PIMD, in decision-making (Figure 1-4) presents the cyclical and individual nature of support required by persons, living with PIMD, in decision-making. Through connecting and personalising support described in ‘sensing a union’ supporters are positioned to assert meaning to the supported intent, wishes, preferences and ‘frame representation’ when required. This is a continuous process reflecting the capacity-building endeavours in ‘steering affairs’ necessary for persons, living with PIMD, being and self-determination.
In this approach, however, there are times, when uncertainty as experienced by supporters requires inferences, guesses or estimates contextualised within the disabled persons narrative founded in ‘knowing the person’ and valuing the ‘uniqueness of their ways’ (Sensing a Union). Thus, the cyclical nature of support creates opportunities for further realisation of choice making and aiding the person, living with PIMD, to engage in being and self-determination. Not without its challenges and described in detail in Chapter four findings.

Now presented an overview of the dissertation.

1.7 **Overview of Dissertation**

Chapter *Two* presents the background to the study and describes the literature reviewed. The evolved conceptual framework introduces readers to ‘becoming and being a carer’, ‘understanding PIMD’ and ‘supporting decision-making’. These concepts reflect the practical perspectives of family carers, intertwined with other theoretical perspectives and government policy that aim to support caregivers and persons, living with PIMD, in Ireland including the UN CRPD. The chapter clearly outlines not only the rationale and justification for this research study, but the novel and leading nature of its contribution.

Chapter *Three* provides an in-depth discussion of philosophical approaches to research. This chapter outlines how these discussions guided the research methods in terms of appropriateness to conduct the research and compatibility with the researcher beliefs and values. Having articulated philosophical positioning and clarifying appropriateness of methods a discussion of the design and management of data collection and analysis occurs. Described in detail this section concerns ethical considerations, data generation, analysis and academic rigour of the study.
Chapter Four presents the rich, in-depth findings as experienced and co-constructed with family carers. It is the main contribution to knowledge of this dissertation. Chapter Five presents a synthesis and discussion of these findings. The succinctness of the discussion aims to hit home to readers the relevance and significance of not only the inductive approach to this knowledge, but the seismic shift in understanding of the importance and relevance of support beyond assessment of capacity but capacity building through supporting decision making.

Chapter Six concludes the dissertation, outlining the significance of the theory, implications of the theory for families and carers of persons, living with PIMD, policymakers and service providers is presented. Implications and reflections on the study with recommendations highlighted concluding the dissertation.

1.8 Chapter Conclusion

This chapter introduces readers to the rationale and study domains that formed the base for exploring family carers’ experiences of supporting profoundly intellectually disabled people in decision-making. This area of study deserves attention in light of recent international and national policies, legislation, guidelines and standards for family carers and disabled persons in relation to supporting decision-making, in addition to the ethical and moral imperative. Family carers supporting persons, living with PIMD, voices not often heard in society and in research in general, and so there is a gap in understandings of what the experience of supporting another in decision-making is like. This study goes some way to addressing this gap and the following chapters demonstrates the merits of an inclusive and co-production approach to research.

The next Chapter two ‘Literature Reviewed’ includes theoretical, political and empirical literature contributing to current knowledge of supporting decision making and family carers role in this process contextualising the research.
2 Chapter Two Literature Reviewed

This chapter at a glance …

- Provides an overview of literature contributions to the research process
- Presents the conceptual framework, that evolved as the study progressed, concordant with constructivist grounded theory approaches

Recognition of the importance of family carers’ contribution to health and social care systems is growing reflected in social, academic and professional literature. Chapter Two provides an overview of these contributions as they relate to the research process. Firstly, the role of literature in ‘constructivist grounded theory’ studies, the focus of the research in this dissertation, provides a rationale for describing literature ‘gleamed from and within the data’. Parallel to data collection and analysis the literature review occurred. Secondly, the conceptual framework introduces the constructs ‘Being and becoming a carer’, ‘Understanding PIMD’ and ‘Supporting decision-making’.

The Wallace and Wray (2011) approach to literature reviews complemented this study. They identify four categories of literature, Theoretical literature, Research (empirical) literature, Practice literature and Policies (Wallace and Wray 2011). Such an approach demonstrates ‘openness to new insights’ and elicited a broader eclectic perspective presented in the following sections. Therefore, a multi-method search strategy of electronic databases and manual search of reference lists with articles retrieved when meeting the aim of the study. Firstly, a general introduction to family carer literature followed by ‘approach and purpose’ of the literature in grounded theories.
2.1 **Family Caregiving**

It is evident that family caregiving is receiving much attention with a large, and growing body of literature examining family carers’ experiences caring for people with various medical and social conditions. Examples include intellectual physical and sensory disabilities (Cummins 2001; Gallagher *et al.* 2010; Cairns *et al.* 2014), foster care (Schofield *et al.* 2013), mental illness, acquired brain injury, multiple sclerosis (Hughes *et al.* 2013), dementia and aging family members in the family home (Macadam and Savitch 2015).

Family carer related evidence and knowledge is complex and fragmented, and the demand for such evidence led by grass root organisations such as Family Support Groups and Organisations. The evidence comes from a wide variety of sources including academic institutions, peer reviewed journals, national and local government bodies, policy and campaigning organisations, and grassroots bodies representing carer voices. What this evidence demonstrates is that the role of family carer is demanding, primarily facilitated by women and becoming increasingly complex, regardless of which cohort of people family carers are supporting (Appendix 1).

The ‘gender related’ view of family carers as female exists, and perhaps related to the notion of caring for a family member as a natural element of maternal relationships particularly giving satisfaction (Durà-Vilà *et al.* 2010) and an expression of altruism, duty and kinship obligation (Resch *et al.* 2010, Noddings 2013). It is perhaps difficult to appreciate that less than 50 years the term ‘carer’ was barely used (Bytheway and Johnson 1998) with the term now having legal recognition by way of a ‘Carers Leave Act’ (2001) in the UK, and more public, political and social representation here in the ROI within our first national carer strategy (Department of Health 2012a). While the terms ‘caregivers’ and ‘informal carers’ are used interchangeably with ‘carers’ the term parents of children with ID, and/or parental carer are also utilised.
Various definitions of ‘carer’ exist in the literature. For example in Ireland, the Census of Population defines carers as those who provide ‘regular unpaid personal help’ for a friend or a family member with a long-term illness, health problem or a disability (Central Statistics Office 2018). The Department of Social Protection requires that a carer must be providing ‘full time care and attention to a person in need of such care’ in order to qualify for a social welfare payment. This has further implications in that carers or potential carers may be included or excluded from certain rights such as leave from work, or benefits such as Carer Benefits, thus an understanding of the discourse of identifying and defining the carer is not just a question of semantics but has significant social consequences.

Hereafter, I refer to this group as ‘family carers’ (other than in research which used participant and parents, I kept to the researchers original intention) and acknowledging that ‘naming’ is not straightforward. The term ‘family carer’ in this dissertation adapts the definition from the Irish Carers Strategy:

'A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty’ Irish Carers Strategy pg. 8

Ongoing ‘significant’ levels of care applies to family carers supporting persons, living with ID and PIMD, known to deliver care over longer periods of time, per day, in addition to longer periods in time (Mansell 2010, Resch et al. 2010) thus this definition is fitting for this study. This group of carers deliver intensive physical and adaptive living supports (Gallagher et al. 2010, Gallagher and Whiteley 2012, Gallagher and Hannigan 2014) having significant effect and affect. Family carers supporting persons, living with PIMD, report increased demands in physical caring tasks such as washing, dressing, nutritional supports, incontinence care and pressure relief supports in conjunction with physical therapies benefitting their sons and daughters. Consequentially, family carers spend most of their time providing essential supports that without their assistance would require specialist therapeutic interventions (PMLD 2001; James 2011; Mencap 2011; Brown 2t al.,2016)(Network 2001; James 2011; Mencap 2011).
Notably in the literature is the increased stress associated with parenting children with disabilities in comparison to parents of children without disabilities (Jacques 2006; Gallagher et al. 2010; Hall et al. 2012). Research indicates that a family has to respond to a complex array of protective and stress variables to fulfil its caregiving functions alongside its other family functions (Saloviita et al. 2003; Hassall et al. 2005; James 2011; Hall et al. 2012). Stress, coping and adaptation are reported to be influenced by many factors associated with family or environmental features (Cairns et al. 2014), parents’ cognitive styles (Saloviita et al. 2003), and the child characteristics (Green 2007).

Stress does not always lead to negative family outcomes when a child has a disability. Quantitative and qualitative studies have suggested that parenting a child with a disability can lead to positive emotions and positive family outcomes (Mullins 1987; Hastings et al. 2002; Green 2007; Griffith and Hastings 2014; Beighton and Wills 2017). For example, Mullins ‘Authentic Voices’ a synthesis of 60 books written by parents of ‘exceptional’ children (with a variety of impairments and disabilities) identifies the didactic material of the parent authors divulging how their lives have been enriched and made more meaningful by virtue of parenting a child with a disability (Mullins 1987).

2.2 Literature Reviewed ‘approach and purpose’

The placing of the literature review in grounded theories, occurring simultaneously or after data collection, is deliberate. Traditional deductive approaches present a review first, and deduce from the literature a hypothesis or find a gap in the literature requiring further inquiry. The intention in delaying the literature review prevents imposing ideas and concepts on theory development in addition to utilising the literature as an approach to generating data. Therefore, specifying the conceptual framework that underpins the study from the outset was not possible; however, theoretical construction arising from data generation and analysis occurring simultaneously drove the literature reviewed (Torraco 2005; Gelling 2011; Hunter et al. 2011; Charmaz 2013).
This process required patience and 'trust in emergence' (Glaser and Strauss 1977) and while free from extraneous pressure to remain 'open' and not forced into determining a theoretical framework at the outset within supervision the absence of a framework proved to be challenging. In addition, annual review boards require theoretical perspectives and clarification of their contributions early on in the study, a challenge associated with grounded theory studies being conducted for PhD examinations (Elliott and Higgins 2012). Supervision and the reflective journal was helpful in maintaining patience and reiteration of ‘trust in the process’. The following Venn diagram (Figure 2-1) illustrates the set of constructs and their intersections reflecting the foci that family carers’ experiences of supporting persons, living with PIMD, in decision-making.

The study’s conceptual framework acknowledges the interplay of the 1) family carers being and becoming 2) understanding profound intellectual and multiple disability and 3) supporting decision-making influenced by broader theoretical perspectives of Bronfenbrenner's Process-Person-Context-Time (PPCT) model and Rights represented in figure 2.1.

![Figure 2-1 Conceptual framework](image)
This conceptual framework provides the substantial framework for the research undertaken for this PhD discussed herein. The interplay of the three inner constructs in addition to the two surrounding perspectives gleamed from the data aided the co-construction of the GT ‘Interactional Guesstimating: Growing confidence with uncertainty’. Each stage of Figure 2-1 now outlined from left to right. This leads to the first domain of the conceptual underpinnings of ‘Interactional Guesstimating: Growing confidence with uncertainty’ ‘Bronfenbrenner’s Theory of Human Development’.

2.3 Bronfenbrenner's Theory of Human Development

Bronfenbrenner’s ecological systems theory (2005) contributed to framing family carers’ senses, in that the immediate thing that jumped out at me following meeting family carers and during initial coding of the data was the variations of personal development that family carers described in their experiences. The context of this development attributed to the relationship with sons and daughters in addition to the interaction and involvement of other people in their wider families, organisation and professionals.

Prior to the creation of his model in the mid-1970s, behavioural science research, focused on the individual, rather than on the individual and the environment as a whole. Bronfenbrenner argued that scholars believed the relationship between the individual and his/her environment was linear (unidirectional) rather than interdependent or mutually beneficial. This interactive aspect was the impetus behind his model.

Bronfenbrenner’s theory emphasises the way that an individual’s development formulates by the interactions between themselves and the systems of which they are part. Bronfenbrenner’s model attempts to explain the interdependence of the individual and the layers of society surrounding him or her (family, work, community, and so on) (Bronfenbrenner 1989) fitting for this study. Since 1970’s, postulating that functioning of an individual or family depends on how they relate to the wider context, which exerts influence upon them, and how they influence the wider context underpins the thinking derived from the bio-ecological model.
The defining properties of the model involves four principal components, Process-Person-Context-Time (PPCT), and the dynamic interactive relationships among them. This thinking challenged the then prevailing conventions in the field of psychology and medicine that primarily focused on observations and the ‘*strange situations that strange children and adults entailed for the briefest possible periods of time*’ (Bronfenbrenner 1989). Instead of these observations representing lived experience Bronfenbrenner argued that human development should be studied in context; that is the actual environment in which human beings live and grow.

Bronfenbrenner’s arguments reflect the parallel movements in research endeavours questioning the way we learn about subjects and the world we study, and the methods of developing theories to understand them, as Charmaz’s articulates;

‘We are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvement and interactions with people, perspective and research practices’ (page 10) Charmaz 2006

Bronfenbrenner’s theory now in its third decade originally developed to study child development continues to evolve recognising the contribution over the lifespan therefore application to family carers is pertinent. This study asserts that family carers, and their families, exist not in isolation but in the context of wider relationships within society. Therefore, understanding family carers’ roles in supporting persons, living with PIMD, in decision-making, relevance of this theory emerged within analysis. Bronfenbrenner’s bio-ecological model of human development in its developed form deals with the interrelations among the following four interrelated concepts Process-Person-Context-Time (PPCT) (Bronfenbrenner and Morris 2006).

Defining properties of the PPCT model as:

(1) The developmental *process*, involving the fused and dynamic relation of the individual and the context
(2) The **person**, with an individual repertoire of biological, cognitive, emotional, and behavioural characteristics

(3) The **context** of human development, conceptualized as the nested levels, (macro, micro, meso levels) (Bronfenbrenner, 1977, 1979, 1989).

(4) In addition, **time** conceptualized as involving the multiple dimensions of temporality part of life course theory. These dimensions include ‘life’ or ‘ontogenetic’ time (one’s age from birth to death), ‘family’ time (one’s location within the flow of prior and succeeding generations), and ‘historical’ time (the social and cultural system that exists in the world when one is born and the changing circumstances regarding this system that occur during one’s life) (Lerner et al. 2002).

These concepts now briefly described.

### 2.3.1 Process

The first concept plays the crucial role the primary mechanisms in development. Proximal processes feature in two central ‘propositions’ firstly, acknowledging human development occurs through processes of progressively more complex reciprocal interaction between an active, evolving bio-psychological human organism and the persons, objects, and symbols in its immediate external environment. Secondly, to be effective, the interaction must occur on a regular basis over extended periods. Such enduring forms of interaction in the immediate environment are referred to as proximal processes (Bronfenbrenner and Morris 2006).

Noted in research findings are such enduring forms of interaction and support. Using family members and carers as informants, Mencap (2011) researched the needs and services of 81 adults, living with PIMD, in a single London borough. Their findings suggests on average people, living with PIMD, were away from home for only 20-35 hours per week (3-5 hours per day) and awake at home for an average of 12-15 hours per day. This suggests that the high support needs are primarily addressed within the home by supporters, and in this study, primarily non-paid family carers.
2.3.2 Person

Bronfenbrenner acknowledged the relevance of biological and genetic aspects of the person denoting to the personal characteristics that individuals bring with them into any social situation. He divided these characteristics into three types of ‘Person characteristics’ as most influential in shaping the course of future development through their capacity to affect the direction and power of proximal processes through the life course. First, dispositions can set proximal processes in motion in a particular developmental domain and continue to sustain their operation.

Next, bio-ecological resources of ability, experience, knowledge, and skill are required for the effective functioning of proximal processes at a given stage of development. Finally, demand characteristics invite or discourage reactions from the social environment that can foster or disrupt the operation of proximal processes. The differentiation of these three forms leads to their combination in patterns of Person structure that can further account for differences in the direction and power of resultant proximal processes and their developmental effects (Bronfenbrenner 1989; Bronfenbrenner and Morris 2006). In this study, disposition, resources and demands were all reflected on by family carers hence recognition of Bronfenbrenner understanding within ‘Interactional Guesstimating: Growing confidence with uncertainty’ is pertinent.

2.3.3 Context

The context or environment involves four interrelated systems. The first is any environment, such as home, school, or peer group, in which the developing person spends a good deal of time engaging in activities and interactions i.e. the microsystem. As people spend time in more than one microsystem Bronfenbrenner wrote about the interrelations among them i.e., the mesosystem. There are also important contexts in which the individuals whose development is being considered are not actually situated but which have important indirect influences on their development i.e. the exosystem.
And the fourth, the *macrosystem* as a context encompassing any group ‘culture, subculture, or other extended social structure’ whose members share value or belief systems, ‘resources, hazards, lifestyles, opportunity structures, life course options and patterns of social interchange’ (Tudge *et al.* 2009). The final element of the PPCT model is time.

### 2.3.4 ‘Time’ the final element in PPCT

Bronfenbrenner and Morris (2006) wrote about time as constituting three successive levels: (1) micro (2) meso and (3) macro. Microt ime refers to continuity versus discontinuity in ongoing episodes of proximal process (what is occurring during the course of some specific activity or interaction). Mesotime is the periodicity of these episodes across broader time intervals, such as days and weeks, (the extent to which activities and interactions occur with some consistency in the developing person's environment). Constancy and change within which cultures undergoing with some periods of historical time rates of change are much faster reflects Bronfenbrenner’s final ‘Macrot ime’. This factor focuses on the changing expectations and events in the larger society, both within and across generations referring to the fact that developmental processes are likely to vary according to the specific historical events that are occurring as the developing individuals are at one age or another (Bronfenbrenner and Morris 2006; Tudge *et al.* 2009).

This theory of human development contributed to examine family carers’ experiences and understanding. Other literature examined were Voysey (1975, 2006) and Twigg and Atkin (1994), now discussed.

### 2.4 ‘Being and Becoming- a Family Carer’

In attempting to build a comprehensive picture of family carers’ experiences supporting persons, living with PIMD, in decision-making the seminal work of Margaret Paun Voysey’s ‘the constant burden’ model (Voysey 1975; Voysey Paun 2006) is examined. A ‘tragedy and constant burden perceptive’ of disability and the challenges that disabled children bring to a family, this work describes a pathological model of disability which family carers ‘endure’.
In addition, Twigg and Atkin influential ‘typology of family carers’ is described as it contributes to our understanding of family carers and their role in supporting another (Twigg and Atkin 1994). Following these seminal works examination of current research exploring family carers ‘being and becoming’ concludes this section of literature reviewed.

Firstly, Voysey's perspective is impossible to ignore in exploring family carers experiences of supporting person, living with PIMD, in decision-making. Disputed and rejected by many, it would be remiss not to acknowledge the contribution of this work and its relationship to the present study. Namely, how this model has influenced and shaped our understanding of family carers’ role and response to parenting a disabled child.

2.4.1 Voysey’s ‘the constant burden’ model

A classic study conducted in the 1970's into family carers’ perspectives Voysey, a medical sociologist, asked the question; ‘what it is like to have a disabled child and the effects of a disabled child on family life’. This seminal work was one of the first to research the lived experiences of family carers in the disability domain within the changing landscapes of attitudes, service provision and research itself. First published in 1975, her book ‘the Constant Burden; The reconstitution of family life’ (Voysey 1975) has since been republished in 2006 (Voysey Paun 2006) as one of a series of ‘classics in sociology’.

As the title of her book indicates, Voysey regards ‘disability’ as not simply a ‘constant burden’, but as she reiterates in the 2006 introduction ‘…I certainly believe that having a child with a significant disability is one of the worst things that can happen to anyone these days …’ (p. xiii), despite what the parents were often telling her to the contrary (Paun 1975; Voysey Paun 2006). Voysey’s (1975) study was based on parental responses to questions about what it is like to have a disabled child, and the effects of a disabled child on family life developed through a constructivist-interpretivist paradigm framed on Blumer's symbolic interactionist perspective (1975 pg. 25).
Voysey sample consisted of 21 mothers, and partners or friends and other family members present when the interviews occurred. The data for Voysey’s study consisted of interviews with mothers seen 4 times and focused on areas of diagnosing the condition, parental perceptions, condition management and feelings. Voysey writings reflect what parents stated as expressions of objective meanings of their situation as ‘*competent members of society, person reasonably assumed to know what behaviour is expected of parents in general, and knowledge of the specific disadvantaged situation*’. At first interview, the youngest child was 2 weeks old and the oldest child nine years ten months diagnosed with a physical and/or intellectual difficulties. It is interesting to note the range of conditions the group of children had, as not all children had an intellectual disability, but a physical disorder. Conditions such as

- congenital breach of the oesophagus (1)
- three ‘mongol’ children (now referred to as Down Syndrome) (3)
- asthma (1)
- three retarded children (now referred to as ID children) (3)
- two children with diabetes (2)
- spina bifida and hydrocephalus (1)
- obesity (1)
- mental sub-normality (intellectual and/or developmental delay) (1)
- two children with epilepsy (2)
- galactocamia (1)
- congenital absence of bile duct (1)
- hole in the heart (1)
- coeliac disease (1)
- meningitis with hydrocephalus (1)

In all 21 children with a diverse range of physical and intellectual difficulties.

Voysey constructivist approach and interactionists’ perspective influences her analysis which motivates her to seek ‘meaning’ in participant’s words. Voysey wide reading of the then current literature on ‘deviance’ and related subjects is evidenced in her analysis, as she describes her challenges to come to grips analytically with what the parents told her about their experiences, relaying stigma and avoidance as parental strategies induced to normalise the condition within their family.
In 2006, Voysey states that she feels there is a shift away from the culture of acceptance and adjustment to the facts of disability, ‘Stoic acceptance’ except ‘perhaps in cases of profound sub-normality is no longer necessary’. Voysey argues that parents’ say what they say because such responses are legitimated by others, and other responses negatively sanctioned, recognising that meaning is not inherent in things, but through interaction. In that regard, Voysey argues that parents constitute the appearance of a normal family life because it is as normal parents that others, both informal and formal agencies treat them. Overall, the majority of parents claim that their disabled child ‘has not had deleterious effects on their family life’.

The question is ‘how they construct such claims in the face of questioning which implicitly asserts the contrary’ (Voysey 2006 Voysey 1975 pg. xx). They do not have to face this hardship 'alone' (pg. xx). Voysey discusses various cultural resources, derived from religion, medicine, psychiatry and/or sociology, and institutional agents, such as medical ones, social workers, voluntary associations and/or press publications, that can be seen to 'assist' ‘them in making sense of their unexpected burden’. As such, parents appear to be in a no win situation, and Voysey postulates that raising a disabled child places an enormous burden on the parents' capacities to accept the child’s condition and all that it entails, and they must present an image of parental adequacy and normality-in-the-circumstances to the outside world.

‘Pressure of the burden of care’ thus came to represent these parents’ experiences and formed the basis for Voysey theoretical perspective. Parents are then encouraged to 'accept and adjust' by a generally expressed or implied positive ideology as Voysey Paun (2006) writes:

‘[i]n general it can be seen that the ideology acts to define the situation of parents with a disabled child in such a way that it appears congruent with the normal order of child-rearing. Evident discrepancies between the parent's situation and that of normal parents are symbolically transformed so that, far from constituting a challenge to, they appear to affirm the validity of that order’ (pg. 195)
A critique of Voysey work is treating all disabled children and children with physical conditions as a homogeneous group, as the experiences for families with children with different types of impairment are markedly different (Ryan and Runswick-Cole 2008). The experience of raising a child with physical impairments and complex health needs will differ substantially from raising a child diagnosed as having diabetes or asthma (Ryan and Runswick-Cole 2008, Mansell 2010).

What Voysey does highlight is the experiences of mothering (as her sample was all mothers) a disabled child is complex and contradictory at a number of levels. This is partly due to the way in which disability as a concept is experienced by the mothers and other family members. Structurally, parents of disabled children are operating within a very narrow and often inflexible system of benefits, allowances and access to various resources (Jansen et al. 2016). This system enforces perceptions of disability as negative and undesired, which in turn parents mirror the dominant views of disability within society as a whole, adapting to processes and disability. Implications of this burdensome view of disability have traditionally been ‘humanitarian’ i.e. to help those perceived to be in need and ‘social control’ tendencies to hide or rid ourselves of those among us who don’t ‘fit in’ (Woodill and Velche 1995).

The humanitarian position of ‘assistance’ relieving a burden contributed to protections and separation policies from mainstream society (Woodill and Velche 1995). In part influencing parents to place children in institutional care, believing this was best for child and the family, a position disputed in the 21st century (Tøssebro and Lundeby 2006; UN 2006; HSE 2011) amongst other marginalised practices within schools, employment, clubs and societies. A practical application of this burden perspective within the ‘resources’ and ‘assistance in making sense of their situations’ appears embedded in medical and nursing responses to family carers.
These professions have traditionally viewed disabled people as burdens to the family from which the family may never recover (Chou et al. 2011, Irazábal et al. 2012) and whose response is to cure and protect (Kearney and Griffin 2001). Within this context, institutional care overseen by professionals is purported to offer ‘support’ by preventing the child disabling the family. This evidenced in a contemporary quotation reflecting the dominant narrative of despair at this time:

‘The permanent, day-by-day dependence of the child, the interminable frustrations resulting from the child's relative changelessness, the unesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child, all these join together to produce the parent's chronic sorrow’ (Olshansky, 1962 cited in Jacques 2006).

Craft et al., (1985) influential work ‘A multi-disciplinary approach to Mental Handicap’ describe historical eugenic nations that disabled people were sick and better off in an institution where doctors and nurses, and later the professions supplementary to medicine created the lifestyle giving a cradle to grave service intended to replicate an old village or self-sufficient colony.

‘Admissions were frequent for negative reasons, because the family could not cope; or the child was too dependent or too disturbed; rarely had that child a full investigation by a child-centred service. An embryonic welfare state and a disparaging attitude to mentally handicapped people, many who lived in institutions, were ’saved from the much worse fate of an unsupported community existence’ (Craft 1985)

Such views illustrate that the early ‘supports’ offered to families based on a pathological model, in which families reacted to dominant paradigms of knowledgeable professionals. Klotz earlier words ring true here. The origins of many present day supports and services for family carers lie within these burdensome, medical, social deviancy and warehousing ideologies. Uncritical application of these models in the interpretation of the behaviour of family carers has negative implications.
For instance, Kearney and Griffin found professionals use expressions such as ‘They’re not being realistic’; ‘They won’t accept the child’; ‘They’re shopping around, looking for someone who’ll say there’s nothing wrong’. When professionals interpret parents’ words and behaviours as denying reality, rather than demonstrating the ideals of ‘acceptance’ and ‘being realistic’, the parents may be viewed as dysfunctional (Kearney and Griffin 2001). Current streams within the literature recommends a broader conceptualisation of family adjustment and theoretical perspectives that suggest successful adaptation rather than crisis or pathology (Twigg and Atkin 1994; Hall et al. 2012; Giallo et al. 2015).

2.4.2 Twigg and Atkin ‘typology of carers’

The seminal work of Twigg and Atkin also requires acknowledgement in this dissertation. Their work was one of the first to advocate for family carers status requiring responses and active interventions in policy and professional debates in addition to the person they support. Twigg and Atkin recognised the contribution of pathological models of disability in establishing concrete and visible the personal costs of caring and partly developing objective measures of the impact of different interventions. Nevertheless, Twigg and Atkin were concerned that research was generating measures of burden and stress more like chimeras whose pursuit yields increasingly diminishing returns, with stress or burden reified and pursued in ways that are ‘detached either from how people cope with their lives or the policy issues posed by caring, arguably not reflecting how many carers live their lives, perceive their situations to be and that the language is pathologising’ (Twigg and Atkin 1994).

Developing research with family carers supporting persons, living with dementia, Twigg & Atkin (1995) conceptualised a typology of carers to convey the complex patterning of professionals’ engagement with carers.

Briefly summarised, these are:
Carers as resources

The main model – representing general, free, available, preferred sources of family support. They exist separately from statutory provision, which may have to step in when such care is not or is no longer available.

Carers as co-workers

Working with or alongside professionals, carers carry out tasks and their work interweaves with formal systems of support. Carers’ needs are responded to so that they can continue with the job.

Carers as co-clients

Supported in their own right by services, which attempt to provide relief. The carer’s needs and well-being are a key focus of support. The problems of the carer are considered and responded to, even if this may divert attention from the person with disabilities.

Superseded carers

Often referred to as relatives or family, seen as distinct from the person with disabilities, indeed, there may be unsolvable conflicts of interest. Services may help support such carers and person with disabilities by starting the healthy process of separation.

Table 2-1 Twigg and Atkin (1995) Typology of Family Carers

This typology in table 2-1 serves to clarify the ambiguous and uncertain position that family carers exist within health and social care systems noting in this study how family carers are rarely themselves the focus of interventions, supports or financial compensation for providing care and support.

Twigg & Atkin (1994) study also identified carers attitudes to their role associated with the emotional physical and social adaptations (1995, p. 10). They conceived these falling into three models: engulfment, balancing/boundary setting and symbiosis. Family members can feel ‘engulfed’ when overwhelmed by circumstances and help perceived as ‘unsuitable’ or ‘threatening’. In the second attitudinal model, family carers consider their position and the boundaries they may wish to choose, and begin to plan. The third attitudinal model, symbiosis, sees carers as identifying themselves with the person with disabilities and unwilling to relinquish responsibility. Unlike carers who set boundaries and are open to assistance, and may indeed make demands on systems and professionals, those in a symbiotic state presented as generally content with services unless they destabilise their way of doing things or relationship.
This view reflects caring as ‘normal within families’ and an inevitable part of life, something that is simply expected from people, particularly women and mothers (Twigg and Atkin 1994, Noddings 2013, Coyle et al. 2014). Implications of Twigg and Atkins model represent family carers supporting those with intellectual disabilities as ‘unwilling to relinquish responsibility’ and rather than recognising the skilful highly committed family carers’ expertise can be viewed as derogatory to their roles. Current understandings recognise carers as experts for example, Brown et al., report the prolonged and skilful nature of caring for children and adult dependents with PIMD and the movement beyond normal parenting responsibilities most noticeably in completing invasive and complex interventions to support their sons and daughters in sustaining a good quality of life (Brown et al. 2016).

What is evident from Voysey (1975, 2006), and Twigg and Atkin (1994) seminal works is recognition of the role of family carer. An evolution of understanding has brought ambiguity and inconsistency with terms carers, informal carer, family carer and parental carer etc. Similar to recent literature, family carers in this study have difficulties in labelling themselves as carers, yet often due to the nature of interactions, and extended roles from parenting involuntary and reluctantly identify with the term ‘carer’ (Kirk and Glendinning 2002; Resch et al. 2010; Sofronoff et al. 2011; Schofield et al. 2013b; Whiting 2014).

Ambiguity and role confusion described by Schofield et al. (2013) presents findings in relation to long-term foster carers has comparative relevance to this study. Schofield et al. describe the concept of ‘role’ as critical to the discussion of what carers do in their work/family lives and how they see their identity. Their analysis accounts for carer’s roles as ‘professional carers’ and/or ‘committed parents’ to explore how they manage different and potentially contradictory role identities. ‘Role conflict’ and ‘role enrichment’ at the interface between work and family in long-term foster care feature as the main findings in Schofield et al report on qualitative data from 40 interviews with long-term foster carers.
Many carers frequently have to adopt multiple and ambiguous roles, which in turn have shifting sets of expectations from family, friends and colleagues (Schofield et al. 2013a). While foster carers primarily identified as carers or as parents, some foster carers could move flexibly between these roles while others could not. For foster carers who could be flexible, the two roles enriched each other rather than causing stress and role conflict. This present study can affirm these contentions for family carers of persons, living with PIMD; detailed in the findings chapter, in addition, relate to the positive aspects of caring which family carers in this studied acknowledged and through analysis became integrated with the grounded theory.

### 2.4.3 Positive aspects of Caring

Families who share positive experiences of raising disabled children and supporting disabled adults has come to be recognised as an important contribution in furthering professionals and the general public way of viewing the experience of ‘raising a child with a disability’ as one that is not necessarily tragic (Hastings et al. 2002; Turnbull et al. 2015; Beighton and Wills 2017).

For example, a study focusing on the role of positive perceptions in helping family members adapt to children with intellectual disabilities was the focus of work done by Hastings et al., (Hastings et al. 2002). The rationale for undertaken this study was when the authors found that existing theoretical and empirical work in the intellectual disability field paid little attention to parents’ positive perceptions of their child and the positive impact that the child may have on the family. In all, 39 biological mothers and two foster mothers of children with intellectual disabilities participated in the study. Respondents were on average 41.40 years of age (SD = 6.54; range 30–59 years), and their children with intellectual disabilities were 11.90 years of age (SD = 3.88; range 4–19 years) on average. Twenty-eight of the children with intellectual disabilities were males and 12 females (one nonresponse).
All the families, barring two, had other children (mean = 1.56 siblings). Thirty-six of the mothers were married or living with a partner, and 19 were engaged in paid work at the time of the research. Forty-six per cent of the mothers had no formal educational qualifications, and 7% had a bachelor’s degree. Data gathered using a self-report questionnaire contained five sections. Section one, demographic information about themselves, their family and their child with intellectual disability. The second section assessed care demands of the child utilising 15 care domains: dressing, bathing, toileting, calming when upset, feeding, giving medication, sleep, shopping, visiting friends, going out, doing enjoyable things, lifting, physically handling, caring, and others' caring involvement. The third section contained an 18-item Family Support Scale (FSS –Dunst et al. 1984). In the fourth section, family coping strategies measured using the Family Crisis Orientated Personal Evaluation Scales (F-COPES –McCubbin et al. 1991). The final section of the questionnaire contained three subscales from the positive contributions scale of the Kansas Inventory of Parental Perceptions (KIPP – Behr et al. 1992).

A convenience sampling of parents via two local schools, for children with intellectual disabilities, in a mixed urban and semi-rural area, in southern England occurred. Data collected via questionnaire, sent home with each child in the schools, with a covering letter requesting the primary parental caregiver complete. Participants completed their questionnaire anonymously with no reminders issued. In all, 146 questionnaires were distributed and 33% returned. The results suggest that psychological rather than demographic and child demographic variables are associated with mothers' positive perceptions about the impact of their child with intellectual disabilities. The positive influence of the child (happiness and fulfilment) and its effect on the family in general (strength and family closeness), were positively predicted, by the use of reframing coping strategies.
The second main finding was the broad range of factors predictive of the positive effects on the mother's development directly, as opposed to the general positive effects of the child and their impact on the family. Thus, using social support, as a coping strategy, and the helpfulness of informal social support resources were helpful to mothers in developing a sense of personal growth and maturity.

Building on Hastings et al., the work of Beighton and Wills (2017) explores what parents perceive to be the positive aspects of parenting their child with intellectual disabilities. Fourteen mothers and five fathers (includes two couples) were recruited through learning disability partnership boards and local MENCAP organizations from London boroughs between October 2013 and March 2014. Inclusion criteria for the parent participants were that the child they supported had a diagnosis of intellectual disability, parents had to communicate using English language, be aged over 18 years and that the child was over 5 years of age and lived in the same household. Participants parented 10 males and 9 females who had a diverse range of intellectual and associated physical disabilities with two families containing more than one child with intellectual disabilities.

All but one parent choose to the interview to occur in their home, and each interview lasted approximately one hour. The findings were interesting. Despite the focus of the interviews being to identify the positives of parenting a child with intellectual disabilities, in every interview a much larger proportion of time was spent by the parent talking about the negative aspects of parenting their child yet only the positive aspects were reported in their paper. Braun and Clarke analysis framework sets the findings presented in seven overarching themes. Six of the themes were broadly similar to the work of Hastings et al., (2002) however; one theme not identified by Hastings et al., ‘the positive effect the child has on others’ was found by Beighton and Wills.
The seven key themes identified covered three broad areas. Intrapersonal factors having a direct influence on the parent themselves (theme 1: increased personal strength, theme 2: changed priorities, theme 3: a greater appreciation of life and theme 4: increased spirituality/religiosity). Interpersonal factors, factors that relate to aspects between persons (theme 5: more meaningful relationships and theme 6: the positive effect the child has on others). Thirdly, theme 7: child is the source of positivity, the child’s accomplishments. These themes identified in the transcripts of all parents irrespective of their gender or the age of the child. While the parents in their study spoke about focusing on specific problems or situations they tried to generate alternative solutions, weighing up the costs and benefits of various actions, taking control, seeking information from professionals and mastering new knowledge and skills from this process, which Beighton and Wills construed as ‘an active coping effort’ that includes ‘positive reframing strategies’.

The differing ‘meaning-focused coping strategies’ included ‘positive reappraisal’ to deal with solving or changing the perceived cause of stress, revised identity, increased growth, changed views of the world, and a mixture of problem-focused and support seeking adaptive coping strategies to obtain emotional support.

These strategies are not distinct coping styles but part of the ‘total coping effort’ that people can draw on to produce the best adaptational outcomes for themselves. Beighton and Wills see this as consistent with Folkman (1997) who described four coping strategies associated with searching for and finding positive meaning ‘positive reappraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and the infusion of ordinary events with positive meaning all involve the activation of beliefs, values, or goals that help define the positive significance of events’ (p. 1215).
In the works of Voysey, Twigg and Atkin, Hastings et al, and Beighton and Wills, it is clear to see how both quantitative and qualitative approaches to research has contributed to understanding family carers’ situations and experiences. The movement beyond Voysey’s (1975, 2006) and Twigg and Atkin (1994) single and static explanatory mechanisms of explanation towards the more sophisticated approach that address the dynamic unfolding of multiple processes over time as demonstrated in Hastings et al., (2002) and Beighton and Wills (2017) represents the paradigm shifts, in the domains of family carers, disability and research approaches. This leads to the next area in the study domain; Supporting decision-making.

2.5 Supported Decision Making

Supported decision making, a central tenet to this study, is described as an emerging concept in disability and legal arenas, and a process of supporting a person with decision-making that recognises legal status and a means of bringing a person’s will and preference to the centre of any substituted decision-making process (Browning et al. 2014). As an emerging legal concept, supporting decision-making is a term now grounded firmly by UN CRPD (2006) and represents a legal status that will be of benefit, in particular, to people with significant or ‘profound’ intellectual, psychosocial, and communication disabilities (Bach and Kerzner 2010; Devi et al. 2011).

The concept supporting decision-making was founded in the need to understand how informal and formal support mechanisms contribute to the goal of maximising an individual’s autonomy (Knox et al. 2015). Supports have been described as assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment (Schalock et al. 2010; Flynn and Arstein-Kerslake 2014b). Individualised supports are characterised as being primarily determined and directed by the person with an intellectual disability in collaboration with their family and or advocate and in consultation with an independent assessor and not a service provider or other ‘experts’ as traditionally has been the case (HSE 2012).
Since 2006; an escalation in papers exploring the concept, construct and approaches to supporting persons, in decision-making has arisen partly due to the implementation of the UN CRPD. Ireland, Australia, Canada, United States of America and the United Kingdom are countries in which the discussion papers mainly derived from (Ryan 2018b). It is evident that supporting decision-making is emerging as a fast liberator in the disabilities domain (Ryan 2018a, Quinn 2009; Devi et al. 2011; Doyle and Flynn 2013).

Disability and legal scholars acknowledge that the CRPD embodies a paradigm shift in the way the world thinks about disability (Quinn 2009, Werner et al. 2012, Doyle and Flynn 2013). This interest is partly due to the influence of the CRPD (Werner 2012) and advances in practices that advocate for replacement of paternalistic substitute decision-making by the autonomous and dignity enhancing concept that supporting decision-making purports to being (Carney 2013). The drive and vision for introducing supporting decision-making is evident in papers reviewed (Stein 2007; HSE 2011; HSE 2012; Werner et al. 2012).

The essence of these papers brings to light the need and value of supporting decision-making in bringing about full legal capacity (both recognition of rights and capacity to exercise those rights) while availing of legally recognised access to supports (Flynn and Arstein-Kerslake 2014a; Flynn and Arstein-Kerslake 2014b). The legal recognition of access to support therefore rejects the notion of capacity as a one for all approach associated with the pathological model of disability. It is proposed that the CRPD transcends the images of disability from being a flaw within the pitied individual in need of charity towards an individual recognised as a full agent within our societal structures and granted the same standing as all citizens (Quinn 2009; Bach and Kerzner 2010; Devi et al. 2011).
Examination of health and social policies and literature provides an understanding of how difficult it is to make such a seemingly normative concept applied (Ryan 2018b). Part of this relates to the lack of a clear or agreed definition of supporting decision-making (Kohn and Blumenthal 2014), and this has proven to be problematic and a contributory factor towards confusion and ambiguity (Bach and Kerzner 2010). Supported decision-making presented with the assumptions and understandings of the UN CRPD (2006) refers to a dyad and a process of

‘Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realise that a person with significant disabilities is also a person with a history, interest and aims in life, and is someone capable of exercising his/her legal capacity’ UN CRPD Handbook for Parliamentarians on the Convention pp.X

Article 12(3) of the CRPD specifically references supports as follows:

States parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity

The American Association of Intellectual and Developmental Disabilities (AAIDD) define support as a psychological construct referring to the pattern and intensity of resources and strategies that promote personal development and enhance functioning that a person requires participating in activities associated with normative human functioning (Schalock et al. 2010) and the personalisation agenda becomes interwoven with decision making (Mc Conkey et al. 2013).

In this light, support requiring resources and strategies underpinning decision making aims to promote personal development and function, is thus personal. As a process Back and Kerzner conceptualise supporting decision-making as a mechanism for enhancing a person’s ability to make his/her own decisions, thus, an apparently ‘incapable person’ may be able to make his/her own decisions with the help of others, and thus exercise his/her own legal capacity.
When considering ‘supports’, and by extension, the concept of supporting decision-making in the context of the CRPD cognizance of the substance of the drafting process is important. Summer schools in the National University of Ireland Galway (NUIG) facilitated this understanding in addition to the literature. Meeting some of the people responsible for drafting the convention and listening to the passionate and determined motivations in fighting for rights was inspiring (Appendix 2). Their commitment, over decades, transpired into the movement recognising support as a ‘natural and community based’ provision enabled through policy and legislative assistance was commendable.

It is purported that the real value of the Convention will be revealed in how Government, human rights organisations, services and organisations of and for people with disabilities internalise the values, principles and rules of the Convention in moving law and policy forward (Quinn 2009).

### 2.5.1 Supported Decision Making Models

Two models describing supporting decision-making ‘Maximising Decision Making Abilities’ by Back and Kerzner (2010) and ‘Enabling Conditions’ (built on the work of the Back and Kerzner 2010) by Flynn and Arstein-Kerslake (2014) will now be outlined. Bach and Kerzner (2010) conceptualise supported decision-making as a process with outcomes viewing supported decision-making as:

> ‘occurring when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behaviour to determine his or her preferences through three different decision-making statuses.

1) Legally independent status - has the ability, by him or herself or with assistance, to understand and appreciate the information relevant to, and the reasonably foreseeable consequences of, making a decision
2) Supported decision-making status - a support person is appointed, by the person with a disability, or by an administrative tribunal or court. Due to a relationship with the person with a disability, the support person can interpret and carry out his or her will or intention, ‘consistent with the person’s identity’ and respecting ‘the individual’s dignity of risk’. The support person would be obligated to consult with the person he or she is supporting and to make decisions based on that consultation.

3) Facilitated decision-making status- a facilitator is appointed by administrative tribunal or advanced planning document (i.e., power of attorney). Facilitated status would not ‘represent a statement or judgment about their cognitive status or abilities’, simply that they do not meet the criteria, above, of legal independence, and do not have anyone in their life who know them well enough to interpret their will and/or intention (Bach and Kerzner 2010)

Within this framework Bach and Kerzner identify three decision-making statuses, all aiming to be consistent with the person’s identity, namely (i) legally independent decision-making; (ii) supported decision making; and (iii) facilitated decision-making. They acknowledge that some movement between legally independent and supported be made, depending on the decision in question, in general they conceptualise these points as distinct ‘statuses’. The conceptualisation of supporting decision-making purported by Bach and Kerzner (2010) views decision-making capability as a relationship between decision-making abilities, decision-making supports and accommodations, and decision-making status. People move between statuses as abilities supports and accommodations evolve, or alternatively regress, reflected in their image below:
The approach to ‘decision making capacity’ advocated by Bach and Kerzner (2010) focuses on what accommodations and supports a person requires to manage the decision-making process in a way that maximises their decision making capacity and thus exercise legal capacity. The first point on Bach and Kerzner continuum is Legally Independent Decision-Making, where an individual has the ability to make decisions on her own and recognised as such. This may require reasonable accommodation to assist the decision-making process. An example of accommodations include ensuring information relating to the decision is made available in a format which the person can understand (Goldbart and Caton 2010). Giving the person plenty of time to come to a decision, and enabling the use of informal support where the person can consult those closest to them in making the decision (The Office of the Public Advocate 2014) are other accommodations. Arguably, these points reflects the ways in which most people make decisions by consulting others, but being free to accept or reject their advice.

The second point on Bach and Kerzner continuum is supporting decision-making, in which assistance in decision-making in all areas desired. This assistance can take the form of a circle of support, whereby the person chooses a number of trusted individuals to assist in the decision-making process (Atherton and Gates 2007).
These should be people who know the individual well, and can help interpret the person’s will and preferences and communicate these intentions to third parties (Schalick et al. 2012), who are obliged to accept the decision as a valid one. The state should have a role in providing opportunities for support, enabling support agreements to be formalised and ensuring that decisions made through this mechanism are respected by third parties (Bach and Kerzner 2010).

The third point is Facilitated Decision-Making, which applies as a last resort, where there is no circle of support or other person who could reasonably interpret the will and preferences of the individual. In this case, an appointed facilitator takes decisions on behalf of the individual, but does so with the will and preferences of the individual at the centre of the decision-making process and in the manner which best augments the person’s autonomy and decision-making capability (Bach and Kerzner 2010). The facilitator’s role is to imagine what the person’s will and preferences might be and to make the decision on this basis.

This distinguishes facilitated decision-making from substitute decision making (Flynn and Arstein-Kerslake 2014a). Understanding the mechanism of supporting decision-making through ‘decision making capacity’ focuses on what accommodations and supports a person requires to manage the decision-making process in a way that maximises their decision making capacity and thus exercise legal capacity, given their unique decision-making abilities. This model sounds paradoxical, for by saying that a person is accorded legally independent status on the basis of an assessment of decision making capacity, Bach and Kerzner seem to concede what they intend to deny: namely that a person’s level of decision making capacity determines whether a person has the right to make her own treatment decisions (Scholten, and Gather 2018). It could be argued that this approach falls in to the trap of ‘capacity assessment’, which ultimately is a challenge to Article 12 of the UNCRPD.
It is important to acknowledge that Back and Kerzner did not intend this model to be used to determine whether a person has legal capacity, but rather the status through which legal capacity is exercised in particular when disputes arise in this regard among parties in a decision-making process. Building on the work of Back and Kerzner (2010), Flynn and Arstein-Kerslake (Flynn and Arstein-Kerslake 2014b) propose the ‘Support Model’ to support decision-making presented in the image below:

![Support Model](image)

Image 2-2 Support Model Flynn and Arstein-Kerslake 2014

This model builds on the work of Back and Kerzner (2010) and acknowledges the enabling conditions a person needs moving between the different statuses of decision making. Flynn and Arstein-Kerslake (2014) supporting decision-making ‘Support Model’ image represents the overarching support model of legal capacity. The cogs in the centre of the circle represent the three clusters of decision-making: legally independent, supported and facilitated as previously outlined by Bach and Kerzner (2010).
The difference in the models relate to the area surrounding these clusters ‘the enabling conditions’ which include advocacy, reasonable accommodation, accessible information and communication, recognition of different forms of expression, advance planning tools, and so on. The first principle of Flynn and Arstein-Kerslake model is that every person enjoys legal capacity regardless of level of decision-making ability a principle of Article 12 UN CRPD, and each person should empowered to exercise legal capacity through the expression of their will and preference. Second, this requires the abolition of any assessment of decision-making ability (capacity assessment) which may results in the loss of legal capacity.

Any assessment which takes place in a support model of legal capacity should be centred on the support that is needed in decision-making to augment an individual's existing strengths, rather than the deficits of the individual (Flynn and Arstein-Kerslake 2014b). Finally, the support model requires the abolition of substitute decision-making in which subjects the will of an individual to the dominance of another's will or notion of what is in her ‘best interest’. This does not prevent a representative from making a decision for another person who is not expressing her will and preferences in a way which anyone can interpret, rather, it requires representatives making such decisions to do so in a way which attempts to draw out the ‘imagined will and preferences of the person’ (Flynn and Arstein-Kerslake 2014b).

Underpinning both of these approaches to supporting decision-making is the aim to provide individuals opportunities to exercise their legal capacity and demonstrate self-determination through choice and decision-making. The assumptions that all persons can make decisions are implicit and explicit in their discussions.
However, challenges to the concept of supporting decision-making and these supporting decision-making models exist. We need to question if the representation of ‘the imagined will of another’ promotes self-determination or promotes the supporters understanding of another’s identity and intended choice making. The subtle difference between these two is crucial to the purpose of the model itself, and the danger of camouflaging the person, living with PIMD, identity and choice making assertions may be lost in the supporter asserting an ‘imagined will and preferences’ in the absence of corroboration or confirmation. A suggestion to replace ‘imagined’ with ‘attempt to assert the person's will and preferences’ may be beneficial to the model being implemented and more realistic to the challenges that people face in this endeavour.

Agreements in the theoretical literature and policy documents relate to the fundamental aspect to supporting decision-making in that it challenges the ‘ways of knowing’ people. From a model of service that traditional relied on pathological models of disability to seeing people as masters of their own lives, with a life plan and pathway, a life story or narrative (Department of Health 2009; Bach and Kerzner 2010; Barnes and Mercer 2010; HSE 2011; Lashewicz et al. 2014) notwithstanding the uncertainty and ambiguity surrounding supporting decision-making.

This leads to the next point of discussion, looking at the practical implementation of supports.
2.5.2 Circles of Support

Flynn and Arstein-Kerslake (Flynn and Arstein-Kerslake 2014b) identify various types of supports which come within the ambit of the UN CRPD, Article 12(3), with the most well-known being a support network or circle of support. These circles of support emulate principles similar to that of the social model of disability which emphasises person centred approaches of support through assistance of local volunteers and often professional supporters, but should not consist solely of paid workers (Lay and Kirk 2011). Circles of support are influential in shaping a person's life structure and life experiences (Kaye-Beall 2016).

Circles have been given a variety of names and follow different models such as: ‘Self-Directed Support Corporations’, ‘Circles of Support and Accountability’, and are similar to methods of organising like ‘Family Group Conferencing’ (Neill and Sanderson 2012). Circles of support are designed to target social isolation and emotional loneliness, and have been used as interventions in care and social episodes such as reducing recidivism in treating sex offenders (Kemshall et al. 2014) and empowerment strategies with early onset dementia (National Development Team for Inclusion 2016).

While there are important differences between these ways of organising and planning circles of supports they are all based on a form of subsidiarity: taking ‘decision making power’ directly to the point closest to the people who will be affected by that decision (Neill and Sanderson 2012). A move welcome in intellectual disability circles (Quinn 2009; HSE 2011; Werner et al. 2012). Supporters therefore understand a person’s life history, unique communication forms likes and dislikes, often proven challenging for persons, living with PIMD (Maes 2010; Mansell 2010; Hostyn et al. 2011).
Choice, control and co-production lie at the heart of the process of person centeredness within Circles of Support (Lewis and Sanderson 2011). These support forums have shown to encourage independence, increase resilience and self-reliance, encourage creativity in planning, delivering support in a way that makes sense for the person, and also an increasing use of ‘natural’ supports (Lay and Kirk 2011; Lewis and Sanderson 2011; Neill and Sanderson 2012). Every circle is different because of the uniqueness of the individual at the centre and the uniqueness of the contribution of each circle member, therefore, it is important to recognise that there is no one way to support people to make decisions, everyone is different and will need different supports at different times (Browning et al. 2014).

A practice within circle of supports entails a co-production process between the individual, as the focus, and supporter(s) in which elicitation of dreams, desires, wishes and wants are acknowledged, planned for and consideration given to achieving them (Lay and Kirk 2011). A supporter’s role has been described as providing and explaining information, supporting receptive communication skills in addition to helping an individual understand the consequences of making a decision with perhaps the use of assistive and augmentative communication devices in expressive communication skills (Belva et al. 2012) if required.

Understanding person centeredness and circles of support contribute to understanding the ideology of supporting decision-making by facilitating individuals independence in decision making, legal capacity and avoid having their right to control their decisions taken over by a substitute decision maker through a co-production approach. Popularity of circles of support in practice are emerging partly due to the philosophy and ideology surrounding the approach, and perceived outcomes related to guidance (Macadam and Savitch 2015), tangible resources and practical assistance (Lay and Kirk 2011) and emotional support (Kaye-Beall 2016). However, a dearth of research in relation to circles of support, notably, in the areas of sustainability (Kaye-Beall 2016), productivity and cost effectiveness (Atherton and Gates 2007) therefore raises concerns.
2.5.2.1 Support with versus Supported

While we all seek support with decision making it can be argued that supported decision-making can result in increasing capacity if we frame understanding of capacity to take into account the effect of supported decision making (Browning et al. 2014). This is based on studies that shows people who have been found to be ‘incapable’ but with supported decision making in place are then found capable (Knox et al. 2015; Watson 2016; Watson et al. 2017).

2.5.3 Challenges to Supporting Decision-Making

Supported decision making has been reported by many authors as a nebulous concept (Carney 2014) with many facets namely a process, a mechanism, a system, a framework and an end that legally recognises the process of supporting a person with their decision making (Browning et al. 2014). In general, the concept of supporting decision-making is identified as discursive with ‘perceived benefits and challenges’ nevertheless a lack of evidence to explore effective evidence-based supporting decision-making practices to develop policy and practice exist (Kohn and Blumenthal 2014). No comprehensive working model exists and warrants ‘a task at hand for the future’ (Werner et al. 2012).

Since this assertion, two models Back and Kerzner, Flynn and Arstein-Kerslake, previously described, have addressed this task, albeit more evidence of their contribution and value may now be the ‘task at hand for the future’. The first status ‘legally independent’ within both models is relatively self-explanatory and common to most persons understanding therefore there is little critique of this status.
Challenges to the second statuses of supporting decision-making and the third facilitated decision making status is abundant in the literature and policy arenas where disagreement and ambiguity come to the forefront (Kohn et al. 2012; Doyle and Flynn 2013; Carney 2014; The Office of the Public Advocate 2014). Confusion may arise between the term ‘Supported Decision Making’ as a status within the models and the term reflecting the overall outcome of the process. This is pertinent when describing the support needs of people with PIMD which is not easy (Petry and Maes 2007). Language and the legal interpretations may appear confusing to the non-legal family carer and persons with ID, PIMD whom these models support. Therefore, to make explicit a concept and process explicit in the face of evolving understanding is challenging.

There are few published reports on the experiences of persons, living with PIMD, in forming ‘circles of supports’ and how they have been developed, experienced or sustained. The establishment of ‘circles of support’ based on the philosophy of social inclusion through planning is welcomed. However, development of groups has been reported as problematic associated with impoverished social lives (Gannon and Nolan 2006) and minimal social networks (Lippold and Burns 2009) in particular PIMD (Lippold and Burns 2009; Mansell 2010; Walker et al. 2014).

Circle of supports have a weak evidence-base for the centrality of its position in support structures. As a mechanism, circles of support depend on charity and voluntary contribution of others, an ideology that seems at odds with implementing rights based approaches to support. In addition, enabling conditions and supports within this ‘circle of friends’ need consideration and a governmental/strategic approach considering time and resources to achieve local and natural supports. For example, a practical implication, do all members in ‘circles of support’ require Garda (police) Vetting? In other jurisdictions, such as the UK (National Development Team for Inclusion 2016), this has perhaps received more attention than here in Ireland (Power 2010).
This links to a discussion paper by Carey and Griffiths who describe current practices where people undertaking the roles of supportive decision-makers (as many have in the past) and the criteria set out for this role requires clarification regarding the skill set that supportive decision-makers ideally require (Carey and Griffiths 2014). To summarise this section, what is clear from the literature reviewed is agreement related to the concept of supporting decision-making ‘as an ideal principle’ yet criticisms of supporting decision-making as problematic (Carney 2014), undefined and challenging (Werner et al. 2012) and complicated aspects as the process evolves (Flynn and Arstein-Kerslake 2014a). Now, to the people requiring such support, the third domain of study in Figure 2 1 Conceptual framework, Understanding ‘PIMD’ now discussed.

2.6 Introducing ‘PIMD’

The 28,275 people registered on the NIDD, at the end of December 2016, have individual, diverse and sometimes complex needs. Arising from a primary diagnosis of intellectual disability, classified from mild, moderate, severe to profound. Individuals may have sensory and physically challenges and or multiple disabilities. Manifestations include neurological disorders such as cerebral palsy, epilepsy, vision and hearing impairments and other congenital malformations such as cardiac, gastrointestinal and renal malformations (Schalock et al. 2010). These conditions and wide range of complications that result from them cause people, living with ID and PIMD, to have more health problems than the general population described as requiring ‘high levels of support from others’ not only in the management of these conditions but ‘with most aspects of daily living’ (Mansell 2010).

Persons, living with PIMD, require the same principles as the general population in the support and management of these conditions. What makes them different in people, living with PIMD, is the increased likelihood of the conditions occurring, how the conditions present and perceived in addition to the impact on all ‘aspects of living’ (Bigby et al. 2007; Hogg 2007; Belva et al. 2012; Simmons and Watson 2014).
The reality for persons, living with PIMD, is that their family carer, their families and support workers are essential to assist in all aspects of managing conditions and most aspects of daily living. In my original nurse training I recall the definition of ‘mental handicap’ as it was ‘coded in a medical classification of diseases of the World Health Organization’ (WHO 1997) and defined as:

‘... a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical condition’

WHO 1997

This definition is something I share with students and ask them to tease out its origins and underpinnings. Given the potential breath and range of needs it can be challenging for society to view beyond the series of needs and procedures. The word ‘arrested’ stands out strongly, and the permanency associated with this viewpoint does not encapsulate current thinking.

Paradigm shifts in disability and rights (explored in Section 2.6) provide knowledge to challenge assumptions in thinking and practices (Barnes 2003, Quinn 2009, Barnes and Mercer 2010, Ferguson and Nusbaum 2012). This is most evident in disability arenas, where deinstitutionalisation, the process of replacing long-stay psychiatric and intellectual disability hospitals with less isolated community services for those diagnosed with a mental disorder or developmental disability has occurred. Closing professional led institutions and creating community based services aims to change the relationships, ways of thinking and social structures to serve and support disabled people and their families.

Resonating with current approaches to defining disability is that advocated by the AAIDD who promote an approach based on the multidimensionality of human functioning that involves: intellectual abilities, adaptive behaviour, health, participation, and context (Schalock et al. 2010) with the aim of reducing the deficit approach and contribute to a ‘supports model’.
‘Intellectual Disability’ is used throughout this dissertation to refer to individuals who as described by the AAIDD (Schalock et al. 2010) live a life with

‘Significant limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills, originating before the age of 18 with the following five assumptions essential to the application of the term:
1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors
3. Within an individual, limitations often coexist with strengths
4. An important purpose of describing limitations is to develop a profile of needed supports
5. With appropriate personalised supports over a sustained period, the life functioning of the person with intellectual disability generally will improve’ (Schalock et al., 2010 p. X)

This understanding of disability has two major components; five dimensions (intellectual disabilities, adaptive behaviour, health, participation, and context) and a depiction of the role that supports play in human functioning (Schalock et al. 2010) represented in the following image;

Figure 2-2 Multidimensional model of human functioning AAIDD (2010)
In figure 2.2 framework individualistic deficit approaches to disability towards a more inclusive and supportive interaction is proposed. The AAIDD emphasises interventions that focus on individual strengths that emphasise the role of supports to improve human functioning. Understanding ‘human functioning’ as a dynamic and reciprocal engagement among intellectual ability, adaptive behaviour, health, participation, context, and individualised supports is consistent with an ecological and multidimensional perspective.

Recognising the self-determination and choice making that profoundly disabled individuals present is often challenging because of complex communication needs, impaired social interaction, limited experience of choice and difficulty making informed choices for themselves (Bigby et al. 2007; Power 2009; HSE 2012). The ‘complexity of needs’ and respecting choices of persons, living with PIMD, has more significance when considering ‘Independent Living’ and ‘Individualisation’ approaches to living (HSE 2011). ‘Time to Move on from Congregated Settings Report’ (HSE 2011) in conjunction with the National Housing Strategy (Dept. of Environment, Community & Local Government 2012) summaries Ireland’s vision for supporting the independent living of all persons with disabilities, in essence acceleration the deinstitutionalisation process. Pat Dolan, Chairperson of the Congregated Settings Report writes in the forward that the main objective to the strategy is that people with disabilities be part of their community, plan for their own lives and make their own choices through the provision of personal supports for their independence (HSE 2011).

Making decisions is an important component of everyday living, and issues surrounding autonomy and self-determination are crucial for persons with intellectual disabilities, often taken for granted in our everyday being. Informing our understanding of profound intellectual and multiple disability and ‘human functioning’ through the provision of personal supports the question of language and shaping perspective arises. The role of language and the significance of language shaping understanding, briefly discussed, alludes to more than semantics, but values beliefs and attitudinal perspectives within the words, now discussed.
2.6.1 Naming, Language and Labels

Throughout history, documentation of ‘intellectual disabilities’ under a variety of names categories and classifications reflecting evolving ideologies has occurred. A confusing aspect of intellectual disability is the multiplicity of terminology and perspectives however, the requirement for a definition relates to legal consequences, types of education provision, eligibility for support services, and many other aspects having real implications on daily experiences in society. Since 1990’s, in Ireland the term ‘intellectual disability’ is the preferred and accepted term yet a number of terms exist such as learning disability, mentally retarded, mentally impaired and mental handicap used interchangeably in the literature. The choice of terminology is contentious, as derogatory labels such as ‘cripple’, ‘spastic’ and ‘handicap’ in English speaking countries appear to have lost their technical meaning and have become terms of abuse and offence (Barnes and Mercer 2010).

There were important considerations about language used throughout this study with deliberate and thoughtful consideration of this literature surrounding this debate. Insights of Blaska (Blaska 1993), Titchkosky (Titchkosky 2001) and Barnes and Mercer (Barnes and Mercer 2010) were reviewed and considered. In Blaska discussion paper, she reflects on ‘what it means to be disabled’. Similar to Voysey’s assertions, Blaska evokes understanding of how

‘Language is a reflection of how people in a society see each other. Historically, persons with disabilities were viewed with sympathy, sometimes as pathetic, and occasionally even with horror. Individuals with disabilities were often hidden from society, which meant the rest of the people did not have the opportunity to understand the disabilities and more importantly to see them as people first and recognize the abilities of this population. With little education available to children with disabilities, they did not have the opportunity to develop to their fullest capabilities’

Blaska pg. 25
Blaska advocates for people-first language to dispel these images of sympathy and horror to recognise the person first. The controversy surrounding disability-first versus people-first language is far more than a ‘choice of words’. Proponents of people-first language argue that an undue focus on the condition distracts from the humanity of the members of the community of people with the condition. Prescribing to ‘people-first’ language aims to resist the ways that disability can, in the words of Goffman ‘spoil’ a person's social identity to the point that society will not see the person behind the cane, the wheelchair, or the diagnosis (Goffman 2009).

It is the experience of many people that disability is responded to first, not their personhood (Titchkosky 2001); in fact, the personhood of disabled people is frequently called into question (Hogg 1999; Giubilini and Minerva 2013) as is the right to life (Giubilini and Minerva 2013). In responding to the power of language disability activists formulated a ‘people-first’ ideology through language to remind society of the need to ‘see the person before you see the disability.’ The most widely used and accepted terminology emerging from people-first language is the term ‘people with disabilities’ rather than ‘the disabled,’ or ‘the handicapped.’

British disability theorists Barnes and Mercer (pg. 11) are in disagreement to people first language, as they believe it ‘blurs the conceptual divisions between impairment and disability and implies that impairment defines an individual’s identity’ as if disability is the ‘property’ of the person rather than of the society, as the social model dictates. This denies the political nature of living with a disability and draws attention away from social responsibility for mitigating it. They suggest placing the disability before the person as a political statement to show that a disability is something that is ‘done’ to a person rather than something a person ‘has.’
This debate causes disagreement and criticism ‘the hallmarks of philosophical life’ (Carlson 2009). Terminology is contentious and significance of the discourse should not be underestimated having fuelled passionate debates. With regard to terminology and choice of words, having considered the debate within the literature, I assert my values within a humanistic perspective. This humanistic perspective emphasises the positive potential of human beings through uniqueness of the individual, adopts a person-centred approach to increasing capacity for personal responsibility and choice (Priest 2011). Rogers’s (cited in Kirschenbaum and Land Henderson 2005) hypothesis:

‘All individuals have within themselves the ability to guide their own lives in a manner that is both personally satisfying and socially constructive. In a particular type of helping relationship we free the individuals to find their inner wisdom and confidence, and they will make increasingly healthier and more constructive choices’ (Kirschenbaum and Land Henderson 2005) pg. xiv

In the dissertation, I predominantly utilised the term person, living with a PIMD. To represent humanistic values that family carers espoused, I have interchangeably utilised the term ‘disabled person’ to represent the social model of disability highlighting the political and social elements of disability from beyond the individual. The final section in ‘Understanding PIMD’ relates to the impairments and conditions associated with health matters and communication which persons, living with PIMD. The purpose of this section is to introduce readers to the breadth and depth of needs and supports that persons, living with PIMD, require on a daily basis and illustrates how co-existing conditions affects daily experiences and interactions that family carers support.
2.6.2 Sensory Support

Recognition of senses and sensory wellbeing is growing as their contribution to wellbeing is acknowledged (Freeman 2008). Impairment in one or more of the five classic senses (vision, auditory, touch, smell, and taste), the sense of movement (vestibular system), and/or the positional sense (proprioception) can affect our ability to experience the environment and our ability to interact and communicate. Therefore, impairments in our senses contributes to our ability to learn, interact and communicate. Syndromes that have sensory impairments and co-existing severe to profound intellectual disability are (but not limited too) Congenital Rubella Syndrome, Klinefelter syndrome, Patau syndrome (trisomy 13), Edwards Syndrome (trisomy 18), Rett syndrome and Fragile-X syndrome.

For example Congenital Rubella Syndrome (CRS), occurs when the rubella virus in a pregnant woman affects the developing baby during the first three months of pregnancy. Symptoms in the infant may include congenital cataracts or other visual impairments, hearing impairment, congenital heart disease with low birth weight, severe to profound intellectual disability, seizures, and microcephaly highly prominent in African countries (World Health Organisation 2012). Worldwide, an estimated 110 000 babies are born with CRS every year with rates highest in African and South-East Asian regions where vaccine coverage is lowest (WHO 2012).
2.6.3 Mental Health Support

In previous centuries, there was little recognition that people, living with PIMD, develop mental health problems however, that thinking is now challenged recognising the complete spectrum of mental health problems in the population (Royal College of Nursing 2010; Vos et al. 2010). Epidemiology of mental health problems in people, living with ID, suggests a high rate of mental health difficulties depending on the complexity of their needs may range from between 40% to 60%, with the presence of the intellectual disability, in itself, being a risk factor of immense significance (Carnaby 2009; Coughlan 2010). This prevalence of mental health problems can be attributed to increased biological, psychological and social factors that may predispose, precipitate and perpetuate mental health problems (Cooper et al. 2007; Carnaby and Pawlyn 2009).

2.6.4 Physical Health Support

The prevalence of physical conditions and physical impairments reported in persons, living with PIMD, is high and well reported (Maes 2010; Tadema and Vlaskamp 2010; Cairns et al. 2014; Manhas and Mitchell 2015; Rubin 2015; Brown et al. 2016; Jansen et al. 2016). Moreover, persons, living with PIMD, are more likely to experience a cluster of health problems related to severe brain damage/dysfunction and thus encounter several risk factors associated with higher mortality rates such as a lower IQ, non-ambulation, poor motor skills, inability to feed oneself, poor communication and self-help limitations (Mansell 2010; Nursing 2013; Timmeren et al. 2017). Advances in medical care and improved treatments and care for intellectually disabled people attribute to life expectancy significantly increased from just 18.5 in the 1930s to 59 in the 1960’s to over 70 years (Emerson 2009; Kelly and Kelly 2011). Persons, living with PIMD, are likely to have different patterns of health problems than those with a milder ID and the general population (Timmeren et al. 2017) requiring intensive and extensive treatments and support.
This leads to the final area of discussion as per Figure 2-1 the concept ‘Rights’ and the role of supporter in assisting and supporting persons, living with PIMD, in decision making.

2.7 Rights

From charity and exclusion to emerging independence (Woodill and Velche 1995) a notable movements to address the rights and responsibilities of persons with ID was that of The Montreal Declaration on Intellectual Disability. Hosted in 2004 by the World Health Organisation (WHO, 2004) it addressed the historical disadvantages and barriers facing persons, living with ID, and affirmed their entitlement to basic human rights and fundamental freedoms, as embedded in many existing international declarations, conventions, and standards (Lecompt and Mercier 2007).

This Montreal declaration reported on persons, living with ID, exclusion from decisions about their human rights, health and well-being, and notably guardianship laws used to deny people their right to make decisions (Lecompt and Mercier 2007; Devi et al. 2011). Significant concerns that the freedom of persons, living with intellectual disabilities, to make their own choices has frequently been unrecognised, ignored, abused or removed (Devi et al. 2011). This Declaration was the first (American) to establish legal standards related to the right to equality of persons with intellectually disabilities, as well as a series of measures to be undertaken in order to support decision making among persons with intellectually disabilities within a context of respect for their fundamental rights.

While Ireland and European countries did not participate in this convention, it is a declaration respectfully advocated within Europe. The Montreal Declaration on Intellectual Disability supported the mandate of the UN Ad Hoc Committee in the International Convention to Promote and Protect the Rights and Dignity of all Persons with Disabilities underpinning the UN Convention on the Rights of Persons with Disabilities (CRPD) (2006) of which Ireland is a signatory.

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Recognising the injustices of depriving peoples liberty and rights to freedom of individual decision-making has been the predominate discourse in disability activists circles. This dissertation concord’s with the view that human rights are “inalienable” and “universal” embracing natural law theories espousing a moral code that is all encompassing as incorporated into the UN CRPD. Meaning, that it accepts the individual as a rights holder and the state as having specific obligations to individuals. This is emphasised in the next section the ‘CRPD’.

2.7.1 Convention on the Rights of Persons with Disabilities

The UN CRPD is the first human rights Treaty adopted in the 21st century. Its specific aim is to change attitudes and approaches of the past that viewed disabled persons as ‘objects’ of charity, medical treatment and social protection towards viewing persons, living with disabilities as ‘subjects’ with rights. This is to ensure that claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society becomes the norm for all disabled persons (Quinn 2009).

The General Principles, listed below, Article 3 of the Convention state

(a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons
(b) Non-discrimination
(c) Full and effective participation and inclusion in society
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
(e) Equality of opportunity; (f) Accessibility; (g) Equality between men and women
(h) Respect for the evolving capacities of children with disabilities and respect for right of children with disabilities to preserve their identities (UN CRPD 2006)

These principles underpinning the CRPD have significance for this study. These are not new principles and exist in codes of professional practice such as nursing (An Bord Altranais 2014), medicine and allied therapies (National Commission for the Proptection of Human Subjects of Biomedical and Behavioral Research 1978).
From a convention perspective, what is significant about the UN CRPD is the requirement to make explicit and relate these principles to intellectually disabled persons, and the need for governments and the societies they represent to recognise that intellectually disabled persons are entitled to the same rights as other citizens. Notably in relation to the literature on rights is the hyperbole associated with the aspirations and vision of the CRPPD and hopefulness being extraordinary by any standard (Kayess and French 2008).

The Convention addresses a broad range of areas such as employment, accessibility, education, freedom from exploitation, independent living and to be recognised as a person before the law (Article 12). These areas of education, accessibility and recognition before the law, have undergone major change in Ireland in the past decade and will no doubt undergo more change in the future years to come.

The CRPD has received support by families, family organisations (Inclusion Ireland) and service providers in Ireland, and while Ireland was one of the first signatories to the convention in March 2007, and on 19th April 2018 ratified and entered force in the RoI. The long awaited ratifying process created frustration and annoyance in many arenas. It is believed that only through ratification that positive systemic changes required to generate commitment from civil society and government be achieved (Quinn 2009; Lang et al. 2011). The major barrier to ratification of the Convention is Ireland's wards of court system which, upon a finding of incapacity, removes all decision-making rights (legal capacity) from an individual (Doyle and Flynn 2013). Relevance to this study is Article 12 of the CRPD which prohibits the removal of a person's legal capacity and requires the provision by States Parties of the supports necessary to ensure that a person can exercise their legal capacity on an equal basis with others (UN 2006), now discussed.
2.7.2 Article 12 Equal recognition before the law

Article 12 of the UN CRPD has relevance to this study. It can be argued that Article 12 hits to the core of the convention spirit in challenging the competence model of decision making in which support is offered via substitute decision-makers or best interest approaches to a more dignity enhancing legal model recognising all people need support that is time specific and decision specific thus requiring support in decision–making not support with decisions.

Article 12 calls for all people to be recognised before the law and shall by protection of the state entitled to:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property (UN 2006 pp. 10-11)
These five statements hold significant meaning for person living with PIMD, and in order to be more than rhetoric serious consideration and implementation reviews are warranted. According to a recent report on mental health and human rights prepared by the UN High Commissioner for Human Rights (UN 2017) 'states should repeal legal frameworks allowing substitute decision-makers to provide consent on behalf of persons with disabilities and introduce supported decision-making’. Challenging times.

Chapter Four and Five describe how to understand the wishes and choices of someone with severe and profound intellectual and multiple disability and developing capacity. Therefore, ‘Interactional Guesstimating’ is proffered as a way of supporting persons, living with PIMD, in decision-making.

2.8 Main contribution of literature

Parallel to data collection and analysis the literature review occurred. What clearly emerged from the data was the challenges of thinking beyond simplistic rationales of inherent deficits as a causation of disability to inform our understanding within an inclusive, comprehensive and supportive interaction with people requiring extensive supports in daily living.

The conceptual scaffold of theoretical models of disability, development and support in a rights paradigm demonstrated a movement beyond single and static explanatory mechanisms toward sophisticated approaches that address the dynamic unfolding of multiple processes over time: illustrated in the following table;
Hearing and listening to family carers and the iterative process of analysis in constructive grounded theory I familiarised myself with and drew on the following frameworks in addressing the research aim; How do family cares support persons, living with PIMD, in decision making?

<table>
<thead>
<tr>
<th>Questions of the analysis (adapted from Charmaz (2006; page 20))</th>
<th>How do carers come to this experience? How do carer’s understandings of supporting persons, living with PIMD, in decision making develop? What are the important influences on this process? How did carers engage in the making of meanings? What were their understanding of the main concepts, ideas and experiences? What sort of knowledge did the carers have - before, during, and after supporting and What mechanisms accounted for this knowledge?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frameworks integrated in the wake of family carers conversations (26) via memoing, theoretical sampling and constant comparison</td>
<td>Bronfenbrenner’s PCTT ‘Being and Becoming’ Voysey ‘constant burden’ Twigg and Atkins typology of carers</td>
</tr>
<tr>
<td>Understanding PIMD</td>
<td>AAIDD UN CRPD</td>
</tr>
<tr>
<td>Focus/Application within analysis</td>
<td>Contributed to examine family carers experiences and understanding</td>
</tr>
<tr>
<td>Lens to appraise how the process, person, context and time (PPCT) impacted on family carers development in their role</td>
<td>Reviewed in light of family carers experiences; comparison in considering knowledge before, during, and after supporting</td>
</tr>
</tbody>
</table>

Table 2-2 Claims examined in co-constructing the theoretical framework ‘Interactional Guesstimating: Growing confidence with uncertainty’
The following summary of definitions represent understanding of these concepts within the dissertation.

**Term 1) Family Carer:** ‘A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty’ as described in the Irish Carers Strategy (Irish Carers Strategy pg. 8)

**Term 2) Supports:** ‘resources and strategies that promote personal development and enhance functioning’ (Schalock *et al.* 2010)

**Term 3) Supported decision making** as described by the UN CRPD (2006) the Handbook for Parliamentarians on the Convention:

‘Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interest and aims in life, and is someone capable of exercising his/her legal capacity’ pp.X

**Term 4) Decision Making:** ‘a capacity to understand and balance the necessary information and to communicate a choice’ Clarke *et al.* (2013).

**Term 5) Person with a PIMD:**

‘A person with profound intellectual and multiple disability have extremely delayed intellectual and social functioning, may have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures), often require those who are familiar with them to interpret their communication intent, frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments. They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support with an individualized relationship with a carer’ (Bellamy *et al.* 2010).

To summarise this section, the conceptual framework, discussion of the concepts and key terms and their role in contributing to the grounded theory. Now presented a summarisation of the assertions underpinning the findings. The importance of family carers' views were supplemented by relevant material drawn from other sources, which included comparison to earlier data as in the constant comparison method, non-participant observations, literature and memoing all described in detail in the next chapter.
Outlining family carers experiences within this myriad ‘Interactional Guesstimating: Growing confidence with uncertainty’ evolved as a process and activity that family carers navigated their role in supporting person, living with PIMD, in decision making.

Underpinning this research are the assertions which hold together and informs a research positioning, a methodological approach and contributes to the analytical framework. Therefore, the interpretive constructivist approach to research that ‘explores family carers’ experiences in supporting persons, living with PIMD, in decision making’ asserts the views that;

1. The perspectives of family carers, and their environment in shaping lives in
   a. Recognising the emotional and motivational interplay of interaction through the life course and the changing and enduring properties of the environment, both immediate and more evolved

2. Changing knowledge, understanding and attitudes towards the means in relation to supporting persons, living with PIMD, to self-determinate grounded in
   a. Lessons from historical treatments and seclusion of disabled persons
   b. Developing and advancing supporting decision-making models

3. The relationship between individuals and society and the way family carers make meaning of events or reality and the way they act in relation to these beliefs
   a. Advances in methodology and research valuing the constructivist interpretivist worldview, demonstrates respect for the contributions of family carers to this knowledge generation.

This concludes the presentation of the conceptual contributions in the evolution of the grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ the major contribution of this dissertation.
2.9 Chapter Conclusion

The inductive research approach to this research, concerned with generating theory from data facilitated the selection of an array of literature relating to the history and nature of offering disabled people support, highlighting the complex ethical and legal possibilities and challenges of supporting another in decision-making. The literature reviewed reflects family carers experiences of personal development and their ‘becoming’ (Bronfenbrenner’s PPCT), and family carers erudition of disability (Understanding PIMD). While practice and policy highlight family carers’ key role and contributions in supporting disabled people, the lack of theoretical and empirical evidence supporting their contribution became evident.

The third section of the literature review related to the rights based approach to supporting decision making demonstrating how supporting decision-making, as a concept is largely based on ideology and principles. Little empirical evidence of the mechanisms and processes that deliver on its implementation found and those that have researched supporting decision making frameworks have done so from the perspective of those with mild or moderate intellectual disabilities, and professional or paid supporters. This research goes to the heart of this research gap looking at both mechanisms that aid implementation and from a minority group of people, living with PIMD, and their family supporters. Prior to the findings however, the next chapter presents the methodology of the research placing the findings in context.
3 Chapter Three Methodology Methods and Process

This chapter at a glance …

- Explains the approach to conducting the research
- Describes the methods of the research specifically
  - Timescale and implementation of the study
  - Ethical approval process and considerations
  - Access and informed consent processes
  - Specifics of data generation and analysis

This research aimed to explore family carers’ experiences of supporting persons, living with PIMD, in decision making by hearing and listening to their stories. Methodological considerations to best meet this aim are described within this chapter, hence an outline of both quantitative and qualitative approaches to research justifies the rationale and suitability of a qualitative approach to this study. The research design underpinned by constructivist grounded theory makes explicit the methods as to what the research process entailed.

Thereafter, ethical considerations and approval are described as is access too participants. An outline of processes inviting participants to participate, and how data was generated from 26 conversational interviews and a ‘Carers Group’ is detailed. A description of data generation in conjunction with data analysis concordant with grounded theory principles reflects the active and participatory nature of the research. These methods forms the basis for the next Chapter.

Questions about the nature of truth and objectivity have always occupied a central place in philosophy. Tensions of accuracy, supremacy and ‘blurring of genres’ has created much debate and controversy that inquiry methodology solely treated as a set of universally applied rules or abstractions cannot be justified (Denzin and Lincoln 2011). Rather, methodology is interwoven with and emerges from the nature of the discipline and particular perspectives (McCann and Clark 2004; Denzin and Lincoln 2011; Charmaz 2013) and this chapter addresses these intersects of discipline and perspective.
Firstly, a recap from Chapter One; the research aims and objectives; Aim: To ‘explore family carers’ experiences of supporting persons, living with PIMD, in decision making’ with the main objectives of:

- Hear and listen to the stories of family caregivers
- Gain insight and understanding of the success and challenges that family caregivers have when supporting people, living with PIMD
- Engage in a participatory process with participants
- Consider the process of gaining this insight
- Develop a substantive theory

Two points are apparent when examining the aims and objectives of the study. Firstly, it was implicit in the written aim that an inductive rather than a descriptive methodology was appropriate. Second, the emphasis within the objectives of the study alluded to developing a participatory experience for participants and researcher, aligning with advocates for movement beyond respondent validation to influence on and within research. Thus, after exploring both quantitative and qualitative paradigms a rationale justified the constructivist interpretivist approach in conducting this research. The rationales and justification of such an approach is herein detailed.

### 3.1 Paradigms

Paradigms as a system of beliefs and practices influencing how researchers select both the questions they study and methods that they use to study them examined in the supervision process early on in the research founded the rationale and reasoning for aligning this research to a qualitative, constructivist approach. Conventional approaches to research described as quantitative and qualitative have been described as opposing, and arguments in the literature and within practice as to which approach quantitative or qualitative is the better can be invidious if recognition of how both offer guidance and formats in which the breath, depth and rigour of research can be conducted. Both quantitative and qualitative approaches to research having their benefits and weaknesses, two ways of obtaining data, neither one better than the other, possibly incompatible ways, nevertheless equally legitimate (Begley 2008).
An outline of both quantitative and qualitative approaches to research is presented with the aim of demonstrating the foundation for a qualitative approach to this research and how the methods of data collection and analysis came to be, guiding the findings of the study noting professional influence and researcher perspective.

3.1.1 Quantitative Paradigm

Quantitative research described as the process of testing theory by describing variables, examining relationships among variables, and determining cause-and-effect interactions between variables has contributed much to knowledge generation (Allen and Lyne 2006). The aim of quantitative research is to test the researcher's premises by methodically testing a hypothesis. Based on a branch of philosophy called ‘logical positivism’, which operates on strict rules of logic, truth, laws and predictions, quantitative research aims to find the ‘truth’ which is absolute and a single reality can be defined by careful measurement (Burns & Grove 2010). The positivist stance posits that valid knowledge is that scientifically studied. It is the formal, objective, rigorous, systematic process for generating information about the world (Burns & Grove 2010).

The principles of design within quantitative research has specific criterion as described by LoBiondo, the provision of a plan or blueprint, which is the vehicle for systematically testing research questions and hypotheses providing the structure for maintaining control in a study (LoBiondo-Wood and Haber 2013; Toles and Barroso 2013). The development of research with control and objectivity to ensure specifications and accuracy supports the development of reliable and valid findings. Measures of control and ensuring accuracy include the use of a homogenous sample, consistent data collection procedures, training and supervision of data collectors and interventionists, manipulation of the independent variable, and randomisation.
These measures of control offer generalisation of results and findings to the population studied. Experimental, quasi-experimental and non-experimental designs formulate the main groups of research classified within this paradigm. Experimental designs are considered the gold standard for testing cause and effect relationship due to the control manipulation and randomisation components (Toles and Barroso 2013). Strong positivism roots in nursing and development of the profession closely aligned to the medical and surgical practices is recognised. Historically, the idea of a nurse using a research approach to examine nursing problems was alien not alone to the profession itself, but to other professions, such as medicine, and indeed to patients and the public in general (Munhall 2011).

Nursing research is a young discipline within the nursing profession, as not all nurses make a clear pathway to conduct research but rather utilise nursing and other research outcomes and findings in the provisions of safe and effective care (Watson et al. 2008). Nurses, in attempting to gain academic respect with other more long established professions originally adopted the quantitative approach to knowing over other forms of enquiry (Wuest 2012; Parahoo 2014). Reliance on empirical knowing had practical implications. For example, to make our discipline scientific in the natural sciences and emulate the stance taken by medicine, for example in general nursing practice where measuring and recording of observations, signs and symptoms took precedence over talking to patients (Cutcliffe and McKenna 2002).

The following ‘student nursing notes’ from 1965 which our department received anonymously in 2014, and is maintained in the Department of Nursing and Midwifery, University of Limerick with other memorabilia received by former nurses and from the closure of former ‘schools of nursing’ provides some insight into nurses socialisation into positivistic beliefs. These following inserts under the heading ‘Ethics of Nursing’;
Most notably, in 1965 the first quality of the good nurse was obedience and loyalty (primarily to the doctor) followed by tact and sympathy (to the patient). The next two qualities, ‘Initiative and a sense of responsibility, Accuracy of statement even in the smallest detail cannot be overstressed’ to inform the doctor. ‘Generosity, intelligence, personal neatness, adaptability and gentleness of manner and movement’ noting intelligence placed number 6. Attributes which differ greatly from those of the student nurse today in the University of Limerick (UL) ‘to be Knowledgeable, Proactive, Creative, Responsible, Collaborative and Articulate’.
Perhaps due to the predominant influence of psychiatry, psychology and education research in the intellectual disability field, there is a very definite trend towards quantitative research from a positivist or post-positivist epistemology (Porter and Lacey 2004). As nursing research develops, questions and critics of existing approaches to research have emerged. A major critic of the quantitative methods of data collection such as questionnaires, surveys and RCT’s is a lack of recognition of the ‘situated context’ in which nurses believe to play an essential feature in the therapeutic relationship. The concept of holism is reduced in quantitative approaches and fundamentally opposes current approaches to nurses’ aspirations of providing ‘holistic care’ and the importance of subjectivity in our understanding (Munhall 2011).

Modern nursing moving away from the ‘sympathetic towards patients’ and ‘subservient to medicine’ approach has broadened its landscape of practice (Begley 2008; Watson et al. 2008; Munhall 2011). For nursing, challenges with positivism rigidity and inflexible approaches are inconsistent with the multifaceted, ethically complex and realities of supporting family carers and persons, living with PIMD. Consideration of readings from Munhall (2012), Denzin and Lincoln (2011), and Creswell (2012) aided clarifying philosophical underpinnings in justifying this research approach I originally explored in a reflective journal entry;

The 'Holy Grail' of the quantitative claims of 'conclusive evidence' regarding what works, when, how why and with whom I question more. Influenced by the spoken language in nursing changing from medical and atomistic to a distinct nursing holistic interactive model (NMBI, 2014). This represents a paradigmatic innovation for nursing; the way in which phenomena are viewed in nursing is changing in a way described as 'irrevocably conflictual in its basic premise and assumptions with the medical model' (Munhall, 2012). These changes in nursing and healthcare philosophy from a mechanistic approach to families and individual recognise the need for holistic perspective on care, leads to more emphasis on person centred and family centred approaches to care. This change in emphasis entails the adoption of research methodologies that rather than aiming to uncover relations of cause-and-effect but an approach to explore and uncover the experiences, understandings and motives that lead people and families to certain actions.

Journal Reflection 3-1 ‘Moving on’
Coinciding with this reflection and readings recognition of the shift from doing research on and about populations of people to doing research with these populations emerged as significant. Discussed now in the following paragraphs is an exploration of some of these more inclusive approaches to research.

3.1.2 Qualitative Paradigm

Qualitative research represents another, not necessarily opposite but more diverse set of techniques and philosophies that underpin research practice in the human sciences that have a shorter and less well-defined history (Hesse-Biber and Leavy 2010).

Qualitative approaches based upon structuring knowledge that utilises methods of inquiry emphasise subjectivity and the meaning of the experience to the individual differs from the aforementioned quantitative approaches. As a mode of inquiry qualitative approaches adopt questions of ‘how’ and ‘why’ rather than the more quantitative perspective of ‘how many’ or ‘how often’. A range of approaches including but not limited to are qualitative descriptive research, action research, ethnography, phenomenology and grounded theory often described as ‘naturalistic’ referring to research that occurs within the ‘everyday world’ (Brockopp and Hastings-Tolsma 2003; Creswell 2012).

Qualitative research is an inductive approach to discovering or expanding knowledge. It requires the involvement of the researcher in the identification of the meaning or relevance of a particular phenomenon to the individual. Analysis and interpretation of findings in this method are not generally dependent upon the quantification of observations (Brockopp & Hastings-Tolsma, 2003 pg. 328)

Qualitative research is an approach to research which Toles and Barroso identify suited in understanding human experiences, uncovering social processes, learning cultural patterns and capturing unique stories (Toles and Barroso 2013). They summarise potential outcomes of qualitative approaches to inquiry as informing theory, practice, instrument development and further research.
Qualitative research crosscuts many disciplines and subject matter in developing understanding of human experience. ‘Influences of a dynamic reality’ are recognised within this paradigm and reductionism is challenged, as humans are not subjected to the sum of parts that requires separate investigations with holism recognised as a central feature of this approach (Munhall 2011). The principles of design within a qualitative paradigm differ from that of the quantitative paradigm. Qualitative research entails a detailed exploration of a topic in which data, collected through case studies, narratives, interviews, writings, and reflections amongst other techniques, elicits experiences and understanding.

Inherent in this approach is the description of the interactions among participants and researchers in naturalistic settings with a flexible and open research process: another distinguishing factor from the quantitative approach. Central to the qualitative inquiry approach is the presence of multiple ‘truths’ that are socially constructed (Crotty 1998). An iterative approach, qualitative research designs are described as ‘inductive’, ‘indeterminate’ and ‘open-ended’ in that a researcher may construct theories or hypotheses, explanations, and conceptualizations from details provided by participants (Charmaz 2006).

Again, this differs from the quantitative approach to truth as singular static and verifiable by facts. Qualitative research identifies ‘truth’ as both complex and dynamic and found by studying individuals as they interact with and in their socio-historical settings. These unique interactions imply that different data could be obtained from the same participant depending on who the researcher is, because results are created by a participant and researcher in a given situation (Munhall 2011) again differing from the quantitative approach.
Another major difference between qualitative and quantitative research is the underlying assumptions about the role of the researcher during data collection and analysis. Qualitative data includes data obtained from interviews, observations, and documents. Analysis of data is not easily ‘crunched’ by statistical software. In-depth description of people’s lived experiences, events, or situations requires attention to the rich detail, meaningful social and historical contexts and experiences in qualitative analysis. Statistical software such as NVIVO and ATLAS facilitate qualitative techniques that help in managing, exploring and finding patterns in data but cannot replace analytical expertise. The significance of emotional content in an attempt to open up the word of whoever or whatever is being studied (Denzin and Lincoln 2011) has major significance in qualitative approaches in comparison to quantitative research, and the researcher is part of this world.

Qualitative data analysis and collection may occur together (Glaser and Strauss 1977; Joniak 2003; Denzin and Lincoln 2011) with the goal of qualitative data analysis to uncover emerging themes, patterns, concepts, insights, and understandings (Charmaz 2006; Savin-Baden and Major 2010). Qualitative findings do not intend to make the findings an extension of the participants to the population at large. In some cases, this may apply but the research aim is not to generalise the findings. Transferability of findings in qualitative research is more appropriate. Transferability of findings does not involve broad claims but invites readers of research to make connections between elements of a study and their own experience, allowing readers to make up their own assumptions (Denzin and Lincoln 2011).

3.2 Determining the Research Process

Observing the reductionist and empirical observations in practice and questioning of their potential and contribution to the everyday realities of families supporting people, living with intellectual disabilities, set the scene for articulating a ‘worldview’.
Reflection and supervision required an exploration of research approaches. Recognising changes in disability care and supports, inclusive methods of research, and importantly the purpose of this research ‘to explore family carers’ understandings and experiences of supporting persons, living with PIMD, in decision-making’ the shift in thinking from objectivism to ‘constructivism’ was evident. In developing the research further and establishing a clear process to the study, the decision as to which research approach to employ being derived beyond the rational or logical analysis of paradigms, but, from the research goals (Guba and Lincoln 1994; Knox 2004; Munhall 2011) an examination of which qualitative methodology was considered. Considerations of action research, phenomenology and ethnography, now briefly discussed, clarifies why they were not utilised and justifies the constructivist grounded theory research design, and subsequent data collection and analysis methods chosen.

Action research is ‘learning by doing’ where a group of people identify a problem, do something to resolve it, see how successful their efforts were, and if not satisfied, try again (Koshy 2005; Koshy et al. 2010). Choosing an action research methodology considers both action and research as intended outcomes (Dick et al. 2009). Discussions with the centre manager demonstrated that the potential for change was welcome, however, the focus of the research was not to place too many demands on family carers and not to place an expectation of change at this point in time, and therefore action research was deemed not the appropriate methodology.

Phenomenology was also reviewed as a potential approach to explore family carers’ experiences. Phenomenology is an approach began by Edmund Husserl and later developed by Martin Heidegger that seeks to study the lived human experiences and the way things are perceived and appear to the consciousness (Munhall 2011). Phenomenology provides rich and detailed views of human experience, however, data gathering methods and analysis are not inclusive approaches per se, and therefore, not concordant with the research aim and objectives.
Ethnography concerned with participants’ culture relies either partially or mainly on participant observation where the researcher immerses in the customs and lives of the people under exploration and notes observations in extensive field notes (Denzin and Lincoln 2011). This close scrutiny while contributing greatly to knowledge was considered invasive in this research setting and therefore deemed inappropriate in meeting the study aims.

At its simplest level, I was eager to engage in a research approach that valued a dialogic relation between researcher-researched from the outset. Such a position goes beyond respondent validation and through this relationship aim to recognise the ‘multi-layered’ levels of meaning. My philosophy resonates with Pesut and Johnson beliefs that ‘as a human practice discipline nursing must also seek to address some of the broader philosophical issues inherent to personhood’ (Pesut and Johnson 2008).

3.2.1 Positionality

To pin my colours to the various paradigmatic masts, I describe myself as post-positivist and pursuant postmodernist. I reject the view of reality that is singular or solely objective. I believe that knowledge, truth and reality are subjective constructs and no two people have the same worldview. In research terms, I recognise that phenomena best understood when considered holistically rejects the simplicity of linear cause and effect. Guided by a pragmatic approach to research I bring my values to the research methodology, conscious of the realisation that this research needs to be fit for purpose.

In this present study the constructivist approach assumes a relativist ontology (many realities) and subjectivist epistemology (participant and researcher co-create understandings) (Denzin and Lincoln 2011). By adopting this constructivist approach, this research shares the following about the nature of knowing and reality:
1. A relativist ontology assumes that reality as we know constructed inter-subjectively through the meanings and understandings, developed socially and experientially, was employed in this study.

2. Subjectivist epistemology - assumes that we cannot separate ourselves from what we know. The researcher and the subject of inquiry are linked such that who we are and how we understand the world is a central part of how we understand ourselves others and the world. Therefore, this research theory co-constructed between researcher and subjects developed and transmitted in a social context.

In the constructionist view, as the word suggests ‘meaning is not discovered but constructed' (Crotty 1998) in opposition to objectivism interpretation that knowledge exists independent of state or quality of being and exists outside of a subject's individual biases, interpretations, feelings, and imaginings (Begley 2008; Polit and Beck 2010). Furthermore, the major elements and assumptions of a constructivist-interpretive worldview incorporated into this research include:

`Realities are apprehendable in the form of multiple, intangible mental constructions, socially and experientially based, local and specific in nature (although elements are often shared among many individuals and even across cultures) and dependent for their form and content on the individual persons or groups holding the constructions ... The investigator and the object of investigation are assumed to be interactively linked so that the `findings' are literally created as the investigation proceeds ... Methodology ...hermeneutical and dialectical' (Guba and Lincoln 1994): 110-111)

In this study, as is consistent with constructivist grounded theory, the assumption that reality co-created by the participants and researcher. In the process of shaping this contribution to knowledge founded in the ‘family carers experiences of supporting persons, living with PIMD, in decision making’ the constructive grounded theory, part of the interpretive tradition facilitated the inclusion of meanings, endorsed by being immersed in the family carers’ world which brought an element of subjectivity to the study(Charmaz 2013).
Summarising this section, in meeting the research aims and objectives of the study alignment of philosophical values with the nature of the research project yielded a constructivist and interpretivist approach to conducting the research. This approach recognised knowledge generation as co-constructed and therefore, subjectivity of the researcher in the process of data generation and analysis was a valuable contribution to the research. This lays the foundation for the next section describing the methodology and methods of the research.

3.3 **Grounded Theory and Nursing Research**

Since the 1970’s many authors describe the suitability and applicability of GT approaches to nursing research (Jacobson 1971; Hutchinson 1993; McCann and Clark 2004; Munhall 2011; Wuest 2012; Corbin and Strauss 2014). It is claimed that nurses and nurse researchers choose GT methodology to conduct their research because of its ability to provide insight into experiences and its inherent power to provide deeper understanding of individuals worlds thus providing a beneficial impact (Hernandez 2010). This is primarily related to epistemological underpinnings of GT premised on an interpersonal process between nurses and individuals in addition to its utility when there is little prior information about a topic (Hutchinson 1993; McCann and Clark 2004; Munhall 2011).

Significantly, the value of GT lies in its contribution to areas in which there is little research (Charmaz 2006). Previous chapters have highlighted the lack of information and evidence in family carers’ experiences thus this study addressed this gap in exploring family carers’ experiences of supporting persons, living with PIMD, in decision making and what family carers found to be important about that experience. Clarification of GT approaches is now presented.
3.4 **Grounded Theory Approaches**

Gelling’s identifies GT as a complex methodology where data collection and analysis occurring simultaneously can be challenging (Gelling 2011). The emphasis in GT approaches to research is allowing findings to emerge through an iterative process of data gathering, analysis and conceptualising, rather than setting out to verify an existing theory or hypothesis. Originally developed by Glaser and Strauss in the 1960s, this approach to research aims to develop theory about phenomena inductively and through ‘emergence from the data’ in opposition to hypothesis testing. Hunter et al., presents GT under three headings classical GT, Straussian GT and constructivist GT (Hunter et al. 2011). The following descriptions serve to outline the reasoning for applying a constructive GT approach to this study with each approach briefly outlined.

Classic GT originates from the work of two sociologists, Barney Glaser and Anselm Strauss and represents GT in a pure form that stems from the original 1960s work (Glaser and Strauss 1977). Their rationale for introducing this new approach lay in their desire to see the development of new contextualised theories. The classical approach of that advocated by Glaser and Strauss is common in nursing.

In contrasting grounded theory with logico-deductive theory and discussing and assessing their relative merits in ability to fit and work (predict, explain and be relevant) we have taken the position that the adequacy of a theory for sociology today cannot be divorced from the process by which it is generated. Thus one canon for judging the usefulness of a theory is how it was generated-and we suggest that it is likely to be a better theory to the degree that it has been inductively developed from social research. We also believe that other canons for assessing a theory, such as logical consistency, clarity, parsimony, density, scope, integration as well as its fit and its ability to work, are also significant dependent on how the theory was generated (Glaser and Strauss 1977 pg. 5)

In the book authored by Glaser and Strauss ‘Discovery of Grounded Theory; strategies for qualitative research’ the ‘openness of inquiry’ when obtaining data recognises
‘the diverse structural conditions of each group, schedules, restricted areas, work, tempos, the different perspectives of people in different positions, and the availability of documents of different kinds’ ............... ‘data collection in a multi-faceted’ ............... ‘there are no limits to the techniques of data collection, the way they are used or the types of data acquired’ pg. 65 (Glaser and Strauss 1977)

Researchers are encouraged in this approach to use GT strategies flexibly in their own way. A challenge to this openness of inquiry requires the researcher to approach participants without prior knowledge understanding and assumptions. In this classical approach, the idea of a researcher who collects and analyses data without any prior theoretical knowledge and preconceptions (no literature review) has been criticised (Charmaz 2006). Having acknowledged my role as a nurse, and the relevance of this role to the study this ‘pure’ or ‘classical’ approach to GT was therefore not applicable.

The second approach described by Hunter et al., is that by the second of the original authors Anselm Strauss ‘Straussian GT approach’. This represents the first fracture from classic GT in that it offers a modified approached aimed at making GT more transparent to researchers by introducing more specific procedures and guidelines to researchers. What becomes apparent in the literature of the two approaches is the original Glaser and Strauss classical GT emphasises on induction or emergence, and the individual researcher's creativity within a ‘clear frame of stages’ is essential for a theory to be developed, while Strauss develops the second generation GT in addressing validation criteria and a systematic approach.
Prior to Strauss’s death the debate between the two authors centres upon the notion of emergence in GT and the debate about ‘force-fitting’ theory through overly forced conceptual description. Debates as to similarities and differences of these two approaches are abundant in the literature. In contrast to the classic approach to GT and the Straussian approach to GT, a third approach described by Hunter et al., the ‘Constructivist GT’ is recognised as ‘the most recent re-modelling of the GT’ (Hunter et al. 2011). Constructivist GT is rooted in pragmatism and relativist epistemology, assuming that neither data nor theories are discovered, but are constructed by the researcher as a result of his or her interactions with the field and its participants.

Cathy Charmaz, a former student of Barney Glaser, credited for this third approach ‘constructivist GT’ presented ‘Troubling Grounded Theory: The Constructivist Revision’ at the Irish Research Methods Social Sciences (IRMSS) (2011). Charmaz’s keynote described her view of GT as a set of principles and practices emphasising flexible guidelines, not as prescriptions or packages or methodological rules, recipes and requirements, arguing that;

I assume that neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices’ Charmaz pg. 10

A central tenet of constructivist grounded theory is to give voice to participants. Charmaz (2006) has encouraged grounded theorists to incorporate the multiple voices, views and visions of participants in rendering their lived experiences. In so doing, constructivist GT has deviated significantly from the original intent of the original classic methodology. Charmaz’s book ‘Constructing Grounded Theory A Practical Guide through Qualitative Analysis’ (Charmaz 2006) eloquently supports the novice researcher through each phase of the research, acknowledging the combination of involvement and interpretation in constructing the finished work of the researcher.
3.5 \textit{Timescale}

As a part time student this research occurred in the following timescale:

<table>
<thead>
<tr>
<th>Year</th>
<th>January-June</th>
<th>July/August</th>
<th>September-November</th>
<th>December</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td></td>
<td>1st IRMSS: met Charmaz</td>
<td>Commenced discussions with 'The Organisation'</td>
<td>Finalised research proposal</td>
</tr>
<tr>
<td>2012/13</td>
<td>Registered for PhD Ethics approval and commence data collection</td>
<td>Summer school(s)</td>
<td>Data collection and concurrent data analysis *memoing, literature review and reflective journaling etc.</td>
<td>Progress Review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DCU 'Invitation to GT' met Brown NUIG: met Quinn and Kayess</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013/14</td>
<td>Data generation (plus Carers group) and concurrent data analysis*</td>
<td>Summer school(s)</td>
<td>Data collection and concurrent data analysis*</td>
<td>Progress Review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IRMSS and NUIG:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2014/15</td>
<td>Data generation (close Carers group) and concurrent data analysis*</td>
<td>President Michael Higgins' Ethics in Public Life: discussion and debates</td>
<td>Data generation and concurrent data analysis* - saturation point</td>
<td>Progress Review</td>
</tr>
<tr>
<td>2015/16</td>
<td>Commence theory write-up</td>
<td>IRMSS: met Denzin</td>
<td>Continue writing process</td>
<td>Progress Review</td>
</tr>
<tr>
<td>2016/17</td>
<td>Complete theory development</td>
<td>Writers workshops</td>
<td>Formulate dissertation</td>
<td>Progress Review</td>
</tr>
<tr>
<td>2017/8</td>
<td>Write dissertation</td>
<td>Writers workshops</td>
<td>Submit and Prepare for Viva-Voce</td>
<td></td>
</tr>
</tbody>
</table>

Box 3-1 Study timeline

The boxes appear deceptive as the reality of the research was not so linear and boxed in, herein described some applied comportments of the research detailing the setting, access to family carers and ethical considerations.
3.6 Study Setting

The study occurred in the South-West and Mid-West of Ireland. A brief description of this area situates family carers’ lives and conveys the sense and community studied. Also known as the ‘Shannon Region’ the west, south west and mid-west regions of Ireland encompasses County Limerick, County Clare, North County Tipperary, Northwest County Kerry and south Offaly, with its focal point centred on Limerick and its environs. Regional imbalances in population trends, employment, income and related social conditions have long been a feature of the west of Ireland. Contrast between the more prosperous east capital Dublin and the less developed west is acknowledged (Green 2014).

The less developed west of the ROI can be explained in terms of its more difficult physical environment, its remoteness from external influences, markets and financial sources, its heavy dependence on small-farm agriculture and its lower levels of urbanisation and infrastructural provision of services. The result attributes to lower incomes, high unemployment and underemployment and heavy migration from the area with social consequences (Green 2014). The study is conducted against this environmental backdrop, recent economic downturn and against rapid policy changes previously described in Chapter Two.

3.7 Access

This ‘Organisation’ is situated in a city in the Mid-West of Ireland, affiliated to other regional centres, and connected to a larger National Organisation through association, forums, policies procedures and activities. Established in 1987 ‘The Organisation’ initial role of advocacy and lobbying has expanded to service provision. By service provision, the main services provided are education to family carers, provision of home help and respite services, in conjunction with social and fundraising events. ‘Walk in’ and ‘drop in’ facilities are welcome to existing and new family carers. The mission statement of the organisation states its aim in gaining ‘recognition and social justice for carers’ invaluable contribution to Irish society’.
Family carers in this organisation range across the lifespan and support people with various medical and social conditions such as but not limited to intellectual, physical and sensory disabilities, mental illness, acquired brain injury, multiple sclerosis, dementia and aging family members. All carers support a family member(s) in the family home in addition to periods of hospitalisation when required.

Access to ‘The Organisation’ (pseudo name), located in southern Ireland occurred prior to finalising the research aim. Initial contact with the centre manager of ‘the Organisation’ was via email (Appendix 3). This email provided details of the researcher and interest in commencing research. This site approached over ‘disability voluntary organisations’ facilitated immersion in family carers’ concerns as opposed to exclusively disability issues. This centre manager replied, and re-directed me to the Social Policy Officer in the Head Office who deals with ‘research and policy development’ for review and consideration. Re-directing the email to the Social Policy Officer, subsequent telephone conversations and emails with the Social Policy Officer of ‘the Organisation’ transpired. In these discussions, questioning the purpose of the research, the research approach, and ethical considerations occurred.

These discussions highlighted the value ‘the Organisation’ places on research, and noted the benefits and challenges that family carers have in partaking in research. In October 2011, a completed research proposal forwarded to the Social Policy Officer of the Organisation (Appendix 4) received favour and access to ‘The Organisation’ granted, with support (Appendix 5). This led in period served to ensure that the ultimate research proposal and research design was informed and grounded, as such, co-constructed and underpinned by both researchers and ‘the Organisation’ beliefs and values to research and inquiry prior to Ethical Approval application now discussed.
3.8 Ethical Principles

The research process considered from an ethical perspective ensures that participants receive adequate knowledge about the study aim, data collection methodology and the measurement instrument(s) used so that they can make an informed decision and give consent to their participation in the research. The ethical principles identified by many authors in the professional literature include respect for persons autonomy, beneficence, non-maleficence, justice and fairness, veracity, fidelity and confidentiality (Royal College Of Nursing Research Society 1998; Beauchamp and Childress 2001; Kittay 2006; ICN 2012).

Implementation of ethical principles in this research process commenced with acquiring ‘Ethical Approval’ for the study for the period March 2012-2018. Guiding the ‘Ethical Approval’ application, the principles of respect for persons, beneficence, and justice as they would be implemented and overseen throughout the study, in addition to how data storage and data disposal were addressed. In March 2012, ethical approval received from the Faculty of Education and Health Sciences (EHS) Committee, University of Limerick categorised under EHS29021282 (Appendix 6). These procedures and considerations are now, briefly outlined.

3.8.1 Ethical Considerations

Within this study, the process of ‘informed consent’ set about ensuring family carers made an informed decision about whether to participate in the research process. To facilitate the informed consent process sharing of information via an ‘Information Sheet’ occurred (Appendix 7). This information sheet acknowledged the purpose of the study and the benefits and potential risks of participation. Along with the procedures of ensuring confidentiality and anonymity, the information sheet described the voluntary nature of participation having had the opportunity to ask questions. In addition, the sheet referred to ‘withdrawal’ of consent at any time.
The information sheet made family carers aware that the interviews were to facilitate the collection of information with the understanding that excerpts from the interviews were to be included in a dissertation and publication with the understanding that all information was confidential and no identifiers in the dissertation, summary report or future publications to protect anonymity. The information sheet also included the names email and telephone numbers of the supervisor and ethics committee to provide family carers the opportunity to contact either of the aforementioned to ask any questions and address queries. Agreeing to partake in the study, family carers were to sign ‘An Informed Consent Form’ (Appendix 8) and in the second approach to data collection a confidential agreement (Appendix 11).

The EHS committee made one recommendation in the application, ‘that audio tapes must be destroyed once the transcription is complete and the transcripts must also be made anonymous’ as per Appendix 6. This request discussed in supervision with regard to ‘destroying the voice of participants’ post transcription. This discussion focused on the significance of this recommendation as opposed to destroying audio tapes at the end of the study period. Reviewing policies and practices from other national and international committees there does not appear to be standard guidelines with the protocol of ‘when to destroy audio interviews’ post transcription or post study, in fact transcribing tape-recorded interviews into text is a process that remains relatively unexplored in most research books.

All ethics committees acknowledge the principle of anonymity of participants in transcription and a statement as to when data to be destroyed. The main issue in the request to ‘destroy post transcription’ as opposed to ‘post study’ was when working with audio data, it was anticipated early on in the research stage that listening to the audiotape while reading the transcriptions would ensure accuracy during interpretation and analysis. Having given the request some consideration by acknowledging the value of voice to researcher immersion techniques in the data, the written verbatim translation of the interview deemed acceptable for the study, in conjunction to transcriptions made anonymous and amendment to the ethics committee was completed.
On study completion, this aspect to the process was re-visited. Initially, it was thought that the audio-recording would have been valuable to the interpretation and analysis of the data, however, on reflection, the contribution of the voice of participants is now recognised as beyond hearing dialogical conversation, but rather listening, comprehending and interpreting moving beyond hearing in the analytic process. Now that the outline of the ethical principles is complete, the following paragraphs address the practical elements of inviting participants to partake in the research in addition to the methods of data collection.

3.9 Sample

Sampling is a familiar yet intricate process of selecting representative units of a population in order to derive knowledge (LoBiondo-Wood and Haber 2013). Fitting for a qualitative approach ‘non-probability purposive sampling’ techniques provided theoretical reasons for the choice of family carers to be included in this study. In ‘non-probability purposive sampling the technique implies the ‘representative units’ are gathered in a process that may not give all the individuals in the population equal chances (equal probability) of being selected.

As the Centre Manager and researcher considered requesting participation in this study, an agreed strategy occurred as follows. The manager of ‘The Organisation’ approached family carers on behalf of the researcher. In doing so, the manager forwarded the information sheet to potential family carers and discussed the background to the research. In addition, the manager forwarded, for display, a poster (Appendix 9) to allied centres in the Mid-West Region. Inclusion criteria stated that participants must be a family carer supporting a person with PIMD, aged 18 years or older and willing to participate in an interview. In conjunction with this purposeful sampling approach snowball sampling occurred. Snowball sampling techniques, used for groups of people that are rare or hidden, involved the researcher following the conversation interview asking a family carer participant, if they knew of other family carers that may be interested in the research.
If so, participants were requested to forward an information sheet to the proposed participant, and if interested the potential participant could contact the research via telephone to clarify any questions and agree a meeting if desirable. The following table represents outcomes of the sampling strategy employed:

<table>
<thead>
<tr>
<th>Sampling Approach</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposeful sampling technique via the Organisation</td>
<td>14</td>
</tr>
<tr>
<td>Snowball sampling technique via family carers</td>
<td>10</td>
</tr>
<tr>
<td>Poster recruitment</td>
<td>2</td>
</tr>
<tr>
<td>Total conversational interviews</td>
<td>26</td>
</tr>
</tbody>
</table>

### 3.10 Data Collection

The data generated within this study was personal, insightful and constructed with participants. Data collection represents the purposeful activity of meeting and engaging in and with family carers emphasising relationships (Hannigan 2006), planning, actioning of activities ‘with purpose’, reflection and memoing. In this study the main approaches to data generation were:

- Dialogue with family carers ‘learning through conversation’ in the form of individual conversational interviews
- Dialogue with and within ‘The Organisation’ ‘learning through conversation’ in the form of group work

These approaches now described.

#### 3.10.1 Conversational Interviews

The interview is by far the most common method in qualitative data collection (Dicicco-Bloom and Crabtree 2006) where rich data are detailed, focused and full of participants views, feelings, intentions and actions as well as the contexts and structures of their lives (Charmaz 2006). Concurring with Dicicco-Bloom and Crabtree (2006) description of less structured interview strategies the person interviewed is a participant in meaning making than a conduit from which to retrieve information.
The choice of ‘Conversational interviews’ as an interview strategy builds on this understanding embracing the free flow style, which required ‘dialogue with’ rather than examination and investigation format. Taking Charmaz’s advice of ‘Being there to listen’, to ‘observe with sensitivity’, and ‘to encourage response’ where the ‘participant does most of the talking’ was the aim throughout these conversational interviews. Conversational interviewing is a recursive process whereby the agenda for the interview is established interactively by both the researcher and the participant. As in GT studies, there was no predetermined interview schedule, the questions asked built on the participants’ responses to previous questions as well as the stories told by others interviewed. The interviews were informal, flexible, and akin to a conversation.

Evident in the meeting of family carers was the frank and open conversations, welcoming into their homes, tea coffee and cakes ready for the conversations. The general thrust of family carers stating that they were happy to meet and talk, ‘doing something, anything if it helps’ emerged strongly through initial introductions. Conscious of the vivid details, at times intense emotion shared and the apparent need to do so. In all, these conversations commencing in April 2012, spanned over three years, and ranged between 40 minutes and 2 hours with 26 family carers. In 2012 nine conversational interviews occurred, in 2013 thirteen conversational interviews occurred, and 2014 four conversational interviews occurred. The following paragraphs of pre, peri and post interview aims to describe to readers the sense of engagement and facilitation that encompassed this approach to generation of rich and detailed data.

3.10.1.1 Pre-interview process

Awareness of the objective of going ‘beneath the surface of ordinary conversation,’ the grounded theory interviewer uses strategies that include requesting further detail or explanation, clarifying points to check for accuracy, validating the participants’ ‘humanity, perspective or action,’ (Charmaz, 2006, p. 26).
This approach involves an appreciation for participants as ‘experts by experience’, therefore, participants express thoughts and feelings that they may often not be asked. The interview consisted of a preliminary ‘tell your story’ stage before the discussion of specific ‘core topics’. Participants spoke for as long as they wished. The main opening question posed to participants was ‘can you tell me a little bit about yourself and as the information letter describes how you support your (name of son or daughter) in making decisions’. Other questions followed based on findings derived from the initial interviews reflecting the nature of the conversation interview evolving generating rich and in-depth data rather.

Facilitating understanding, or ‘verstehen’ (Glaser and Strauss 1977), the researchers’ knowledge of terms, and practices, such as PEG feeding, nighttime sleep systems, names of medications and familiarity with procedures such as suctioning, PRN medication enabled understanding. The intensity of the family carer role was evident in making time to meet the researcher, as family carers had limited time, and needed to plan very carefully around their busy schedules. In planning the conversational interviews to suit family carers schedules in practice meant often re-scheduling and rescheduling as many family carers emergencies or other commitments took priority to meeting for the purposes of this research. In several scheduled meetings, there were cancellations. One parent cancelled three times, and each time apologetic and upon meeting expressed a desire to contribute.

**3.10.1.2 Peri-interview-how the data were co-constructed**

Through the conversational interviews shared decisions about the subjects for discussion, the direction of discussions, and the extensiveness of an account of a particular event or reflection, in addition to, identify topics to avoid or accentuate occurred. Such decisions voiced through the questions ‘Could you tell me more about that?’ by the interviewer seeking confirmation from the interviewee or the interviewee voicing ‘Is this relevant?’
Embodyed gestures, stance, or other vocalised and non-vocalised responses
designed to encourage or discourage the flow of the conversation (grunts,
sighs, raised eyebrows, smiles, laughter, and tears) accounted for in shaping
the conversations, and noted in transcribing. Such interactions highlight the
social nature of the interview. Encouragement to participants through
nodding, gestures and at times silence. I asked questions slowly, aimed to
foster the participants’ reflection, and conscious that we are exploring not
interrogating. ‘That is interesting, have you any more thoughts in this area’,
‘as you look back on that experience are there any other events that stand
out’ are two examples taken from Charmaz that were found beneficial in
interviews. Thus, through listening, reflection, probing yet addressing
pertinent areas these interviews generated data in a way that demonstrated
how grounded theory interviewing:

‘differs from much in-depth interviewing because we
narrow the range of interview topics to gather specific data
for developing our theoretical frameworks as we proceed
with conducting the interview’
Charmaz 2006 pg. 29

Facilitating interviews in people’s homes allowed ‘sensitive observation’ and
visualisation of the realities of family carers’ experiences. The conversations
that occurred in participants’ homes also provided me with the opportunity to
meet with the majority of participants’ child or adult child with a PIMD in
addition to some other siblings and partners. Observations of interactions with
persons living with PIMD and the home environment all contributed to
understanding.

3.10.1.3 Post interview reflections

Observations and ‘off line’ conversations were noted in post conversational
interview notes in addition to influencing memos and stored them with the
printed version of the conversational interview. An example of the off-line
conversation was the ‘post interview field note’ as below;
Post interview;

After chatting and tape recorder off family carer showed me bathroom, teeth chart, beds and then into kitchen. Chatted with Daughter, some pictures of family and book on ‘syndrome’, the fridge like may fridges was loaded with pictures and magnets, family carer took a picture of her daughter and said to me ‘here take this, so you don’t forget’. I was really touched by this act; and the meaning this act had for the mum; the words ‘don’t forget’, it was a powerful moment, loaded with meaning.

I am reminded of my interview preparation and the reading of Donalek (2005) ‘The interview in qualitative research’ who describes interviews as a paradox, and while appearing simple to observers the discerning eye will notice the sensitive and skilful interviewer. Donalek notes that ‘When the interview is over, time is allotted for both the participant and the interviewer to wind down. This is a time for more social conversation. The participant might offer the researcher a snack or express the desire to show the researcher family pictures. It is crucial that the researcher be comfortable in staying through this seemingly less important phase of the interview’. While I was comfortable in this phase of the interview, I disagree with this statement ‘the less important phase of the interview’. This phase has shown me insight and understanding, often taken for granted, into family carers’ life. I saw this interaction as more than social conversation, this act of showing and giving me a picture; displayed an act that represented many carers feelings of ‘forgotten-ness’ by society, the government and at times close family and friends. ‘The giving of one’s story is a deeply valued gift. The researcher has a responsibility to care for and respect that gift and to use it as it was intended, that others may benefit from the participant’s story’ (Donalek 2005) as I leave this interaction, I feel a sense of this responsibility.

Field notes 3-1 ‘Importance of off-line conversations’

These conversations were audio-recorded, transcribed verbatim by the researcher within a week of conducting the interview, read and re-read for immersion to develop understanding prior to conducting another interview. As per ethical approval, voice recordings of individual interviews were destroyed post transcription. The typed transcripts maintained by the researcher in a locked office in a locked filing cabinet ensure data is secure and maintaining privacy of participants’ information. Meeting family carers’ children and adult dependents, listening to their stories, developing insight into personal thoughts has been a privilege and I acknowledge ‘a sense’ to do justice with and for these participants. The next section describes the second approach to data generation- collaborative and reflective dialogue.
3.10.2 Collaborative and Reflective Dialogue-Group Approach

While the conversational interviews yielded rich in-depth data of family carers’ experiences, the second approach to data generation reflects a collaborative stage of the study further contributing to the co-construction tenets of the Constructive GT philosophy. Charmaz notes how the grounded theory method not only calls for using comparisons to generate categories but also builds in checks that keep the researcher’s ideas grounded in data, and this method of data generation served well in that regard. Collaborating with family carers through establishing, facilitating and evaluating a ‘Family Carers Group’ formed the second approach to data generation ensured ongoing connections with family carers providing opportunities for comparisons in generating categories in addition to ensuring the researcher’s ideas were grounded.

3.10.3 Establishing the ‘Family Carers Group’

The ‘Family Carers group’ was initially envisaged as creating opportunities for family carers to reflect on and articulate their own experientially-based perspectives, share their experiences, feelings, ideas or concerns in the knowledge that they were in a safe and trusted environment with other family carers in similar circumstances. Both positive and challenging experiences were encouraged. The growing body of research exploring the conceptual basis for collaboration in research identify key attributes of ‘sharing’, ‘working together’, ‘role awareness’ and ‘support’ along with ‘interdependence’ and ‘trust’ to impact on inequalities (McLaughlin et al. 2014).

Guidance by Simpson and Repper (2011), ‘Good practice guidance for collaborating with family carers and family members and close friends of service users in research’ proved beneficial in shaping this approach to data generation (Appendix 10). Simpson and Repper refer to family carers supporting persons experiencing mental health problems; however, their guidance is applicable across the spectrum of family carers.
Several conversations between the manager of ‘The Organisation’ and the researcher prior to the group beginning discussed strategies of engaging family carers and the use of reflection. Reflection as a process of engaging in being mindful of self, either within or after experience, to confront, understand and move towards recognising successes and or resolving challenges and contradiction(s) between vision and practice (Johns 2009, Ghaye 2008). ‘Reflection’ as purported by Johns (Johns 2009; Johns 2017) and Ghaye (Ghaye and Lillyman 2012) was recognised a tool to supporting family carers in identifying knowledge and questioning this understanding from a personal, interpersonal, contextual and critical perspective. Building on this premise, reflection within the family carers group encompassed different purposes (thinking, learning and assessment of self and social systems) together with different forms and domains of reflection (personal, interpersonal, contextual and critical).

Now discussed are considerations outlining the process of inviting family carers to partake in the family carers group in addition to facilitating meetings and evaluation of the group.

3.10.2.2.1 Inviting Family Carers to partake

Following the individual conversational interview the researcher asked family carers if they would like to participate in a ‘Carers Group’ with an initial verbal explanation of what the group would entail regarding time, commitment and purpose, supported by an information letter (Appendix 11). This information sheet provided family carers with details of the purpose and suggested outline of the group and the voluntary nature of participation and informed consent detailed (Appendix 11).
The sample for the ‘Family Carer Group’ originally consisted of five family carers supporting their son or daughter, living with a PIMD and the researcher as facilitator. Consideration of participation was easier for some carers than others, but all family carers asked to partake gave the matter consideration. As the centre manager predicated, the first concern that most family carers uttered was consideration of time and finding someone to help their son or daughter. All family carers were eager to participate and again the enthusiasm of ‘anything if it helps’ attitude became evident.

The decision to make the group closed was based on previous experience in facilitating undergraduate BSc Nursing programmes ‘Guided Group Reflections’ and findings of facilitators that sharing of experiences is easier when there is a feeling of safety within the group (Mc Carthy et al. 2013). In practice, this meant that family carers interviewed in the first year of the study participated in the group, disadvantaging carers interviewed at a later stage. This however was unavoidable as to allow the carers group to commence and proceed over time.

Confidentiality agreements and guidance procedures for support groups are gaining popularity perhaps related to the growing nature of support groups and the intentions of demonstrating ‘what says in the group stays in the group’. In this study, the ‘confidentiality agreement’ represented a shared responsibility of all group members and the facilitator to support building trust and openness for family carers to share experiences (Appendix 11).

3.10.3.1 Format of Meetings

In all, eight group meetings occurred in the evening time over a period of a year, each meeting lasting approximately 1-1½ hours duration. Each session comprised of a group discussion, and in some sessions distribution of handouts for participants to take home. The family carers’ group meetings occurred from January 2013-January 2014, with meetings held in January, March, April, May, June, September and October of 2014. An evaluation of group meeting occurred in November and a social event closing the group in January 2014, over dinner.
‘The Organisation’ accommodated the meetings in their state of art ‘training room’ with a heater, flip chart and comfortable chairs and table provided. Teas coffees and cakes provided at the beginning of the meeting aimed to make people at ease, and set the scene for a sociable engagement. The average attendance was four family carers, with two family carers who attended all sessions. Attendance in the group reflects the time challenges and other commitments that can be taxing for family carers, with family carers being unable to attend some sessions due to their sons and daughters, living with a PIMD, physical health deterioration and the need for more care and attention at home. These family carers kept in touch with the researcher via text, email and/or telephone in confirming non-attendance.

As a ‘closed group’, meaning new members could not join after the first meeting, accommodation of new participants was not possible, and upon reflection, this may change going into the future. Topics were not pre-determined, in an attempt to ensure the group was as carer-led as possible but relayed to the reflective writings and considerations that occurred outside of meetings. Writing was not compulsory, and writings were private.

Writing as a strategy aimed to offer family carers an opportunity to identify specifics thoughts, feelings and concerns. Family carer writings were private, if a family carer choose to share their writings this was encouraged, some family carers choose to verbalise their experiences in discussion format at the arranged meetings, and this was equally valued. Therefore, the meetings entailed two main aspects: 1) sharing of writings, thoughts and considerations. This aimed to ensure family carers presented the issues that were of concern to them 2) Peer review or opportunity to question supporting further analysis. This aimed to promote interaction within the group and the facilitator, hence the trusted element of the group via closed memberships facilitate questioning and analysis of personal reflections. A summary of the group topics were: January ‘ground rules, expectations and trusting in the process’, March ‘our lives are no different,’ April ‘feeling the many feelings,’ May ‘managing it all’ June ‘July provision Yeah!’ September ‘community resources’ and October ‘looking after oneself’.
Research Process

In November the art evaluation facilitated by an art therapist ‘was not therapy per se but rather using aspects of art therapy to allow for an expressive, non-verbal response to the emotional content involved in our work together’ eliciting a ‘number of deeply personal responses’ (Art therapist’s words). In this evaluation, there was no onus on the participants to explore in any depth the essence of the work created and in conclusion, the session offered another means of reflection on personal circumstances, shared and private responses and personal reactions to the finished artwork. An evening dinner in January 2014, ending the group with reflections of the process and the empowering nature of the conversations chatted freely over dinner.

3.10.3.2 Facilitating the ‘Family Carer Group’ meetings

Facilitating meetings in ‘The Organisation’ was advantageous in that family carers were familiar with the venue and comfortable in this surrounding. Content and delivery evolved over the course of the study, consistent with the study’s constructivist paradigm. Building on previous experience of ‘Guided Group Reflection’ with undergraduate student nurses (Mc Carthy et al. 2013) the researcher facilitated the meetings conscious of the fact that this group of family carers were not ‘student nurses’ on placement. Their ‘practice’ was much closer to the bone.

While the group was personal and the family carers set the agenda as facilitator of the group I was conscious to focus family carers attentions of engaging in being mindful of self, either within or after experience, to confront, understand and move towards recognising successes and or resolving challenges and contradiction(s) between vision and practice. This was realised by including strategies of writing a diary, sharing of writing at meetings and sharing of articles for discussions, with personal and critical reflections shared.

The free flow style of the group promoted fruitful discussions yet a number of planned discussion/activities incorporated into the Carers Group meetings designed to generate data comprised of
Research Process

- Meet, greet and establish ground rules
- Review the concept and purpose of reflection. Group members recording of a reflective diary outside of meetings and share these writings when re-grouping
- During group discussions, family carers asked what decisions they made in their own lives and what decisions they supported. Group discussion comparing decision-making support options, opportunities and achievements
- A review of focused codes and affirm or disagree with categories in asking family carers in this group to review and offer their opinions

This element of data generation served to enhance credibility and resonance in this study through prolonged engagement and exploring the context of the experiences in which embedded therefore minimising misrepresentations that might appear in and within the data.

3.10.4 Reflexivity

Irrespective of the approach, questions in relation to the researcher and the degree of influence of the researcher on the data gathering processes requires consideration. The ability to attend systematically to the context of knowledge construction, especially to the effect of the researcher, at each step of the research process was through Journaling Reflections, extracts of which appear throughout the dissertation. In addition, supervision and guidance through university processes such as the Annual Progress Review set forth a mechanism to articulate and demonstrate the rigour and processes of data construction.

Although a constructivist GT methodology has the assumption that “data reflect the researcher’s and the research participants’ mutual constructions” (Charmaz 2005), it is still extremely important to avoid fitting the data into preconceived categories. The main feature of the Reflective Journal was to maintain self-awareness within the research process, to acknowledge this influence and identify how this influence contributed to the findings. Therefore, Journaling Reflections recognised as a strength of the constructivist GT approach supports the congruence between ontology, epistemology and methods thus allowing the reader to assess the value of the findings.
3.11 Data Analysis

The data analysis procedure used in this study followed guidelines described by Charmaz (2006). The components of this process are initial (or open) coding, focused coding, theoretical sampling, memoing, raising some focused codes to categories, and then using those categories to develop the conceptual theoretical framework (Charmaz, 2006).

3.11.1 Questions of the analysis

The purpose of the study was to explore family carers’ experiences of supporting persons, living with PIMD, in decision-making. The following questions assisted in the analytical processes adapted from Charmaz (2006, page. 20) guidance:

1. How do carers come to this experience?
2. How do carer’s understandings of supporting persons, living with PIMD, in decision making develop?
3. What are the important influences on this process?
4. How did carers engage in the making of meanings?
5. What were their understanding of the main concepts, ideas and experiences?
6. What sort of knowledge did the carers have - before, during, and after supporting and
7. What mechanisms accounted for this knowledge?

3.11.2 Initial Coding

Initial coding is the process of attaching ‘labels to segments of data that depict what each segment is about’ (Charmaz 2006). This form of coding helped the researcher remain attuned to family carers’ views of their own realities rather than assuming the researcher, and family carers shared the same views and worlds. Codes serve to summarise, synthesis and sort the many observations made of the data in order to gain a clear rendering of the data. When rendering the data Charmaz advises researchers to ask ‘What do I see going on here?’ To illustrate when reading the interviews of family carers initial coding in the right column quickly represented many diverse and illuminating codes representing family carers’ experiences. An example follows in Box 3:2
Research Process

<table>
<thead>
<tr>
<th>Data</th>
<th>Initial Codes</th>
</tr>
</thead>
</table>
| Interview statement XX: I went up and what I saw through the window didn’t entice me at all, they weren’t making any effort with Person with a PIMD, don’t get me wrong they weren’t actively dragging him around the place but they were a bit rough with him, they made no attempt to explain to him, he was just being put here and just put there, they weren’t even trying to engage him on whatever level he had, which was a total shock from the experience we elsewhere. | Feeling sorrow  
Noticing the injustice  
Seeing carer ‘mishandle’  
Valuing individual communication needs  
Feeling shocked |
| Interview statement XX: he’s quite content in his own world, I would love it if he was developed more, if he liked toys or something like that, his big thing is the ‘Argos’ catalogue and tearing the pages, and making a mess of things but he doesn’t have a lot of things that seem to interest him, now they are great at school, they bring him swimming once a fortnight, I wouldn’t dream of doing it, put myself under the stress not in that area any more, but he’s quite content, pleasant personality and easy going. | ‘Longing for’  
Fantasying opportunities  
Seeing abilities  
‘Doing it’  
Realising practicalities of activities  
Living the practicalities of self-care activities |

Box 3-2 Sample of Initial Coding

As seen from Box 3-2 initial codes were lengthy, descriptive and lacked the analytical grab required in a grounded theory study. These initial codes were provisional and comparative allowing the researcher to remain open to other analytic possibilities. ‘Focused Coding’ now discussed follows this ‘Initial coding’ process.

3.11.3 Focused Coding

The codes developed during focused coding were more selective and conceptual than the initial coding. The process is selective because having weeded through data a set of categories develops. It is conceptual because the codes employed ‘raise’ the sorting of data to an analytic level rather than one that is used to summarise large amounts of information (Charmaz 2006).
‘Focused Coding’ forces you to develop categories rather than simply label topics emanating from an earlier frame applied to them (Charmaz 2006). A constructivist approach to GT acknowledges that the researcher constructs codes because they are interpreting and naming what they see in the data based on their previous knowledge and experience. The following Box 3-3 represents the outcome of the process of sifting, sorting and synthesising the initial codes into focused codes.

<table>
<thead>
<tr>
<th>Substantive Theme</th>
<th>Sub themes</th>
<th>Conceptual interpretations after comparisons</th>
<th>Focused codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensing a Union</td>
<td>Personalising care and support</td>
<td>Aiding another</td>
<td>Seeing the need</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Working intimately</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Claiming confidence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-identifying</td>
<td>Claiming knowledge</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Seeing many roles</td>
<td></td>
</tr>
<tr>
<td>Connecting</td>
<td>Establishing understanding</td>
<td>Questioning understanding</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Observing cues and gestures</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Responding to cues and gestures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Having concerns</td>
<td>Seeing vulnerabilities</td>
<td>Feeling worried</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Familiarity with expressions</td>
</tr>
<tr>
<td></td>
<td>Developing empathy</td>
<td></td>
<td>Appreciating contributions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Substantive Theme</th>
<th>Sub themes</th>
<th>Conceptual interpretations after comparisons</th>
<th>Focused codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Framing Representation</td>
<td>Facilitating Participation</td>
<td>Acting 24/7</td>
<td>Being busy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Constantly doing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Planning everything</td>
</tr>
<tr>
<td></td>
<td>Structuring support</td>
<td>Relying on significant others</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Questioning services policies</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Articulating wishes and needs</td>
<td></td>
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<tr>
<td></td>
<td>Considering sons/daughters ways</td>
<td>Co-determining ways</td>
<td>Feeling 'knowing and not knowing'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Orientating situations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Second Guessing</td>
<td>Weighting up likes/dislikes</td>
<td>Debate understanding of preferences</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Rationalising conclusions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Substantive Theme</th>
<th>Sub themes</th>
<th>Conceptual interpretations after comparisons</th>
<th>Focused codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steering Affairs</td>
<td>Guiding Activities</td>
<td>Driving Courses of Action</td>
<td>Managing activities and affairs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overviewing choices</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Handling Situations (ethics)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Embracing Leadership</td>
<td>Leading care and support</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Constantly Learning</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Appreciating time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Influencing lifestyle</td>
<td>Nudging and being nudged</td>
<td>Doing the right thing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Giving them what they want</td>
</tr>
<tr>
<td></td>
<td>Balancing the risk</td>
<td></td>
<td>Developing realistic choices</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mulling over</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Grappling with right or wrong</td>
</tr>
</tbody>
</table>

Box 3-3 Coding Framework
This focused coding process is fundamental to the development of substantive categories and the properties of those categories (Harris 2015). It is importance to acknowledge the researchers ‘renderings’ and the ‘Memoing’ process that facilitated this part of the analysis, now discussed.

3.11.4 Memoing

Memos are records of the researcher’s developing ideas about codes and their interconnections describing the thoughts that weaves data generation to another level. Memos aid to transform raw data and field-note descriptions into theoretical accounts (Montgomery and Bailey 2007). In generating memos ‘creativity, free style and engage with categories in a way that ‘let’s your mind rove freely in, around, under, and from the category’ is required. Such writing prompted thinking about important recurring statements and concepts and allowed comparisons between participant experiences and views necessary to help direct and focus further data collection. Questioning through memoing, explanations and descriptions explore what the participants are saying, and what processes are at issue, and under what conditions these processes develop.

Memos documented were stored in a single word document and saved in a separate folder next to the data. It was easy to see as the study progressed the development of ideas and level of analysis that emerged as time passed, the move from descriptive memoing to more creative and theoretical memoing. Coding and memoing therefore occurred simultaneously. Advanced memos ‘trace and categorise data subsumed by your topic, describe how your category emerges and changes, identify the beliefs and assumptions that support it, places it within an argument, in addition to making comparisons’ Charmaz (2006 pg. 80 and 81). Memos are presented in Chapter Four and Appendix twelve as they demonstrate how understanding and gaining insight into family carers’ experiences came to be.
3.11.5 Constant Comparison, Theoretical Codes, sorting and write up

In GT studies, the researcher’s decisions, the questions that (s)he is asking of the data, the way (s)he is using the method, as well as his or her (personal, philosophical, theoretical, methodological) background shape the research process and, ultimately, the findings. As a result, the theory produced constitutes one particular reading of the data rather than the only truth about the data.

In constantly comparing data and coding of data with 1) other primary data 2) evolving original data 3) evolving concepts and 4) evolving theories (see (Glaser and Strauss 1977; Charmaz 2006) grounded concepts and the relationship between them become more visible. Data analysis in GT approaches value the iteration process of constantly comparing data, concepts and evolving theories in developing insight.

Theoretical sampling refers to ‘data-gathering toward explicit development of theoretical categories derived from analyses of their studied world’ (Charmaz 2006 page 102). Theoretical sensitivity is based on immersion in the field of investigation and associated general ideas, so that a researcher understands the context in which the theory is developed what the researcher brings to the study as well as immersion in the data during the data collection and analysis phases (Charmaz 2006).

Sensitivity to theoretically relevant concepts was central to recognising the characteristics of the themes in the data with ‘Interactional Guesstimating: Growing confidence with uncertainty” emerging because of this analytical process. This interaction and creative process through memoing reflection and constant comparison created an explication, organisation and presentation of the data rather than discovering order within the data.
3.12 Chapter Conclusion

This chapter outlines how this research adhering to the principles of grounded theory occurred. While there are many valid and critical views of grounded theory as a research methodology, this chapter highlighted the theoretical and practical value and congruence of the constructivist grounded theory approach to ascertain family carers’ experiences supporting persons, living with PIMD, in decision-making occurred.
4 Chapter Four Findings

This chapter at a glance …

- Describes the findings of the study
- Presents the theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ describing family carers’ experiences of supporting people, living with PIMD, in decision-making
- Profiles the categories that formulate the origins of these experiences and understanding
- Explains the relationship between these categories

This research set out to ‘explore family carers’ experiences of supporting persons, living with PIMD, in decision making’ and this chapter presents the main contribution to knowledge arising from this aim. While grounded theory ‘can be presented either as a well-codified set of propositions or in a running theoretical discussion, using conceptual categories and their properties’ (Glaser and Strauss 1967, pg. 31) this chapter as per Charmaz (2006 page 128) guidance presents a running theoretical discussion evocative of family carer experiences.

The research was about family carers’ experiences, which they freely expressed, and through an interpretive constructivist perspective, a sense of family carers’ presence in keeping participants words intact during the process of analysis maintains their understandings without reducing their experience to small parts. Therefore, this chapter presents a delicate balancing act, enabling participants accounts to retain a degree of visibility in the text so that the reader can make the connections between analytical findings and the data from which derived.

Firstly, a brief overview of family carer demographic data.
4.1 Summary of Sample Profile

In this study, family carers (n=26) were all parents. Elicited from the data information in relation to age and marital status, gender and age of the person family carers are providing care and support too, presented in the table below.

| Table 4-2 Demographic data of family carers and those they care for |
|---|---|---|---|---|
| **Male Participants** | | | | |
| **Title** | **Age (approx.)** | **Marital Status** | **Employments status** | **Caring for** |
| Mr. C | Late 30’s | Married | Employed | Daughter aged 10 |
| Mr. G | Late 50’s | Married | Employed | Son aged 28 |
| Mr. J | 46 | Married | Employed | Son aged 14 |
| Mr. Q | Early 60’s | Married | Retired (early) | Son aged 22 |
| Mr. T | Early 60’s | Widower | Retired | Son aged 32 |
| **Female Participants** | | | | |
| **Title** | **Age (approx.)** | **Marital Status** | **Employments status** | **Caring for** |
| Ms A | Mid 40’s | Separated | Full time carer | Son aged 16 |
| Mrs. B | Mid 50’s | Married | Part time (am) | Son aged 26 |
| Mrs. D | Mid 40’s | Married | Part time (am) | Daughter aged 9 |
| Mrs. E | Early 60’s | Married | Full time carer | Daughter aged 42 |
| Ms. F | 48 | Single | Full time carer | Son aged 19 |
| Mrs. H | Late 40’s | Widow | Full time carer | Daughter aged 17 |
| Mrs. I | 40 | Married | Full time carer | Daughter aged 12 |
| Mrs. K | Early 50’s | Married | Full time carer | Daughter aged 32 |
| Mrs. L | Early 70’s | Widow | Full time carer | Daughter aged 42 |
| Mrs. M | 68 | Married | Full time carer | Daughter aged 30 |
| Mrs. N | 74 | Widow | Full time carer | Daughter aged 40 |
| Mrs. O | 50 | Married | Full time carer | Daughter aged 22 |
| Mrs. P | 40 | Married | Full time carer | Daughter aged 17 |
| Ms. R | 45 | Single | Full time carer | Son aged 24 |
| Mrs. S | 60 | Married | Full time carer | Son aged 19 |
| Mrs. U | Early 50’s | Married | Full time carer | Daughter aged 23 |
| Ms. V | Late 40’s | Partner | Full time carer | Daughter aged 27 |
| Mrs. W | 68 | Married | Full time carer | Daughter aged 32 |
| Mrs. X | Middle 50’s | Married | Full time carer | Son aged 28 |
| Mrs. Y | Early 50’s | Married | Full time carer | Daughter aged 23 |
| Mrs. Z | 41 | Married | Full time carer | Son aged 15 |

All participants lived in the Southern part of RoI in suburban and rural neighbourhoods. The majority of family carers were of Irish nationality (n=25) and one participant from central Europe.
Table 4.2 identifies how family carers were engaged in caring and supporting persons, living with PIMD, in their homes from a range of 9 to 42 years, a mean score of 23.8 years’ experience. The following Table 4.3 presents the range of ages of the persons, living with PIMD.

<table>
<thead>
<tr>
<th>Title</th>
<th>Caring for child 9-18’s</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mrs. D Daughter aged 9</td>
</tr>
<tr>
<td>2</td>
<td>Mr. C Daughter aged 10</td>
</tr>
<tr>
<td>3</td>
<td>Mrs. I Daughter aged 12</td>
</tr>
<tr>
<td>4</td>
<td>Mr. J Son aged 14</td>
</tr>
<tr>
<td>5</td>
<td>Mrs. Z Son aged 15</td>
</tr>
<tr>
<td>6</td>
<td>Ms A Son aged 16</td>
</tr>
<tr>
<td>7</td>
<td>Mrs. H Daughter aged 17</td>
</tr>
<tr>
<td>8</td>
<td>Mrs. P Daughter aged 17</td>
</tr>
</tbody>
</table>

Table 4.3 Age Profiles of care recipients
<table>
<thead>
<tr>
<th>Title</th>
<th>Caring for young adult 19’s-30</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ms. F Son aged 19</td>
</tr>
<tr>
<td>2</td>
<td>Mrs. S Son aged 19</td>
</tr>
<tr>
<td>3</td>
<td>Mr. Q Son aged 22</td>
</tr>
<tr>
<td>4</td>
<td>Mrs. O Daughter aged 22</td>
</tr>
<tr>
<td>5</td>
<td>Mrs. U Daughter aged 23</td>
</tr>
<tr>
<td>6</td>
<td>Mrs. Y Daughter aged 23</td>
</tr>
<tr>
<td>7</td>
<td>Ms. R Son aged 24</td>
</tr>
<tr>
<td>8</td>
<td>Mrs. B Son aged 26</td>
</tr>
<tr>
<td>9</td>
<td>Ms. V Daughter aged 27</td>
</tr>
<tr>
<td>10</td>
<td>Mr. G Son aged 28</td>
</tr>
<tr>
<td>11</td>
<td>Mrs. X Son aged 28</td>
</tr>
<tr>
<td>12</td>
<td>Mrs. M Daughter aged 30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Title</th>
<th>Caring for adult 31’s-42</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mr. T Son aged 32</td>
</tr>
<tr>
<td>2</td>
<td>Mrs. K Daughter aged 32</td>
</tr>
<tr>
<td>3</td>
<td>Mrs. W Daughter aged 32</td>
</tr>
<tr>
<td>4</td>
<td>Mrs. N Daughter aged 40</td>
</tr>
<tr>
<td>5</td>
<td>Mrs. E Daughter aged 42</td>
</tr>
<tr>
<td>6</td>
<td>Mrs. L Daughter aged 42</td>
</tr>
</tbody>
</table>

These tables demonstrate the breadth and depth of experience contributing to the constructivist grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’.
While the sample consisted mainly of mothers (80%), five fathers partook. Employment status was a feature that emerged from participants’ conversations with 92% of female carers staying at home to care full time, 8% worked part time around school or ‘day care’ hours showing that no female carers worked full time. This differed for the male sample with 60% of males in full time employment and 40% retired from employment. Table 4.5 below represents a synthesis of these findings.

Table 4-5 Summary of Participants demographic details

<table>
<thead>
<tr>
<th>Demographic details</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants</td>
<td>5 participants</td>
<td>21 female participants</td>
</tr>
<tr>
<td>Place of Conversational Interviews</td>
<td>2 Researchers Office</td>
<td>5 Researchers Office</td>
</tr>
<tr>
<td></td>
<td>1 Participant home</td>
<td>15 Participant home</td>
</tr>
<tr>
<td></td>
<td>2 Coffee Shop</td>
<td>1 Coffee Shop</td>
</tr>
<tr>
<td>Employment Status</td>
<td>• 3 Full time</td>
<td>• 0 Full time</td>
</tr>
<tr>
<td></td>
<td>• 1 Unemployed</td>
<td>• 19 full time carers</td>
</tr>
<tr>
<td></td>
<td>• 1 Retired (early)</td>
<td>• 2-part time employed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 0 Retired</td>
</tr>
</tbody>
</table>

This concludes the descriptive data of the study. In relation to the main findings presented herein, maintaining the principle of anonymity required participants’ names, places and identifying characteristics to change slightly.

4.2 Main Findings

The main findings present family carers’ multifaceted activities and attributes experienced in supporting persons, living with PIMD, in decision-making reflecting their ‘process of intervening’. When supporting their sons and daughters in the milieu of life, inclusive of decision-making, family carers’ main concern was identified as ‘getting it right’ with the mechanism ‘Interactional Guesstimating’ acting to overcome this concern.
Data analysis identified that in developing the skills and competence to assert and support the wishes, preferences and life choices of profoundly disabled people a similar pattern was evident. In this analysis, understanding the family carers individual context in addition to three core themes ‘Sensing a Union’ ‘Framing Representation’ and ‘Steering Affairs’ emerged as critical to the study’s substantive explanation ‘Interactional Guesstimating: Growing confidence with uncertainty’. The following figure 4.1 provides a visual overview.

Figure 4.1 ‘Interactional Guesstimating: Growing confidence with uncertainty’

Figure 4.1 represents the cyclical nature required in supporting persons, living with PIMD, in decision-making with the family carer experiencing each stage, to various degrees, before moving onto the next, and returning at another point in time, notwithstanding substantial personal, professional, legal and organisational pressures. In time and over time, family carers confidence increases, yet the paradoxical nature of being unsure in their claims gives rise to the overall theory of ‘Interactional Guesstimating: Growing confidence with uncertainty’. Here forth, each aspect of Figure 4.1 is described in detail.
4.3 Context: Being and Becoming

As figure 4.1 illustrates, the first element to the grounded theory is context noting family carers’ and their circumstances to place the themes in perspective. Questions one and two of the analysis play out here. Firstly, ‘How do carers come to this experience?’ and secondly ‘How do carer’s understandings of supporting persons, living with PIMD, in decision making develop?’ Typically, the development and future prospects of profoundly disabled persons was unclear to family carers, particularly in the early phases of childhood and adolescence. In supporting the development and future prospects of profoundly disabled persons family carers’ personal growth and understanding occurs through constant interactions, poise, knowledge acquisition and skill development. The grounded constructivist theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ reflects these experiences.

Data revealed how ‘being’ was unexpected and experienced as demanding and unpredictable forcing family carers’ ‘responsibility awareness’ and an intense commitment requiring the need for strategies and management approaches supporting the milieu of activities in and outside of home. Supporting the milieu of activities represents the physical social and emotional collaboration and interaction in which the dyad existed. By support, family carers alluded to and described actions as per AAIDD (2011) understanding of supports as ‘resources and strategies that promote personal development and enhance functioning’ and therefore, this understanding is adapted within this dissertation.
In ‘Being’ family carers clearly stated that supporting persons, living with PIMD, their roles are not ‘static’ or far from ‘superseded’ as originally suggested by Voysey (1975, 2006) and Twigg, and Atkin (1994). This study found the opposite, critical for family carers was the multiple and ambiguous roles, which in turn have shifting sets of expectations from self, family, friends and other supporters (Schofield et al. 2013a) evident in the changing landscapes of care. Family carers primarily attached humanistic values when orchestrating understanding of their sons and daughters’ choices reflected in ‘Becoming’ a family carer. While unique for each family carer interpreting the disabled person’s expressions, will or intention three core principles were found namely 1) Sensing a Union required eliciting the disabled person’s identity, 2) Framing representation to establish a life and lifestyle and 3) Steering affairs to enhance this life and lifestyle.

Through ‘Being and Becoming’ family carers in their ambiguous and multiple roles use interaction, questioning, seeking information and learning in which they come to see that profoundly disabled people, can and do, participate in decision-making. Moreover, family carers presented the need to establish circumstances that are conducive to the participation of profoundly disabled persons in decision-making, broader than legalistic notions of cognitive attributes as central criteria in decision-making. The first core principle now described-Sensing a Union.

4.4 Sensing a Union

‘Sensing a Union’ aims to conceptualise family carers’ feelings of closeness to their sons and daughters and understanding of ‘their ways’ when supporting them in decision-making. Established through familial connections which generally hold strong emotional ties, ‘Sensing a Union’ is motivated by other factors such as the additional need for support required, the complexities of support required and the duration of support required.
‘Sensing a union’, a substantive theme in ‘Interactional Guesstimating: Growing confidence with uncertainty’ emphasising family carers’ views of the relational and interpersonal elements in support, beyond transmission of information, contributing to aiding the profoundly disabled person in decision-making. Question three of the analysis ‘How do carer’s understandings of supporting persons, living with PIMD, in decision making develop?’ comes to play here. The theme ‘Sensing a union’ denotes the humanistic, intensive and eclectic resources and strategies required in supporting persons, living with PIMD, which family carers strove to establish.

In ‘Sensing a union’ family carers describe a disposition of ‘knowing’ the person and their ways of expressing as Mrs. Y demonstrates

‘oh she knows her own mind alright, for example if she is unhappy about something she pushes her body back into her chair and raises herself slightly, it’s her way of telling us’

Mrs. Y

‘Sensing a union’ describes experiences of ‘working intimately’ and feelings of ‘closeness’ within the dyad, Mr. G words aim to demonstrate

‘I was chatting to him, asking what it is, I can’t exactly describe what the response was but it was a feeling, a feeling everything was alright’ Mr. G

The intuitive and personal nature to ‘Sensing a Union’ identified by family carers through experiencing reassurance from their sons and daughters displayed in the physical, social and emotional interactions described within two subthemes ‘Personalising care and support’ and ‘Connecting’.

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4.4.1 ‘Personalising care and support’

‘Personalising care and support’ encapsulates family cares actions of establishing what is important to their sons and daughters and align their preferences with available resources. Motivation for ‘personalising care and support’ arises out of the need for support; need to discern preferences and to aid improvements in living. The following vignette inspired by a participant of the study reflects the physical, emotional and social response of family carers in ‘Personalising care and support’.

<table>
<thead>
<tr>
<th>Vignette 4-1 ‘Personalising care and support’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very much his own man and has his own ways, but needs someone here all the time. You see him there now, banging his head, if I only knew why, its heart breaking to watch. Now, now....take it easy little man.......this is what the worst is for him...........the banging...........it’s hard to watch isn’t it (Family carer fixes the arrangement of cushions on the ground and re-arranges the back of the chair): ‘now all settled, just the way you like it’. That’s his space now, and don’t anyone go near it (small laugh)... the others (siblings) learnt the hard way, when they were younger they’d fight back with him, he always won. It really isolates him from the world. Sometimes I think he is lonely, but then he seems happy in his own world, it is hard to know. They say, (the doctors, psychiatrist, psychologist and nurse at centre) that his self-injury and aggression like the way he constantly punches and bites his hand there is ‘pathological’ related to his condition; ‘XX syndrome’ it’s complex. I don’t know. He will make it his business to roll near you and loves a back rub: he will sit beside me on the couch for an hour or so, more often kicks me off after an hour. I often wonder if the biting is pain, or does he need something. Doctors put it now to the syndrome, I don’t know, it was worse a few years ago, as he is aging or we’re managing it better I don’t know.</td>
</tr>
</tbody>
</table>

In ‘personalising care and support’ family carers described experiences of ‘working intimately’ with their sons and daughters that brought about feelings of ‘closeness’ within the dyad acquiring understanding of the others ‘uniqueness’. The data identified support that requires a level of intimacy, empathy and commitment that is not easily sustainable, but necessary for people, living with PIMD that family carers perceive is a core dimension when supporting their sons and daughters, living with PIMD, in decision-making (Appendix 12-Memo 3 ‘Developing intimacy’).
The broad array of support and in-depth nature of ‘Personalising care and support’ impacts family carers’ feelings related to identity. Altering and forming new identifies emerged strongly from the data, and the roles of carer, advocate, specialist and non-specialist roles contributed to developing the role of supporter. A taxonomy of common interventions undertaken by family carers summarised in the following table underpins this identity in multiple roles:

Table 4-1 Taxonomy of Interventions

<table>
<thead>
<tr>
<th>Range of Interventions</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interventions with a specific learning focus</td>
<td>‘Special School’ (none of the children/adult dependents in this study attended mainstream school) Post Primary</td>
</tr>
<tr>
<td>Interventions to enhance wellbeing through managing symptoms</td>
<td>Hospital admissions and outpatient appointments</td>
</tr>
<tr>
<td></td>
<td>Functional Assessments</td>
</tr>
<tr>
<td></td>
<td>Specific assessments (all family carers alluding to)</td>
</tr>
<tr>
<td></td>
<td>• Physiological: Fundamental</td>
</tr>
<tr>
<td></td>
<td>o Help with washing, dressing, eating, using the toilet, continence care</td>
</tr>
<tr>
<td></td>
<td>o Help with walking, lifting, hoisting</td>
</tr>
<tr>
<td></td>
<td>• Physiological: Complex</td>
</tr>
<tr>
<td></td>
<td>o Nutritional support,</td>
</tr>
<tr>
<td></td>
<td>o Sleep, positioning and postural care</td>
</tr>
<tr>
<td></td>
<td>• Personal safety</td>
</tr>
<tr>
<td></td>
<td>• Co-existing conditions (sensory, physical and psycho-social)</td>
</tr>
<tr>
<td></td>
<td>Prioritising care; urgency, needs and desires</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Alternative and assistive communication programmes</td>
</tr>
<tr>
<td></td>
<td>Being strong, putting own needs second</td>
</tr>
<tr>
<td></td>
<td>Explicitly acknowledge, elaborate, legitimise, and contextualise (sons and daughters) feelings and perspective to professional supporters</td>
</tr>
<tr>
<td>Household tasks</td>
<td>Shopping, cooking, cleaning, driving to activities</td>
</tr>
<tr>
<td>Technical Interventions</td>
<td>Medication administration</td>
</tr>
<tr>
<td></td>
<td>Enteral tube feeding</td>
</tr>
<tr>
<td></td>
<td>Seizure management</td>
</tr>
<tr>
<td></td>
<td>Safety, wheelchairs, transport</td>
</tr>
<tr>
<td>Interventions to promote child’s/adult dependents self-determination</td>
<td>Accepting and valuing the innate qualities and attributes of persons, living with PIMD</td>
</tr>
<tr>
<td></td>
<td>Identifying individual needs and promoting opportunities</td>
</tr>
<tr>
<td></td>
<td>Identifying and respecting choice and preference</td>
</tr>
<tr>
<td>Activism</td>
<td>Formal roles in parental or carers’ groups</td>
</tr>
<tr>
<td></td>
<td>Political campaigning</td>
</tr>
<tr>
<td></td>
<td>Establishment of support groups</td>
</tr>
<tr>
<td>Interventions supporting Advocacy; monetary and legal provisions</td>
<td>Seeking and co-ordinating the contribution of professional support</td>
</tr>
<tr>
<td></td>
<td>Financial oversee</td>
</tr>
<tr>
<td></td>
<td>Power of Attorney</td>
</tr>
<tr>
<td></td>
<td>Living accommodation</td>
</tr>
</tbody>
</table>
Identifying a taxonomy of interventions elucidates the nature of the role and function of family carers supporting persons, living with PIMD; implying required decision-making support is thus far reaching and wide ranging.

Evident from and within the data was family carers’ development of knowledge and roles in a range of specialisms for example; fitting orthodontic footwear, wound management of PEG sites, applying sleep equipment to ensure alignment at nighttime are some examples that family carers described developing skills to ensure comfort and life supporting practices. Developing competence and mastering these skills, described by some family carers as evolving in nature, is essential in ‘personalising care and support’ for example this family carer describes responding to her daughter following a seizure:

‘I don’t panic as much as I did initially. Now I know to have the buccal meds first and then go to her but she only gets that after 5 minutes, I keep it handy (the medication) and usually she overs them in 2-3 minutes, she usually sleeps for a few hours after or just wants to be on her own’ Mrs. X

‘Just wants to be on her own’ Mrs. X demonstrates as many other family carers did how through knowing her daughters habits and preferences she can support her to make that choice by respecting her desire for sleep or to be alone, an example of supporting decision-making in-action.

All family carers of this study spoke of their sons and daughters with love, compassion and demonstrated a wealth of information and knowledge in relation to the personalities and abilities. Nevertheless, the extent to understanding their sons and daughters wishes and preferences raised concerns. An underlying concern that all family cares expressed, in different ways, was the extent to their sons and daughters decision-making capacity noting ‘level of understanding’ as a major concern. Mrs. L words are clear in this regard

‘With the level of brain damage done I don’t think she will ever communicate well with us and I wonder at times what she is thinking.’ Mrs. L
Tensions in relation to decision-making capacity were experienced by most family carers, for example Mrs D explains over inflating the efforts of the person, living with PIMD

‘There is nothing worse when they say she did this and that, this brilliant piece of artwork: I mean really, your telling me she did this?’ Mrs. D

In conceptualising ‘personalising care and support’ I recall the writing of James Hogg’s in addressing a pertinent aspect of support services for persons, living with PIMD, that is addressing fundamental human rights

‘The view that children with profound disability do not possess personhood, on the grounds that they lack the capacity to reason, of consciousness of self, and of self-determination, has recently still had to be challenged’ (Hoggs 1999)

Challenges in ‘personalising care and support’ were prevalent. All participants described communication with their sons and daughters as a complex process hindering decision-making. The data indicates that essential for ‘personalising care and support’ to occur sensitivity to signals and gestures must occur. Many carers described observation as key in ‘personalising care and support’ illustrated by Mrs L

‘I find the key is observation, if you don’t catch it early it could so easily develop into a full blown chest infection and then you’re heading for trouble’ Mrs L

‘Personalising care and support’ as a subtheme alludes to the personal input of the family carer in addition to the personal outcome for the disabled person. In that regard, ‘having others believe their assertions’ was important for all family carers, as evidenced in the words of Mrs. W when talking on behalf of her daughter to a healthcare professional:

‘He looked at me like I had three heads when I said she loves all the things she does, I think he thought I was off the wall’ Mrs. W
To summarise this subtheme ‘personalising care and support’, fundamental to the profoundly disabled persons existence, family carers develop multiple and ambiguous roles in responding to the disabled person. This requires ‘knowing the person’ through intensive and extensive roles, requiring resources and creative strategies discerning the wishes and preferences of the disabled person. This is with family carers overriding concern as to the level of understanding that the disabled person possesses. The next subtheme ‘Connecting’ is now discussed.

4.4.2 ‘Connecting’

In this study family carers described intimate and personal ways of knowing another moving beyond functional aspects of support. All family carers believed that in supporting decision-making ‘connecting’ with the profoundly disabled individual must occur. ‘Connecting’ illustrates the activity of bonding and being concerned, underpinning the nature of the relationship. The ‘tacitness’ to which the experience lends itself made articulating the experience difficult, requiring some moments for reflection. The data indicates how ‘Connecting’ is established through meaningful interactions. Connecting aids family carers to establish their sons and daughters will and preferences most often through normative actions. Observations in conjunction with the family carers’ words aided ‘Connecting’ to emerge.

Memo; ‘what was thought of as unremarkable’

During an interview, an interruption occurred in which the family carer stated ‘back in a sec’. Her immediate exist from the conversation was unexpected. I initially haven’t heard anything; it was only when I noticed the family carer moving off her seat that I heard a slight verbal expression. I can’t say I recognised what the expression was, or gave it any meaning. Observing the interaction between carer and daughter I recall the pace of the interaction, the sensitivity in the interaction, and the attention within the incident. It appeared mutual, a two-way thing; bi-directional.
Mum initially iterates some words and proceeds to change the DVD and then asks would you like some Vaseline on your lips? They have strong eye contact at this point of the interaction, and I don’t know if a few seconds have passed or not, but I see her place the Vaseline on the lips, stimulating both to smile, I smiled, we all smiled; three smiles, ‘now that’s better’ mum states as she places the Vaseline back on the table, and says I’m just here in the sitting room, turns and returns to our conversation. Mutual pleasure was observed; a vulnerable and open-hearted engagement within the moment. I feel a sense of comforting has just occurred.

Memo 4-1 ‘What was thought of as unremarkable?’

This memo represents the subtle and discrete understandings that family carers acquire through their daily interactions with their sons and daughters. Meaningful interactions reflects the nature of the relationship between the dyad. The data indicated how the relationships were intimate, long-term, requiring high levels of interaction. Mostly, family carers elicited the social elements formed through repeated successful social interactions underpinning ‘connecting.’

All family carers believed that a strong connection was required in order to support profoundly disabled people in decision-making. Qualities found in the data facilitating ‘connecting’ were being present, responding, creativity, flexibility and humour in establishing and maintaining support. These qualities serve to enhance familiarity and trust in the relationship. Presence was important for all family carers illustrated in these words:

‘It was about 2am, and I think the nurses wished I’d go away; but a couple of times her eyes opened and she needed to know someone was there with her; they can’t stay there all night minding her, they only look at the technology; I couldn’t leave her there all vulnerable’

Mrs. K

Mrs W. describes knowing ‘the little ways’ as a mechanism in ‘connecting’

‘When you know her little ways, she indicates her preference generally through facial expression, and my tone of voice, sometimes I think it might go over her head, but if you keep it simple she does get it, she will express a preference in ways, although not all people would relate to this’

Mrs. W
Analysis of the data found that family carers believed that not everyone connects with their sons and daughters. Factors described by family carers were too busy, ignorance, dismissive of profoundly disabled people, and having no personal experience, represented by Ms R’s words with her experience of a hospital admission:

‘with someone like (sons name) well; they are not very understanding. The doctors and nurses did manage to find out what was wrong, but overall, it was such a negative experience for us. I mean, someone had to be there all the time, Jesus you couldn’t leave him, I mean they were very good and all, busy, but it’s just his ways, and of course they don’t really have the time for someone like (sons name) do they’

Ms. R

The critical aspect within this subtheme ‘Connecting’ relates to the cumulative and embedded ‘ways of knowing’ that informs family carers’ knowledge and insights of another, and in particular noting the disabled persons ‘expressions’ and ‘ways of expression’. The overriding experiences that family carers contribute to this subtheme was through connecting empathy is established authenticating their sons and daughters uniqueness, in the words of Mrs K representative of many family carers’ sentiments:

‘If they only knew her like we do, they’d see the person she is’

Mrs. K

To summarise this subtheme ‘connecting’ in supporting profoundly disabled persons in decision-making demonstrates empathy to their experiences. Family carers’ value ‘connecting’ which authenticates their experiences in asserting the wishes needs and preferences of their disabled son or daughter.

4.5 Sensing a Union Conclusion

In conclusion, the theme ‘Sensing a Union’ illuminates family carers’ feelings and mechanisms in developing ‘ways of knowing’ in establishing the uniqueness and understanding of their disabled sons and daughters through physical, social and emotional aspects of support.

The second theme of the theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ is ‘Framing Representation’ now described.


4.6 Framing Representation

‘Framing Representation’ the second theme in ‘Interactional Guesstimating: Growing confidence with uncertainty’ represents family carers actions in establishing and postulating their disabled sons and daughters perspective and signification. The premise of ‘Framing Representation’ is that family carers assertions in representing or postulating their sons and daughters perspective and signification is ‘other-oriented’ aiming to support and promote quality of life, opportunities and circumstances for people, living with PIMD.

The sense of responsibility within this theme was palpable, with the family carer describing decision-making support required within an integrated approach in the totality of circumstances (Appendix 12-Memo 4 Letter to Matthew). Examples provided demonstrate the practical and personalised nature of such support to meet the ‘normal social expectations’ such as attending school, playing with friends and filling leisure time. Time, experience, and familiarity help in establishing ‘Framing Representation’ however, the severity of the communication challenges makes the endeavour complex and complicated.

Family carers in this study espoused a process of supporting decision-making similar to the UN CRPD (2006) in which those that assist a disabled person

‘may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realise that a person with significant disabilities is also a person with a history, interest and aims in life’  

(UN 2006 pp.X)

Two main subthemes ‘Facilitating participation’ and ‘Validating choices’ contribute to understanding ‘Framing Representation’ herein detailed.
4.6.1 Facilitating participation

‘Facilitating Participation’ espouses family carers ethic of the sense of responsibility for managing and organising the support required for their sons and daughters to engage in normal everyday activities, and espousing the UN CRPD Article 3 General Principle (c) ‘Full and effective participation and inclusion in society’.

In this study ‘Facilitating participation’ in ‘Framing Representation’ reflects family carers’ actions of ‘enabling’ their sons and daughters to engage in the milieu of life inclusive of decision-making. This subtheme ‘Facilitating participation’ aims to demonstrate family carers’ role in helping their sons and daughters to interact outside of the home noting the wider social ecological factors. ‘Facilitating participation’ as a sub theme in ‘Framing Representation’ reflects family carers experiences of intervening as a mechanism that family carers deliver on moral and welfare grounds (Appendix 12-memo 4 Letter to Matthew), a feature of ‘Facilitating Participation’ was family carers need to seek and at times battle for services. This had personal consequences for family carers.

Firstly, most family carers reflected practical realities required in ‘Framing Participation’ in terms of their physical workload coded as ‘constant’ and the ‘24/7’ nature of support reflected in the busyness experienced by the family carers. Nearly all family carers could relate to this busyness noting that there is always something to be done’, ‘around the clock’

‘It’s so busy; sometimes exhausting’ Mrs. N

The ‘busyness of the job’ experienced by family carers relates to many appointments vividly expressed by this family carer

‘Over the years you see so many doctors, therapists, teachers and each time I have go over it all’ Mrs. Y

In this study, ‘Facilitating Participation’ is motivated by family carers’ ability to envisage their sons and daughters personal development. Mrs. I’s words represent this sentiment
‘There’s so much to be doing; but you know; every little achievement it rallies you on; it lets you see so much more potential’

Mrs. I

A strategy engaged by family carers to ensure that resources are available to their sons and daughters is to seek services. The sense of ‘give them what they want’ featured strongly here, in Mr. C’s words

‘I am passionate about getting her out there and giving her everything she wants and deserves’

Mr. C

The data found that no one system is designed to solely meet the complex needs of families and profoundly disabled persons yet support services can play a vital role in family carer’s ability to support another. Challenges in this regard convey the experiences relayed by family carers as the social and political dimensions required in supporting persons, living with PIMD, in decision making.

This subtheme benefitted in the analyses from drawing on Bronfenbrenner’s (2005) ecological systems framework. Within Bronfenbrenner’s ecological framework, the macrosystem refers to the overarching institutional patterns of the culture or subculture. In this study, most relevant to the macrosystem is the intersection between disadvantage and discrimination and profoundly disabled persons in the RoI across the fields of health, education, social services and cultural, social and economic sectors. Nearly all family carers experienced frustration, bureaucratic approaches and disadvantage in this intersection. At a macro level many family carers describe poor understanding of their situation from a government perspective, Mrs. S’s words signify this sentiment,

‘Not too sure, they really understand, or maybe it is just the state of the country now: you may pull on their heartstrings, but the purse strings need loosening’

Mrs. S

With much re-configuration of services concerns were raised by some family carers and in particular the authentic nature of service consultation, reflected in the following words,
‘I am not sure that the service providers really want the input of the parents in formulating policy’ Mrs X

Family carers also raised the charitable nature of support, in part related to perceived expectation of parental involvement reflective of long-standing practices such as fundraising and providing ‘voluntary donations’,

‘Do all organisations see the parents more suited to fund raising events or is this attitude only prevalent with some of the care providers’ Mrs. D

Some family carers engaged actively in fundraising and awareness practices, year on, believing this was necessary for service delivery,

‘I’ve been doing the church gate collection each year for the past 26 years, this helps services get the little extras they need, I mean they barely get enough from the government to run things’ Mrs. M

The mesosystem, comprise of the interrelations among the major settings a person frequents at a particular point in his or her life (Bronfenbrenner 2005). Of importance for this study are the settings in which the family carer and the family carer interacts with, mostly in seeking services for their sons and daughters. When families are participating in two or more systems simultaneously, these systems are often distinct in their philosophy, focus, and legal requirements.

At a meso level regard for local services was evident in the data as these family carers state

‘I know you hear so much of the bad cases, but to be honest I find the local hospital great, they are very accommodating and the disability services are great, they always listen to me and I’ve little to complain in that regard’ Ms. F

Most family carers were reliant on significant others in the system to share information. This is represented in Mrs. M words,

‘It’s obvious; you trust them with your life as such. For daughter cannot speak or tell me herself; I depend on the nurses and care staff to tell me everything she does during the day; otherwise I have no way of knowing’ Mrs. M
Where significant others (staff in school, disability services and health services) was perceived as being productive, family carers’ confidence and assurance in the service was high, Mr. T exemplifies.

‘They’re great, and I’m be lost without them for the respite: but it can get complicated at times with so many changes in staff, and grades of staff you don’t know who you have half the time, that kind of worries me’ Mr. T

In addition, some family carers while acknowledging the good work of services and staff in these services difficulties with procedures and policies were experienced in which family carers felt made bureaucratic sense more so than support. For example in relation to respite, this family carer was upset when staff refused to administer an antibiotic:

‘This blows me away as it absolutely disregards my role as mother and carer. I can understand that Respite are following guidelines from the Nursing Board or suchlike committees, but they are just covering their own backs and expecting us parents to waste more precious time getting paper work signed up to comply with their system’ Mrs. B

All family carers experienced segregation in terms of school facilities as Mrs. H demonstrates understanding of these experiences,

‘We so wanted her to go to school locally and fought so hard in the beginning. We wanted it so that people would see her, and get to know her, whereas they don’t know her now because she didn’t go to school here. She travels to ‘name of school’ 17 miles from here, and locally people don’t know her, they know of her, that would be my biggest regret for her’ Mrs. H

In this study, no person, living with a PIMD, whose family carer envisaged friends and opportunities for, went to a local primary or secondary school.

Within the busyness, and at the micro level ‘Facilitating Participation’ reflects family carers experiences of ‘Getting a balance’ and ‘the need for protection’ illustrating tensions between paternalism and autonomy, when supporting their sons and daughters in the milieu of life, in Mr. T’s words,
‘You have to get a balance; the reality for me is that he (son) is vulnerable and needs protection, there are a lot of weirdo’s out there, and plenty of people that ‘can take the mickey’ out of the likes of sons name, I mean he can’t defend himself against the likes of those now can he’ Mr. T

These tensions have been largely discussed theoretically reflecting debates in relation to paternalism, ‘over-protection’ and autonomy in general rather than empirically researched.

Feeling responsible for oversight and management of their sons and daughters’ wellbeing, safeguarding issues raises concerns for family carers when ‘facilitating participation’. Mrs. N. provides testament to this tension and rationale for heightened concerns, in her words

‘even the respite now; it’s great to get a break, but you’d worry about her there, the staff they change so much and they don’t know her that well, know her ways, in fact I’d say some of them don’t know the real her at all’ Mrs. N

Family carers described tensions between paternalism and autonomy occurring in the simple everyday interactions. For example, Mrs. X reported challenges with administering medication and the need for utilising a paternalistic practice of ‘nudging’ to encourage her son to take his medication

‘You have to physically sit with the syringe and keep him as relaxed as possible, in that way he’ll swallow it properly, so I put on a DVD to distract him some way, otherwise it could end up all over his face’ Mrs. X

Being present, comfort and assent all formed part of the consenting process enabling Mrs. X to establish the context of agreement. ‘Nudging’ is representative of family carers’ actions of activating and at times coaxing or gently encouraging their sons and daughters to do something. ‘Nudging’ aims to encourage their sons and daughters to do certain activities and fosters choice making rather than mere compliance. ‘Nudging’ reflects the elements of encouraging that family carers brought to the support role
‘You usually have to get down on the ground with her and touch her on the cheek or just her shoulder to get her to shuffle along, nudge her really, otherwise she would be inclined to sit there all day or wait to be lifted’ Mrs. K

‘Nudging’ reflects family carers’ activities of facilitating opportunities represented by the words of Mrs Y

‘Left to her own devices she would never veer towards swimming. I remember in the beginning I had to persist with the strong smell of chlorine and the heat in the changing room she wasn’t keen on but she loved the water so we had to really encourage her getting ready but once she was in you couldn’t get her out of the water’ Mrs Y

Mrs. S described nudging in ‘providing opportunity for her son to engage with the world around him’ yet ensuring some options were not accessible

‘it may be obvious but you can see from the floor the layout of the room is to have his bits freely available for him to choose, and the top shelves then that’s where the I keep the bits that aren’t to be touched’ Mrs. S

‘Facilitating participation’ aims to address the challenges experienced by family carers in discerning the context of autonomy for people, living with PIMD, from the macro, meso and micro perspective recognising the fluctuating, bespoke and subtle ways in which disabled persons are involved in decision-making beyond basic tests of capacity and formal consent procedures.

The next sub theme in ‘Framing Representation’, validating choices, is now discussed.

4.6.2 Validating choices

‘Validating choices’ in ‘Framing Representation’ represents family carers’ actions of interpreting their sons and daughters point of view and drawing conclusions with all family carers alluding to this activity. However, ‘validating choices’ is not always easy.
Resources in ‘Validating choices’ were ‘Considering son/daughters ways’ and ‘Second guessing’. In this study, ‘Considering son/daughter ways’ refers to the actions of seeing and taking into account the likes/dislikes in addition to interest needs and wants. There were many responses from family carers within this group under the following headings; ‘For’ sure’ and ‘Think so’ now described. In ‘Considering son/daughter ways’ many family carers described confidence, certainty and firmness in articulating their sons and daughter’s interests, needs, wants and wishes under the group ‘For Sure’

‘She’s definitely interested in the opposite sex; my god you’d be mortified sometimes when you see her oozing over a fella’ Mrs. K

‘She loves the wind in her face, that’s why she likes the horse riding so much. I don’t think it’s the horses but she likes the whole experience of being on the horse if that, makes sense’ Mrs. Y

‘He loves flicking through catalogues; not too sure if it’s all the colours or what; but try to take it off him when he’s reading it and he’ll get rightly annoyed’ Mr. J

‘I see in him he’s a people watcher and how he’ll manage a situation which amazes me don’t get me wrong not on a very sophisticated level but he does manage to get what he wants’ Ms. F

Within the ‘Think so’ group more caution and less confidence by family carers in articulating their sons and daughter’s interests, needs, wants and wishes was expressed. This ‘think so’ group left family carers feeling questioning their understanding

‘It’s difficult to know if he understands exactly where he is going. Like Tesco’s or if it’s something fun like bowling, you just have to keep doing it; but he does know something is happening with all the fuss in changing and getting ready, and when your there it is obvious he’s either enjoying it or not’ Ms. A

‘By and large she is a very positive person and I think a lot of the time she is happy and likes to have a range of activities; she does like being on the go; but not overdoing it’ Mrs. N
There are times in the ‘think so’ grouping, that family carers experienced difficulty in ‘pin pointing’ factors to explain their sons and daughters considerations. Issues associated with the ‘think so’ dimension of ‘Considering son/daughter ways’ are rarely solved with shortcuts or checklists, and may contain an erratic nature.

‘It’s not always easy to know. For example, the other day after lunch I thought she was tired, and some days she would lie down for an hour. I brought her down to her room and sure, the minute we got near the door she was having none of it, head bopping, meaning ‘get me out of here’. So back to the sitting room, and she was tired cos she dozed off in a few minutes, but just that day she wanted to be in the sitting room’

Mrs. W

The expertise, skill and know-how of family carers in understanding, appreciating and assigning meaning to these interactions moves support beyond rationale decision making formulas to a more comprehensive and substantive process. Solutions to dilemmas aim to orient the situation to meet the needs of persons, living with PIMD. Sometimes however, the data indicates that family carers do not always ‘get it right’. Mrs X provides testament to this opinion

‘You try so hard to get it right for him, but I don’t know, over the years trying to help him get a decent sleep has been impossible, he’s still up half the night. His sleep is all over the shop, and that contributes then to the seizures, the lack of sleep. It impacts majorly on his life’

Mrs. X

The continuous process of ‘trying to help’ that Mrs. X details reflects an iterative process that nearly all family carers related too. Clear from family carers and gleaned from the data was the belief of all family carers in the communication abilities of the person, living with PIMD, in this iterative process to receive and deliver messages, albeit minimal and at times indirect. Another resource that family carers described in ‘Validating choices’ is ‘Second Guessing’ (Appendix 12-Memo 5 ‘Second Guessing’).
‘Second guessing’ is perhaps best represented by the words of Mr. J when during our conversation he spoke of challenges with understanding his sons needs and wants, Mr J spoke of choice in this situation as

‘Sometimes I think I know his choices; others I have to work it out. There is the obvious ordinary ones’ like T.V. programmes, he has his favourites; he loves jazz music and put him in the car he would stay there all day. But, well the big ones it’s hard to know, would he choose one subject over the other, one place to live over another now that would be second guessing all the way. I see his choice when he tells me he is happy with something; I suppose, parents would second guess their sons or daughters choices and decisions, more so the important decisions and that I have to live with’

Mr. J

‘Second guessing’ is a feature of supporting persons, living with PIMD, in decision making that nearly all family carers could resonate with. In ‘Second Guessing’ family carers’ experienced intrinsic debates and adjudicating at times following ‘considering sons/daughters ways’. The following provides testament to these experiences,

‘You ask yourself over and over is this really the right decision; I mean would he really choose to go to the respite house, I mean he likes it when he’s there, but would he really choose to go there: not too sure: you have to see the bigger picture, and I guess we all need the break’ Mr. Q

Other carers expressed assurances when experiencing ‘Second Guessing’

‘I know it looks odd, but I have to weigh up being comfortable in the buggy and the stares in public. She can curl up more easily in it, and she does not care about the stares. To be honest it’s easier for me to get in and out of the boot of the car, but you do get the looks and people must be wondering, what’s she doing in it’

Mrs Y

Other considerations featured as part of family carer’s experiences in ‘Second guessing’ for example, Mrs. I describes how her older daughter often provided ‘food for thought’ in her words,
‘my eldest always gives out to me, and part of me knows she’s right, I mean I buy the elastics pants as they are easier to put on. I imagine more comfortable, but definitely easier to put on and off but you have to think of the PEG button, and when she’s sitting for so long, I mean having a metal button from the jeans pressing against her tummy’
Mrs. I

Family carers demonstrated that ‘Second Guessing’ gives rise to misgivings as Ms. R states,

‘You hear a lot of talk in services like ‘he has to make his own choices’ ‘be empowered’ and I know they have brilliant plans in the centre. It’s great, but really, he isn’t going to tell them one way or the other whether he really agrees with them or not, for the most part he’s happy to go along with things’
Ms. R

In overcoming misgivings, nearly all family carers placed value in the ‘pros and cons’ approach to support represented by Mrs. E,

‘Of course, she’ll never understand the need to make plans for the future, so we have had to make that plan to make sure that she’ll be cared for if we’re not in a position to anymore. We looked at the pros and cons of both a nursing home and a disability provider and we both felt that the disability provider would be the one to go for, it would offer her more, more social and peer interaction, so we went with that in the end’
Mrs. E

A strategy family carers drew on to support was weighting up the ‘risks and benefits’. For example, this family carer indicates his approach to supporting his sons’ preference for attending a sports activity and the risk to his son’s health, in Mr. J’s words,

‘He goes to all the local GAA, his sister plays and we try to bring him to all the training as well. It’s his chest at times you’d be watching, but wrap him up, and the bit of Vaseline under the nose around the mouth, missus would kill me if he wasn’t wrapped up properly especially on the colder nights with his chest, but boy is it worth he, he loves watching the trainers and all the commotion’
Mr. J
A third strategy that family carers experienced was ‘advocating what feels right’ in supporting their sons and daughters in decision-making. The sense of ‘advocating what feels right’ relies on what may be referred to as gut intuition evident in family carers’ expressions. This family carer demonstrates,

‘I’ve gone over things so many times in my head, but at the end of the day, what’s most important to all of us is us, so we have to do what is right for all of us’                     Mrs P

Ms V. articulates this sense of ‘advocating what feels right’ in supporting her daughter with decision-making and nutritional interventions

‘Sometimes I have to pull myself back and think, that’s what you think, but is this really what she wants, so many appointments, and stuck to a machine, I guess I just have to go with what feels right’                     Ms. V

The sense of ‘the right thing’ is very much a feature of family carers actions in ‘Validating choices’ in a system in which family carers find themselves, in which they have responded by applying vigorously and compassionately to understanding the choice making activities their sons and daughters espouse.

4.7  ‘Framing Representation’ Conclusion

Macro and meso level challenges, of which state and specialised disability services have contributed to supporting families, influence the opportunities and benefits for all in society and persons, living with PIMD, are no exception. In conclusion, through intense physical and emotional engagement with another, as the primary carer with responsibility for managing and organising support, it becomes incumbent upon family carers too proffer or postulate objective and subjective opinion and speculative comment in relation to the needs, wants, wishes, preferences and opinions of the disabled individual.
This moves support in decision-making beyond a reasoning approach in that family carer’s make assertions based on ‘considering son/daughters ways’ in addition to utilising principles of think so, second guessing and risk and benefit approaches. This serves in maintaining the status of persons, living with PIMD, within family and society. This brings us to the next major category ‘Steering affairs’, now discussed.

### 4.8 ‘Steering Affairs’

‘Steering Affairs’, the third substantive theme of ‘Interactional Guesstimating: Growing confidence with uncertainty’ illuminates family carers understanding of the contingent nature in guiding actions aiming to give effect to their sons and daughters wishes, will and preferences. The central tenet of ‘Steering Affairs’ aims to uphold the character and respect for the disabled individual in a manner that recognises the disabled individual’s wishes in addition to recognising restrictions within choice making.

‘Steering affairs’ recognises relational notions of autonomy in which family carers must present understanding of person, living with PIMD, in relation to the family, friends, and community characterising the individual within these groupings. Family carers experienced a functional approach to decision-making capacity rather than static notions of capacity ‘as a yes or no fixture’. ‘Steering affairs’, therefore, has impact, in deep and lasting ways, in how persons, living with PIMD, relates to and is considered by one's family and community.

For family carers, this category builds upon the source of inspiration that arises from self (family carer), their sons and daughters, their family and extended family, other families in similar situations. Therefore, ‘Steering affairs’, reflects the evolving and changing nature of family carers’ experiences. Two subtheme ‘Guiding activities’ and ‘Elucidating priorities’ contribute to understanding the substantive category ‘Steering affairs’.

The first sub theme ‘Guiding activities’ shall now be outlined.
4.8.1 Guiding Activities

‘Guiding activities’ accentuates family carers’ acuity and acumen in sensitivity, communication and organisation skills in delivering support. ‘Guiding activities’ epitomises the action of ‘giving effect’ and ‘serving to accommodate’ the disabled individual, albeit challenging. ‘Guiding activities’ is achieved through the ‘taking up of action’ as directed and at times assumed by the disabled individual. This understanding of ‘Guiding activities’ contributed to theory development as an outcome of the following memo

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<th>Memo; ‘of service and accommodating’</th>
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<td>From listening to family carers and observing it is clear to see care and support as moving beyond the actions of ‘assistance’. Family carers address the normative actions of being present, acting from commitment, and coalescing with their sons and daughters to modify different tasks and activities allowing their sons and daughters to engage in their individual ways in decision-making. The organisation, the companionship, the constant observation and being present, organising the appointments, the outings and social life, attentiveness and attuned to the subtle changes, the sense of ‘it’s more than doing to’ materialises.</td>
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<td>The action of serving to accommodate the disabled individual, albeit challenging achieved through the ‘taking up of action’ as directed and at times assumed by the disabled individual emerges. The ‘taking up of action’ reflects Kittay’s (2005) contention that the ability of a being to give and receive care is a source of dignity for humans no less than the capacity for reason. This is further developed by Kittay (2013, 2014) who raises the question ‘if an ethic of care is to be a true ethic that guides us and helps us evaluate actions are good or morally desirable ones and steers us away from those that are harmful or gratuitously hurtful, and if we are to build institutions that promote the values inherent in a true ethic of care, then we need to sort out the normative sense of care—that is, those that are prescriptive, that tell us what we ought to do to act in a caring way’.</td>
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<td>Applied to the present study, I believe characteristics that family carers espouse to reflect their normative ethic of care, through their becoming and being are <strong>presence, commitment</strong>, and <strong>coalesce</strong> addressing livelihood, support and inequalities. These characteristics foster family carers ‘being’ in accentuating the voice and direction given to them.</td>
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Memo 4-2 ‘Moving beyond the act of assistance’
‘Guiding activities’ is conceptualised as a process in which family carers take direction from the disabled individual vis-à-vis establishing, managing and overseeing activities. I argue ‘Guiding activities’ is a response by family carers in supporting the life direction and self-determination of the person, living with PIMD. Resources that family carers conceived as facilitating ‘Guiding activities’ are ‘driving courses of action’ and ‘embracing leadership’. Mrs. Z’s words illuminate understanding of ‘Driving courses of action’ when she explains

‘I came from knowing nothing to having to know: making it my business to know. It’s part him and part me, he drives all this, that’s what makes it all happen’ Mrs Z

‘Guiding activities’ fosters independence as Mrs. K described how experience and ‘respecting the voice’ of her daughter facilitates her daughters’ role in choice making

‘She’ll tell you all right if she doesn’t want to be somewhere. Like in shopping centre, sometimes she gets withered with the place and will start moaning, and if I don’t react I get the eye, and it could end up screaming the place down, so you know it’ she’s telling you enough is enough now: time to go, then it’s off we go’ Mrs. K

A longitudinal perspective from Mrs. N reveals a compounded sense of responsibility and ‘overwhelming nature’ in ‘Guiding activities’ when she describes her experience

‘Over the past years I’ve seen big changes, and in some ways you can see maybe it’s getting better, but you know, I feel like saying enough is enough, how much more can you expect a 74 year old woman to carry’ Mrs. N

Family carers spoke of empathy as a feature in ‘Guiding activities’ represented in Ms. V’s words,

‘If we don’t know the answer straight away, we say ‘see it through her eyes’ and that helps in forming answers some times and knowing which direction to go’ Ms. V
There were many legal and ethical issues in the data that family carers experienced which were wide ranging and complex reflected in ‘Guiding activities’, and three relayed here. Number one, supporting a son after the death of his mother. Secondly, supporting financial independence for disabled person and thirdly, reflecting on the disabled individual’s health screening and the issue of consent.

In this experience Mr. T relayed how the sudden death of his wife, mother to his son, living with a PIMD, caused him to question his sons level of understanding and MR. T’s aim to provide emotional security in Mr. T’s words

‘I can’t say he was aware of her death, he certainly didn’t understand how, but he knows something is different, very different for him. The situation was hard. Wondering what he made of it all, I think as time passes by he feels it more, the loss, and the sense of being without her. I show him her picture every night going to bed, and bring it to his lips to let him kiss her goodnight, it’s a sad ritual but I feel he gets something from it, not sure what but he’s always kissed it goodnight’

Mr. T

The data found that issues of banking and financial independence for persons, living with PIMD, is contentious and marred with legalities. In this study, the responsibility of overseeing and managing financial activities was primarily the remit of family carers. The following family carer discussed her experience of ‘Guiding activities’ in supporting her daughters’ independence in financial arrangements, and her words illustrate the adverse effects of this approach and how difficulties arose noting subsequent troubles with obtaining social welfare contributions and personal frustrations

‘I am caught in a conundrum at the moment; we put a fund for name of daughter unfortunately in her name and now she is not allowed a disability allowance because they say she has her own means. I mean, it is laughable if it was not so serious. That’s the thing, spelling it out and certainly reducing it to explanation in terms of law is farcical at times: I mean she will never have her ‘own means’; I don’t bloody have my own means because I have to be here for her.....it’s situations like this they will never get’

Mrs. H
In the next example, Mrs. L reflects on her experience when discussing her daughters’ health, and in particular the possibility of a bone density scan. Mrs. L describes her experience in relation to her daughters’ bone health. Mrs L reflects on discussions with her GP in relation to the need and benefits of a DXA scan for her daughter. Mixed feelings of wanting ‘what is best’ and seeing how the test would aid her daughter yet Mrs. L displays concern in relation to her daughter enduring the procedure and the additional support required to manage the process of screening.

‘I was unsure of whether she’d be able for the scan but my GP said we should try. So my other daughter, got on to the unit and they were great, it took a bit of organising and explaining, and then making sure she would be safe like positioning her to make sure she didn’t roll over in the middle of it but it worked. Now at least we know she has osteoporosis so we are more aware of her diet and physio’ Mrs. L.

The data has evidence to show that such an array of situations arose in which family carers are required to draw on personal knowledge, in addition to policy, ethical and legal systems. The consequences and challenges in responding to the support needs of the many life situations that arise for persons, living with PIMD, is therefore a central tenet of the role of the family carer, carrying many emotional, physical and intellectual demands.

‘Embracing Leadership’ was a strategy identified by family carers in ‘Steering affairs’. The rationale for ‘Embracing leadership’ illustrated by the words of Mrs P

‘You have to take the lead at times, not because of her vulnerability it’s more about services are scarce and you end up organising your own, and then as the years pass you see how you have ploughed away on your own, we can’t wait for services to improve, we have to act now’ Mrs. P

By ‘Embracing Leadership’ family carers alluded to the process of grappling with understanding their situation, and their role in leading care and support, transforming this understanding to make good.
‘Embracing leadership’ is a process that aligns to time, identity and support ethic. In Mr. G’s words:

‘It may take some time, and a pathway you didn’t envisage nor wish for anyone, but you come to realise that you need to take on a leadership role or else very little will get done’

Mr. G

‘Embracing leadership’ resonated with all family carers and is motivated by family carers ‘Constantly learning’

‘You are constantly learning on the job, I mean I once thought he had no interest in sports, and then one day the TV was on and suddenly he was arching he’s neck to see what’s on, it was car racing, a grand prix or something, he loved it, I put it on now more often’

Ms. R

‘At times, you think you know, then other times it’s impossible to say this is her view, or that is, your constantly thinking what it is she wants and needs, and mulling over it all, this I believe builds her viewpoint, although it can take a long time’

Mrs. O

Dialogue, involvement and engagement form facets of the nature of ‘Embracing leadership’ illustrated by Mrs. K words

‘We worked with the staff in day services and they asked us to focus on her sensory needs. They pushed to work more on the subtle body language, I thought it was farfetched but responding to the subtle movements has made a big difference, she seems more responsive to us, or maybe we’re actually responding to her more now’

Mrs. K

Other family carers found talking to people who appreciated and understood supporting persons, living with PIMD, aided ‘‘Embracing leadership’ illustrated by Mrs. D

‘I found listening to other carers in the group helpful, it’s good to speak and know those listening actually understand where you are coming from, I feel I’ve been really empowered thought this process, and it’s funny because it’s been simply conversations’

Mrs. D

The next paragraph describes the next category in ‘Steering Affairs’, ‘Elucidating priorities’.
4.8.2 Elucidating Priorities

‘Elucidating priorities’ represents family carers experience when responding to ‘ways of knowing’ to support or resolve a present decision or develop future action(s). This sub theme ‘Elucidating priorities’ reflects family carers’ systemic thinking and actions in offering support. Family carers’ describe a core feature of ‘Elucidating priorities’ as balancing beneficial, participatory and protectionary tendencies required in support.

Family carers recognised how people with profound disabilities tend to have less choice availability in their lives when they reach adulthood in particular with regard to education, work and leisure opportunities. ‘Elucidating priorities’ reflects the resources and ideas that aid family carers in developing ‘realistic choices’ and personalised care and support to aid participation in these activities, Mr. G demonstrates the practical approach to supporting this agenda, in his words

‘We will always have to act as advocates and bankers (laughs)’

Mr. G

The ‘sense of doing the right thing’ experienced by Mrs. H was a frequent characteristic in ‘Elucidating Priorities’ with many family carers experiencing this sense. In this case, Mrs. H illustrates in suggesting the possibility of introducing an intrauterine device to aid menstrual care and pain relief

‘The potential complications with the coil, like back pain, he (GP) said how I am going to ask name of daughter, so he said no stick to the Ponstan. I just what to do the right thing by her’

Mrs H

Mrs H considering her GP’s words

‘with the coil we’d be guessing again like is it related to the coil, is it not the coil, he said no, that’s my advice to you, and I’d go by him, because he knows her so well, he said you’re heading for trouble making our guessing game more complicated’

Mrs H
Reducing complications is a core feature in ‘Elucidating priorities’, represented by Mrs. I words,

‘The tracheostomy was daunting initially but it makes life easier for her as before she was coughing and choking so much more she could barely catch her breath, but she is more relaxed and content, although there is a lot in getting it right with the humidifier and suctioning, and the cleaning of the stoma’

Mrs. I

As family carers gained experience in supporting their sons and daughters, they felt more confident and freedom in acknowledging limitations. ‘Mulling over’ represents family carers’ reflective activities in ‘Elucidating priorities’ encapsulating family carers’ actions of ‘going back and forth in one's mind to ponder on previous experiences, examine and evaluate them’. Mrs P words denotes ‘Mulling over’

‘Sometimes you have to think long and hard to really work through what’s best’

Mrs P

A nebulous action ‘Mulling over’ represents the mental activity in which nearly all family carers identified with. ‘We do it all the time’ Ms. R states, clarifying ‘we go forward through looking back’. ‘Mulling over’ entailed personal reflections in which some family carers’ elicited feelings of strength and confidence, as Mrs B exemplifies in her reflections after attending reading an article, in her words,

‘One of the documents I read last night was very much an eye opener; it was entitled “My heart is always where he is Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home”. It was refreshing to read it as we are all dealing with the same issues and concerns and I feel as a family we are not doing a bad job of it’

Mrs B

A familiar experience that many family carers alluded to was the act of grappling with decision-making support that often defies conventional approaches. For example, ‘standards of care’ can often misrepresent the issues at hand for disabled persons and their supporters. Mrs H exemplifies ‘Mulling over’ in the following scenario, in her words
she’s comes in from school screeching and my husband had her up on the commode thinking it was constipation, which was a problem but gone since her scoliosis was treated. I mean she absolutely …… screamed……. We took her off, put her lying down on the table; we knew something was wrong because every time we moved her she screamed. We rang ‘NAME OF Doc’. A GP that we didn’t know, arrived and he examined her and he thought ‘maybe her physio over did it with the stretching exercises’ looking back now uh… however then I said ok.

In this scenario, Mrs H ‘knowing’ that something ‘was wrong’ presents her ordering of priorities listing pain management, the need for a diagnosis, compassion, empathy and urgency for an immediate treatment plan. She continues,

So he sent us over to our local hospital we put her sitting into her chair, screamed all the way in the car took her out, did an x-ray and they admitted her for the screaming thinking it was appendix, and this is the big thing it’s ‘guessing’, because her dad’s appendix burst and her brothers did, so I thought it could be this, they discharged her the following day saying there was nothing wrong. We brought her home and every time I changed her the pain, we had her in bed giving her pain relief. On Monday morning, about 2 minutes past 9, the phone rang, the head radiographer saw two fractures and said could I bring her back, I said I am not putting her in... They said we were so lucky in Specialist Hospital that we did not compound the fractures with all the movements. Big learning curve for us’

Mrs. H questioned how her daughter must have suffered on the bus route home and at what time of the day the pain started. The bus driver and school staff had no answers to these questions. In essence, her daughter sustained a fracture to her femur with no understanding as to how this came to be. Mrs. H clarified in her conversational interview her long-term goals of appropriate manual handling, trusting her daughters’ communications and trusting her own intuition in ‘that something is wrong’ from ‘Mulling over’ suggest several different ways in which experience and context can affect decision-making support.
What became evident in the data was how family carers motivation moves beyond rational ethical arguments but the many practical, emotional, social aspects that are relevant to family carers and their sons and daughters. Recognising these aspects is important to family carers as Mrs. O exemplifies, in her words:

‘It’s more than figuring out what’s right or wrong, it’s capturing the whole, and trying to see it through her eyes so that she can have the best quality of life possible’ Mrs O

4.9 Steering Affairs Conclusion

In conclusion ‘Steering Affairs’, the third substantive category of ‘Interactional Guesstimating: Growing confidence with uncertainty’, illustrates family carers experience of the contingent nature in guiding actions aiming to give effect to their sons and daughters wishes, will and preferences. Crucially, ‘Steering affairs’ represents how experience and context affect decision making support beyond the rational and ethical debates.

4.10 The substantive theoretical explanation

Family carers came to understand their sons and daughters functioning and contributions as a dynamic and reciprocal engagement among intellectual ability, adaptive behaviour, health, participation, context, and individualised supports consistent with an ecological and multidimensional perspective related to that in Figure 2.2 postulated by Schalock et al. (2010). It is this premise that draws the three core themes ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering Affairs’ together to explicate the study's substantive theoretical explanation – ‘Interactional Guesstimating: Growing confidence with uncertainty’.

Drawing the three themes together were family carers attempts in articulating and rationalising their experiences and concerns of ‘getting it right’ when supporting persons, living with PIMD, in decision-making (Figure 4.1). In reflecting on these experiences and concerns the ‘process of intervening’ representing a series of overlapping stages of ‘Commitment’ ‘Engaging’ ‘Knowing and not knowing’ and ‘Questioning self’ transpired.
Through intervening family carers’ come to understand the authorising or forbidding assertions of the profoundly disabled individual to state their will and preferences, aligned to the UNCRPD notion of supporting decision-making. Intervening was a long process that had positive and negative impacts. On a positive note, the influence of the disabled person (happiness and fulfilment), the influence on the disabled person (growth and development) and its effect on the family in general (strength and family closeness) were motivators in the process of intervening. Negative aspects of intervening related to enduring nature, reduction in opportunities to work and frustration with ‘the system’ featuring strongly. These overlapping stages of ‘Commitment’ ‘Engaging’ ‘Knowing and not knowing’ and ‘Questioning self’ now outlined.

4.10.1 Stage One: Commitment

Perhaps the most important factor contributing to family carers’ narratives was the nature of their relationships with their sons and daughters, particularly with regard to how close they felt. Family carers are aware that some people grasp the depths of their experiences and some people do not, and family carers persist. This awareness arises from the first stage in the process of intervening ‘commitment’. Commitment refers to the continuing nature of supporter loyalty and dedication.

‘Commitment’ emulates principles similar to that of the social model of disability which emphasises person centred approaches of support through assistance (Kaye-Beall 2016). In providing commitment supporters acquire understanding from interactions. As identified in the three core themes, ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering Affairs’, commitment establishes ‘ways of knowing’ moving beyond the emphasis of activities and busyness moreover identify the values that are important to the person they support and delivering on them.
Family carers have awareness of the importance of their role as decision-making supporters, commitment is core to maintaining this relationship of support. Bronfenbrenner’s ecological systems theory (2005) contributed to framing family carers’ personal development from their experiences of committing to support their sons and daughters. Similar to Bronfenbrenner’s definition of development as ‘lasting change in the way in which a person perceives and deals with his environment’ (p. 3) family carers recognised in supporting their sons and daughters their lives changed. Perceptions of their ‘role’ was critical, ambiguous and multifaceted, the taxonomy of roles and interventions illuminates the extensive nature of family carers’ commitment to support over longer periods than normal parental trajectories.

This level of commitment was considered high, and by its very nature established on the human and personal level is intense and garnered over time. Family carers’ behaviours such as accommodation, adjustments, and willingness to sacrifice, for their son or daughter, helps to sustain a relationship ‘through thick and thin’ (Twigg and Atkin 1994; Hall et al. 2012; Giallo et al. 2015) symbolises commitment. Put another way, people who are more committed, to the supported, act differently towards the supported than people who are less committed. High levels of personal commitment in intervening exists in the micro system of support and reduces at the meso and macro levels.

4.10.2 Stage Two: Engaging

The second stage posited to influence the process of intervening is engaging. Engaging refers to family carers actively participating in support in making positive change. Families are one of the most significant institutions through which intellectually disabled people learn, interact and engage. Through engaging family carers come to understand their sons and daughters uniqueness and ways of expressions, and reject static notions (Voysey 1975) of profound disability.
Engaging required sensitive and responsive characteristics displaying an ability to be mindful of the other person’s experiences, thoughts, and feelings and seeks to meet their needs. Engaging strategies included giving time, performing intimate and personal care, in addition to daily management support, strategic planning, recruiting and overseeing resources, involving others and making long term plans. Like Belva, family carers in this study found engaging features required supporters’ sensitivity and creativity to meaningfully provide and explain information, support receptive communication skills in addition to helping an individual understand the consequences of making a decision with perhaps the use of assistive and augmentative communication devices in expressive communication skills (Belva et al. 2012).

Engaging emphasises family carers’ regard for their son/daughter, the reciprocal acknowledgement they (son or daughter) grant the family carer, and their affective certainty within the relationship. By engaging family carers described the co-production approach to understanding the supported person’s life history, unique communication forms likes and dislikes similar to other interpretivist views such as Maes, Mansell and Hostyn et al., (Maes 2010; Mansell 2010; Hostyn et al. 2011).

Moreover, engaging necessitated an iterative interplay demanding an extension of family carers and movement into another person's world to aid in seeing their sons or daughter’s viewpoints, understandings or values. Engaging gives rise to family carers’ assertions. Having justified beliefs family carers’ sense of ‘Getting it right’ was seen as important, and a high price is paid for not getting it right therefore engaging is an essential yet subjective experience of intervening. This group of family carers’ claims, similar to Twigg and Atkin, Hall et al., and Giallo et al., acknowledges the role of engaging to the enactment of relationship maintenance behaviours in caring relationships.

Two main conditions identified within the data were required in order for engaging to occur. They are 1) level of needs and 2) level of risk.
1) Level of needs: the high support needs of the disabled persons are primarily addressed within the home by supporters. Family carers engaging activities as per tale 4.1 Taxonomy of interventions requires multi and diverse roles from physical social, advocacy and legal dimensions. Engaging is most effective when supporter development, most often dictated by their sons and daughters conditions, requirements or demands, is achieved.

The sense of personal development related to supporting that family carers experienced draws on Bronfenbrenner’s ecological systems theory (2005). Their sons and daughters high support needs required family carers to uptake many roles and advocate for services and resources. Up taking this role required family carers to engage in learning new skills, learning new knowledge and applying this learning in their everyday interactions with the disabled person and other supporters.

Engaging is shaped by broader considerations such as meso and macro factors for example schools, after school supports and health and social services. Broader considerations such as legislation and policy impacts directly on family carers engaging to intervene in supporting decision-making similar to other disability theorist perspectives such as Barnes and Mercer, Goffman and Blaska (Blaska 1993; Goffman 2009; Barnes and Mercer 2010). Engaged carers are proactive because they believe what they do is significant to the disabled persons life. This correlates to Back and Kerzner (2010) contention of Supported decision-making status Due to a relationship with the person with a disability, the support person can interpret and carry out his or her will or intention, ‘consistent with the person’s identity’ and respecting ‘the individual’s dignity of risk’. Some decisions require more support and engagement than others, and relates to the second intervening condition level of risk now detailed.
2) Level of risk: Family carers’ process of intervening raises dilemmas of how to balance their sons and daughters autonomy with their safety and well-being, a notable feature of supporting decision making literature (Devi et al. 2011; Browning et al. 2014; Carney 2014; Bigby et al. 2017). Family carers discussed fear of harm, institutionalisation or abuse as types of risk. Engaging strategies included ‘weighting up the risks and benefits’ and acknowledging the consequences of decision making support. Family carers believed that engaging requires an ethic relating to quality and supporting their sons and daughters in ‘living a good life’ requiring the principles such as do good, minimise harm and treat people justly and respectfully.

Family carers felt that genuine authentic and trustful engaging was crucial to their ability to support similar to Back and Kerzner (2010) and Flynn and Arstein-Kerslake (2014) claims. Family carers espoused an ‘ethic’ of support from a humanistic perspective similar to Rogers (Rogers 1970) emphasising the positive potential of human beings through recognising the uniqueness of the individual and adopting personalised care and support approaches. Through engaging family carers increase the disabled person’s capacity for choice making.

Most family carers described the importance of having professional and personal support in the process of intervening. Primarily, this meant other people including friends, family members and professional’s aid in this process of supporting decision making. Challenges when engaging often arose for family carers when other supporters applied different philosophical perspectives such as economical (social welfare support) and procedurals (acquiring equipment) to support. For most family carers engaging in these circumstances was the most frustration part to intervening.
A sense of accomplishment, confidence builds, and a feeling of self-worth arise through engaging. Generally, disengagement was not an option, not while family carers can physically and mentally continue intervening to support. Family carers were consciously acute of historical positions of ‘assistance’ relieving a burden subjecting families to separation policies from mainstream society (Woodill and Velche 1995). Wanting to be engaged, not having other viable options, and fear of lower standard of living for their sons and daughters are representative of the need for engaging.

In experiencing the intense commitment and engaging strategies family carers’ transition to the next stage of the process where ‘Knowing and not knowing’ occurs.

4.10.3 Stage Three: ‘Knowing and not knowing’

This third stage in the process of intervening refers to the dilemmas and paradoxical nature supporters find themselves in making claims for another person. ‘Knowing and not knowing’ aims to illustrate the dilemma of asserting claims for and behalf of their son or daughter while simultaneously experiencing ambiguity and doubt in these assertions.

Family carers development as supporter espoused an ambiance of ‘embedded’ knowledge representing the accumulated ‘wisdom’ that emerges from the experience of supporting the disabled person over time. Through the lens of Bronfenbrenner’s ‘context of human development’ conceptualised as ‘nested levels’ the notion of family carers as expert rests on the development of schemata which emerges from familiarity with the daily events, rituals and patterns of interaction through interventions with the micro, meso and macro environs, attributing to family carers becoming experts in many domains. ‘Knowing’ refers to family carers’ assertions arising from their active and applied perspective of their sons and daughters views acquired through ‘knowing from practice’.
‘Knowing’ has two levels, the first is ‘full knowledge’ and the second is ‘partial knowledge’. Full knowledge lies in the ‘for sure’ category that family carers experienced and ‘partial knowing’ lies in the ‘think so’ category family carers experienced (Sensing a Union and Framing Representation). Supporting when ‘knowing’ family carers characterised interventions in terms of the respect for inherent dignity of the disabled person aligned to Article 3 of the UN CRPD (UN 2006).

‘Not knowing’ refers to family carers’ unawareness of the supported person’s perspective (as seen in Steering Affairs). Intervening when ‘Not knowing’ required family carers to draw on heuristics and manage ‘not knowing’ by second guessing, following rules of thumb, going on hunches and other times historical preferences of the supported person in the absence of current perspective (if available).

Moving between ‘knowing and not knowing’ illuminates family carers crossroads in asserting value to their sons and daughters will and preferences existing parallel to difficulties in appraising and assessing their sons and daughters will and preferences. Family carers not only explain issues to the disabled person but also interpret the individual's words, demeanour and behaviour to determine his or her preferences similar to the approaches of Bach and Kerzner and Flynn and Arstein-Kerslake (Bach and Kerzner 2010). Yet ‘Moving between knowing and not knowing’ reveals family carers challenges of an ethic based solely on individual rights recognising that decisions about interpretations and ‘right’ and ‘wrong’ can be difficult, and may be related to individual context, and inter-relations.

A contingency that family carers employ to overcome this crossroads is to view choice making beyond single and static explanatory mechanisms toward sophisticated approaches that address the dynamic unfolding of multiple processes over time similar to other studies such as Hastings et al., (2002) and Beighton and Wills (2017). Mrs O sense of intervening ambiance
‘It’s more than figuring out what’s right or wrong, it’s capturing the whole, and trying to see it through her eyes so that she can have the best quality of life possible’ Mrs O

‘Knowing and not knowing’ raises ethical and moral dilemmas for family carers. ‘Figuring out the right thing to do’ was a common concern family carers experienced evident in handling certain situations as illustrated in ‘Steering Affairs’. This leads family carers to the fourth stage in the process of intervening, ‘Questioning self’ now detailed.

4.10.4 Stage Four: ‘Questioning self’

This fourth stage in the process of intervening denotes family carers’ actions of retrospectively going over actions and support in general and pondering in relation to the management of future scenarios, characterising ‘Questioning self’. Family carers influence in shaping the disabled persons life course structure and life experiences was acknowledged in the aforementioned constructs ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering Affairs’. Awareness of this influence and a ‘sense of doing the right thing’ featured prominently in the data as family carers recognise that with appropriate personalised supports over a sustained period, the life functioning of the person with intellectual disability generally will improve aligning to that of the AAIDD understanding of disability (Schalock et al., 2010 p. X).

Support in decision-making raised ethical and moral dilemmas for family carers when interpreting their sons and daughters will and preferences. As memo 4.2 in ‘Steering Affairs’ makes reference to Kittay (2005) ethic of care, similar to family carers claims that through ‘being’ they feel the need to accentuate the voice and direction given to them. It is posited that ‘questioning self’ aims to clarify family carers claims related to their sons and daughters wishes will and preferences in supporting decision-making moving beyond intellectual functioning as an exclusive basis upon which to accept or reject their sons and daughters direction.
'Questioning self” engages activities such as pondering on knowledge from the past, thinking out of the box, questioning the need and contribution of other supporters, questioning what more can be done, ongoing searching, reviewing trial and error approaches, putting oneself in their sons and daughters shoes, and discerning ethical issues. Thereby ‘questioning self” can be viewed as an assurance mechanism in intervening to support decision-making. In this regard, ‘Questioning self” has potential to aid future plans.

‘Questioning self” highlights the relevance of the relational approach to support. It is difficult for family carers to ignore the consequences of decision-making support as in ‘non-consequentialist approaches’ advocated in rights approaches to decision-making (Flynn and Arstein-Kerslake 2014a). Through questioning family carers’ sense and at times negotiate ‘walking a fine line between supporting decision making and tokenism’. This experience challenges notions of independent rights and independent living as sole predictors in the route to making choices similar to the line of thought of Kittay (2005, 2013).

Kittay’s ethic of care understands responsibility to be bound by the connection to and an understanding of the needs and wants of the other. ‘Questioning self” presents a constructive ambiguity for family carers. The guise of asserting their sons and daughters ways (Framing Representation) disguises the challenges in resolving a contentious issue on which the family carers find themselves in (Steering Affairs), ‘can you ever tell what is going on in the mind of a person, living with PIMD’ and ‘is this really what s/he wants’. As family carers gained new information or new perspectives, they reassess their understanding.

As in figure 4.1 the cyclical nature of the process brings family carers to becoming and the cycle re-commences towards Sensing a Union, Framing Representation and Steering Affairs. This cyclical approach to supporting decision-making is enduring and required until the family carer ceases supporting, is not in a position to support or chooses not to support.
4.11 Process of Intervening Summary

This study presents the process of intervening to support another in decision-making through a series of overlapping stages of ‘Commitment’ ‘Engaging’ ‘Knowing and not knowing’ and ‘Questioning self’ founded on understanding disability, rights and social justice and experience emphasising the fundamentals of our human experience: love and communication inherent within human existence reflecting family carers ethic of care.

Concurring with Article 3 and 12 of the UN CRPD family carers supporting profoundly disabled persons recognised the inherent attributes and abilities of the disabled person and recognise the need to intervene so that the disabled person could partake and engage in activities of their choosing. This is in the face of being unexpected, challenging and at a personal cost for the family carer.

4.12 Summary ‘Interactional Guesstimating: Growing Confidence with Uncertainty’

The main contribution of data analysis, ‘Interactional Guesstimating: growing confidence with uncertainty’ reflects the acumen sensitivity and endeavours which family carers’ through supporting decision making assert meaning in relation to their sons and daughters, living with PIMD, expressions. Personal constraints such as physical and mental capacity and limited social supports experienced by persons living with PIMD, emphasis the need for 24/7 individual aid. Recognising the magnitude of decision making support required by profoundly disabled persons family carers feel that their opinion should be sought because they spend more time with their sons and daughters and they are most familiar of their sons and daughter’s ways of expressions.

Family carers feel personal accountability for delivering on this aid, and evidence of highly committed individualised caring, loving and supportive practices to aid their sons and daughters in personal development inclusive of self-determination featured strongly in this study.
Family carers convey that the time, effort, resources and strategies in supporting persons, living with PIMD, to promote personal development and function, is considerable. Balancing the persons need to make decisions and the family carers’ role in maximising their ability to care for their family member was recognised as important yet challenging. In doing so family carers describe how they aim for their sons and daughters to be treated with kindness, consideration and respect and for themselves acknowledgement, respect and services designed to support them as a family carer in addition to the services and resources required for their sons and daughters. With ongoing debates as to best practice in developing informal and formal support mechanisms grow, this group of family carers’ experiences can contribute to the debate.

‘Interactional Guesstimation: growing confidence with uncertainty’ represents a complex practice involving interaction, knowledge acquisition, and actioning. ‘Interactional Guesstimation: growing confidence with uncertainty’ was experienced by means of ‘being present’ through ‘Sensing a Union’ and open to influencing each other’s actions and understanding (Framing Understanding) of which family carers form judgements, often estimates and more often guesstimates, that aid decision-making processes for and with persons, living with PIMD (Steering Affairs).

The theory highlights the necessity for recognition of the essence of human relations in support. Therefore, the process of intervening draws on humanistic and relational aspects framed in in an ecological systems perspective. Furthermore, this constructivist grounded theory presents the process of intervening acknowledging the complexity of communication, learning difficulties and being unexpected in a climate of changing ideologies (from a medically dominated to legalistic rules paradigm). Therefore, commitment, engaging and ‘knowing and not knowing’ and ‘questioning self’ arise for family carers in their endeavours of supporting decision-making.
Findings from an Irish setting will be of interest to national and international audiences. Nationally, as our Assisted Decision-Making (Capacity) legislation (2015) commences these findings can contribute to standards and codes of practices development and revision. Internationally, comparison of the RoI context and experiences noting the differing legalistic frameworks may shape or re-shape understandings.

4.13 Chapter Conclusion

This chapter provides an in-depth understanding of the role in supporting persons, living with PIMD, in decision-making, not previously clearly delineated, and demonstrating a myriad of complexities and challenges to such endeavours. The main contribution of the study reflects the acumen, sensitivity and endeavours that family carers espouse in delivering on support, and in particular supporting decision-making reflected in the phrase ‘Interactional Guesstimating; growing confidence with uncertainty’.

The evidence from this study provides a clear rationale for the value and necessity of interpersonal relationships in establish ‘ways of knowing’ required supporting persons, living with PIMD, in decision-making. This support requires intense commitment, time, and endeavours from family carers found in a cyclical mechanism of Sensing a Union, Framing Representation and Steering Affairs. The next chapter includes the significance of the research findings against the aim of the study.
5 Chapter Five Discussion

This chapter at a glance …

- Compares the study findings with existing policy, theory and research
- Discusses the study’s major findings specifically in relation to the RoI context

This chapter aims to discuss the knowledge claims associated with the study. Three areas of discussion pertinent to the main findings of the study are the focus of this chapter. To the best of our knowledge, this study through co-construction with family carers, presents the first constructive grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ of family carers’ experiences supporting persons, living with PIMD, in decision-making. The first point of discussion draws from the main findings in appraising and critically reviewing the ‘de-facto’ role that family carers find themselves as decision-making representatives.

Secondly, this study contributes to the conceptualisation of supporting decision-making by emphasising family carers’ perspective of the nature, complexity and importance of relationality to the practice, processes and outcomes of supporting persons, living with PIMD, in decision-making.

The third and final discussion point takes a critical perspective of supporting decision-making models. This study finds that current literature and models relate to supporting decision-making are abstract, and present an approach to the concept undervaluing the complex physical, emotional and social process required in support. Presenting a model ‘Interactional Guesstimating’ proposes a way of delivering on the ideology purported by the UN CRPD vision of supporting decision-making grounded in family carers’ experiences.
5.1 The role of Family Carers

In discussing the experiences of family carers, it is important firstly to acknowledge their enormous contribution and significant skill set and abilities, in which family carers’ in this study, demonstrated support in a personalised, principled and most often cost responsive manner, in the midst of uncertainty and dealing with conflicting information, little information or no information. The findings demonstrate vividly the physical, emotional and social aspects in offering support and by doing so influence the lives and wellbeing of people, living with PIMD, arguably their survival and being.

Similar to previous research this study shows the significance of families and positive relationships within their families for persons, living with PIMD (Barron et al. 2006; Chadwick et al. 2013). Like carers in Perez et al., study, this group of carers expressed satisfaction in their roles despite the complexities of caregiving (Perez et al. 2018). Complex needs identified in this study related to a combination of severe learning difficulties and serious physical and/or sensory impairments.

Family carers are essential in supporting this optimal life, quality and wellbeing requires intensive and committed support. The broad array of activities and interventions described by family carers all contribute to developing specific and unique insights of another’s ways, likes and dislikes to support this quality of life was extensive. These activities and interventions involve intimate and personal interactions occurring over long and sustained periods. For the majority of persons, living with PIMD, this comes from their family. This research has made reference to, as previous research has highlighted, the physical (Chou et al. 2011), mental (Giallo et al. 2015), and enduring financial costs (Irazábal et al. 2012) that family carers have sustained throughout supporting complex and high dependency needs.
Theories that emphasise a contextual perspective on individual and family functioning are becoming more prominent in the literature which frames development as a product of the individual interacting with multiple contexts, including the family, school, and the community (Gillan and Coughlan 2010). What is notable in the literature more so in recent years is the nature, approach and environment in which family carers operate is changing, therefore, findings from this study should be interpreted in light of this changing social and political landscape in the ROI. The meso-contexts (organisations, schools) and macro-contexts (policy, law, culture, and economic circumstances) acknowledged as influencing support arrangements in families and influencing family carers.

Findings from this study are consistent with existing literature. ‘Positive aspects’ of supporting another in decision-making connected to feeling admiration and love for their sons and daughters, in addition, to family cohesiveness, pride and a sense of achievement concurs with Hastings, Turnbull et al., Whiting and Beighton and Wills, (Hastings et al. 2002; Chou et al. 2011; Whiting 2014; Turnbull et al. 2015; Beighton and Wills 2017). In addition, family carers in this study recognise their experiences as being unexpected, demanding and unpredictable similar to other carers in similar situations, such as family carers supporting persons, living with dementia (Fetherstonhaugh et al. 2017). Fetherstonhaugh et al., found that family carers who become ‘surrogate decision makers’ for people living with dementia grow into this role over time because of the progressive nature of dementia and the diminishing capacity of the person living with dementia.

This study like Fetherstonhaugh et al., come from real-life questions of practice and perpetuates a realist understanding of ontology in relation to the nature of supporting people contributing to the ‘contextual perspective’. Similar to family carers in Fetherstonhaugh et al., family carers in this study experienced feelings of ‘Did I make the right decision’ in addition to confusion, conflict, and stress related to their role as supporter and having to advocate for the person they support if they believe medical, nursing, or other staff are not providing the best possible care.
This study finds that supporting profoundly intellectually disabled persons in decision-making requires the establishment of a constructive and emotionally responsive caring relationship. In genuine relationships of care, trust is an important ethical principle and it is important to acknowledge that those people (supporters) who provide the most intimate and personal support are key to upholding the dignity and autonomy of people with disabilities (Kittay 2011). Family carers in this study highlight conditions of competence and relatedness as core to supporting persons, living with PIMD to establish cumulative and embedded ‘ways of knowing’.

This level of interaction and connecting by its very nature established on the human and personal level is intense, garnered over time yet connections are often instant. In supporting their sons and daughters, to engage in activities of living and be treated with dignity and respect, family carers first and foremost gave time, commitment and ‘took up’ a personal relationship with their son or daughter, in addition to other relationships. Family carers describe the relationship, with their sons and daughters, founded in kinship and love was intimate and instrumental.

This relationship reflects a knowledge base garnered over time acquiring personal knowledge in relation to their son or daughters’ individual needs, wishes and preferences, communication styles and environmental considerations. This relationship motivated family carers to make it their business to learn the intricate nature of the profound disabilities and associated conditions to ensure meeting needs and support their sons and daughters to engage in the milieu of life, meaningfully and contently. Other relationships most often serve to get the help required, or to help support their sons and daughters. Family carers’ actions in supporting their sons and daughters in decision-making therefore revolved around needs, wishes, interests and preferences acquired through this intimate and personal relationship.
In this light, family carers’ erudition yields intense understanding and skill related to supporting another. While family carers in this study told of their difficulties in supporting their sons and daughters a feature of the findings was how family carers challenged Voysey’s seminal work and her ‘constant burden model’. Key differences between the family carers of this study and the family carers informing Voysey’s model, in addition to the structural conditions, are noted.

This study focuses on family carers supporting people, living with PIMD, whereas Voysey’s study was representative of children with various physical, learning and intellectual disabilities. Voysey’s position maintaining in her revamped 2006 edition of her research, the ‘constant burden model’ in relation to the ‘stoic acceptance’ of people, living with PIMD was not evident in this study. This perhaps related to Voysey wide reading of the then current literature on 'deviance' and related subjects evidenced in her analysis differs dramatically from this study.

In this study, the interpretive portrayal of the data framed in family carers’ experiences on ‘their contributions in supporting another’ presents a more in-depth and fecund understanding of family carers’ identity and development in processing implicit meanings and experiential views of themselves as persons that identify, develop and gain confidence in a challenging and demanding situation is thus presented. In this construction of reality, what initially emerged was the lack of a clear understanding of the support family carer’s themselves require tying the image of family carers to the tasks they perform over the knowledge they possess. Through talking, listening and asking questions to family carers in developing understanding of the support required in addition to their support strategies, ‘Interactional Guesstimating: Growing confidence with uncertainty’ transpired demonstrating the intuitive, learned and relational nature of support.
In establishing cumulative and embedded ‘ways of knowing’ family carers’ knowledge and insights of another’s ‘expressions’ and ‘ways of expression’ creates a realisation that decision making support is in-part reasonable and necessary over long term, rather than one off short term. Conditions of support however, should not be romanticised as this study notes establishing ‘ways of knowing’ is not without its challenges. In particular, family carers challenged existing attitudes towards ‘paternalistic’ and ‘protectionary practices’ in supporting another.

The subject of paternalism is broad and complex, and debates exist as to whether or not paternalism can be justified in any case. It can be argued that ethical debates of paternalism are often avoided by governments and service providers accepting of the inhuman atrocities associated with the history of care for intellectually disabled persons replete with examples of harmful paternalism, including exclusion, imprisonment, sterilization and euthanasia (Stubblefield 2007) in favour of the dignity enhancing and humanistic approaches advocated by human rights approaches. In attempts to overcome these and other atrocities efforts of disability rights activists advocate abolition of paternalism and paternalistic practices seeking more freedom of choice and right to self-determination (Dimopoulos 2016). Therefore, any act of paternalism ruled as unjust in light of historical atrocities.

Family carers in this study highlight complex, ethical and multi-faceted challenges in supporting another, demonstrating the difficulties of balancing respect for self-determination, responsibility and duty of care. In emphasising the self-representation of people with disabilities the position of profoundly intellectually disabled people who require representation of their wishes and preferences—insofar as we can know their wishes and preferences—by another has been overlooked (Bérubé 2009). Family carers in this study are in a precarious position, whereby tension related to the primacy of autonomy over safeguarding in caregiving appears to dominant present day legislation, policy and service provision.
A realist ontology underpinning this study views family carers’ experiences in supporting the self-determination of persons, living with PIMD, as intervening to aid the ordinary everyday activities in addition to the bigger lifestyle choices that people make requires relational, interactional and inference processes, not solely principle-based approaches.

Family carers in this study experienced uncertainty in relation to ascertaining the person’s wishes, preferences and desires and their need to draw on the ethical principle of beneficence in the absence of ‘knowing’. For instance, when their disabled son or daughter is unable to sit or tolerate a prolonged period in a dental chair, but an abscessed tooth and root canal treatment required, the benefit of receiving effective treatment will outweigh the paternalistic administration of sedatives or general anaesthetic. This utilitarian perspective on morality views ‘soft paternalism’ involving coaxing or even some measure of compulsion from others as acceptable in the interest of drawing out the will and preference in addition to wellbeing and safety.

Actions of nudging, coaxing and coaching profoundly disabled people considered practices that support interaction and engagement to do things they may not have done on their own are activities with which many family carers in this study engaged in to support another. Indeed, family carers maybe found guilty of neglect if they did not. For example, there are times when family carers ‘ways of knowing’ draws on what family carers believe is morally acceptable and fitting for their sons and daughters.

This act or intervention classified as offering good care, ‘supporting the disabled individual in decision-making’ or ‘soft paternalism’ depending on your point of view. In this research, the realist perspective pro-offers ‘interactional’ as representing the embedded aspects of the iterative interplay between the family carer and the person they support. Family carers demonstrated that in such a relationship, identifying as a family carer, an extension of oneself and movement into another person’s world to aid in seeing their sons or daughters viewpoints, understandings or values occurs.
In cases where the will and preference is unknown, the family carer, through empathic and relational acquaintance frames choice making towards the characteristics, personality and presumed choice making options based on ‘knowing the person’. Family carers in this study identify this as challenging knowing the vulnerabilities of the person, and having the responsibility to ensure safety, wellbeing and maintaining the person’s dignity. This reality challenges principles based approaches to support. This study therefore articulates new knowledge of the processes that inform family carer’s support strategies transcending an image of helpful and naïve carer to expose the expert, skilful and sensitive contributions that family carers develop deliver and reflect upon. The three constructs ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering Activities’ demonstrates the interplay between the erudition and experiences of ‘disability’, personal commitment and ‘working on the job’ to support their sons and daughters in the milieu of living, across all life domains, inclusive of supporting decision-making.

This study contributes to the scant database on the unique contributions that family carers make. Specifically, Chapter Four, Table 4.1 ‘taxonomy of interventions’ demonstrates the wide ranging nature of support that family carers deliver on, and the extent in which family carers provide their sons and daughters with assistance beyond the physical and social elements, but interventions that promote development, enhance wellbeing, self-determination, monetary and legal provisions. In this regard, this study findings questions Twigg and Atkin ‘typology’ of family carers (Twigg and Atkin 1994) representation of family carers as resources and co-workers who are free, available, and ideally should work with or alongside professionals, rendering a simplistic and unrealistic understanding of the role that this group of family carers presented.
Therefore, the simplistic view of ‘family carer’ as carers who ‘carry out tasks’ and ‘interweaves with formal systems’ of support is very much removed evidenced by these findings. In listening to family carers describe their personal development, and thereafter applying Bronfenbrenner’s framework to the theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ the transition from helpful hand to expert contributor was illuminated with effect.

Addressing social-cultural and economic challenges family carers stressed the necessity for support with less emphasis on charismatic or visionary aspects, often reflected in politic rhetoric, but delivery on pragmatic and personal assessments. This claim lies in the lived experience of ‘connecting’ and ‘personalising’ developing authentic, intimate and caring connections between family carers and their individual sons and daughters, living with PIMD, realising the ‘knowing their son or daughter’.

‘Knowing their profoundly disabled sons or daughters’ in this study was outlined by family carers as crucial to support decision-making with features time, commitment, knowing personal likes, dislikes, ways of expression in addition to the and medical/clinical information and ‘learning on the job’. Other authors assert similar features aiding decision-making support, for example Carney (2014) recommends spending time to determine a person’s preferences and wishes, and the value of informal relationships of support between a person and members of their social networks as core to supporting decision-making (Carney 2014). Like this study, the importance of ‘knowing the person’ in supporting decision-making is referenced by Knox et al., (2015) and Bigby et al., (2017) worth noting here. Knox et al., (2015), paper presents a case study, taken from a larger cohort, that explored processes used by adults with severe traumatic brain injury in making decisions after injury.
For a person with an acquired brain injury, the need for support may more readily be supplied due to the existence of a stock of well-formed life preferences and values expressed prior to injury (Carney 2015). In Knox et al., case study, analysis of the data (constructivist GT) revealed several key themes relating to both the nature of the decision-making process and the factors that underpinned decision-making support. Relational factors included: (a) knowing who I am and what I value (b) understanding the nature of the relationship and (c) working with each other. Process factors included (a) sharing a vision (b) adjusting process to decisional circumstances and (c) developing a supportive network. These findings emphasised that knowing the person well and sharing a focus on maximising autonomy contributed to positive decision-making support. This case study, presents the views and opinion of one man, who acquired a cognitive disability in his adult life and affirms the importance of ‘knowing the person’ in supporting decision-making (Knox et al. 2015).

Bigby et al., (2017), also an Australian study led by a leading disability academic, describes a larger scale study of Australian family carers and paid supporters adopting a social constructionist theoretical perspective reflecting on experiences of decision supporters of people with intellectual disability (Bigby et al. 2017). This study consisted of a sample of 23 people comprising of 11 family members, and 12 workers in disability support services, however the table presented highlights some inconsistency with this describing a total of mothers (n=9), fathers (n=2), house coordinator (n=1), direct support workers (n=2), training manager (n=2) and teacher (n=3).

The data collection was through focus groups; therefore, no detailed personal data about participants accrued. Bigby et al., state they did not collect any information about the supported persons; however, surmise from participants accounts the client profile of the two disability support services involved in the study that most had a mild or moderate level of intellectual disability. An inductive thematic approach guided analysis of the data. While this group differs from the family carers in this study, some similarities exist between the study’s findings.
The first major theme from Bigby et al., analysis captured participants’ ‘underpinning ideas’ about providing support for decision making, the second theme identified their ‘approaches to support provision’ and the third theme described ‘the challenges’ they saw themselves as facing. In ‘Underpinning ideas about support for decision-making’ subthemes ‘Changed perspectives’, ‘Integral to day-to-day support’ ‘Knowing the person well’ and ‘A shared process’ were described. Focusing on ‘Knowing the person well’, similar to this study, participants in Bigby et al., thought that knowing a person well was a prerequisite for providing support.

A participant of Bigby et al., notes

‘to work with the person you’re helping to make the decision you need to have as much information about that person as possible and what their needs are’

In both Bigby et al., and this study, ‘Knowing a person’ represents understanding of the aptitude and abilities, life experiences, strengths, weaknesses, and modes of communication of the disabled person. This includes attributing importance ‘to knowing the intangible’ things about a person or the context in which the decision was to be made. Both studies concur in order to support a disabled person in decision making, it is important to recognise the value of ‘Knowing a person’.

Family carers in this study however, through more nuanced and in-depth interviewing revealed a more complex and intricate approach to knowing and supporting another, established though sensing a union, framing representation and steering affairs. ‘Knowing the person’ presents personal information including the unique characteristics of behaviours, likes and dislikes routines and ways of expression. Information includes characteristics about the profoundly disabled person, the physiological and psychosocial status, as well as trends and identified norms, our norms, as such the gathering of information essential to offer support.
In ‘Knowing the person’ acknowledging these tangible factors are important, yet family carers revealed intuitive and intangible knowledge of the personal characteristics of the person, related to understanding of the past and present narrative of the person, and how the individual interacts in his or her surrounds. Capturing this tactic knowledge requires persistence, time and attention to subtle cues and invitations by the disabled person. This study highlights family carers distinguishing between ‘knowing about’ and actually ‘knowing a human being’, moving from the factual to the experiential in experiencing another human being in his or her uniqueness as a person, as Mrs K articulates,

‘If they only knew her like we do, they’d see the person she is’

Mrs. K

The experience of ‘Knowing the person’ facilitates understanding of the person, living with a PIMD, in a manner, which recognises the value and meaning associated with their uniqueness and ways of expression.

Findings, however, demonstrates that in ‘Knowing a person well’ you may never know what ‘goes on in the mind of another person’ and the challenges this brings to delivering support. Through their questioning of self, family carers recognise at times, the elements related to their sons and daughters that they know well, and the elements that they do not know, what they interpret ‘For sure’ and ‘Think so’. As indicated in ‘Steering Affairs’ in serving to accommodate the profoundly disabled person by upholding the character and respect for the disabled individual in a manner that recognises his or her wishes in addition to recognising restrictions within choice making guesstimates are required.
These actions and questioning of self, highlight the need for support for family carers. There is significant evidence in the literature, correlating with this study, which suggests that a combination of supports, formal and informal, are beneficial for children and adult dependents with intellectual disabilities in addition to ameliorating family caregiver distress and increase confidence (Jacques 2006; Jansen et al. 2016; Bigby et al. 2017). Navigating between informal supports and formal supports presents additional challenges (Care Alliance Ireland 2013).

Formal support operates within the context of bureaucratic structures, having strengths and limitations. One limitation of formal support noted in these findings is the lack of ‘room for manoeuvre’ with less emphasis on experimental and relational features. Therefore, formal organisations, could never hope to meet all of the instrumental, social and emotional needs of the individual. Informal support delivers on these instrumental, physical, social and emotional needs through a comprehensive and desirable range of services such as personal care, intimate care, housekeeping, transportation, care and financial management as well as emotional support, most for people in need of care (Table 4:3 Taxonomy of interventions).

The findings of this study demonstrate that the interface between the two levels of support; formal and informal supporters, is minimal. Evident in the findings was the absence of family carers’ assessment, lack of statutory home care supports and at times the dismissive and negative attitudes of professionals to individual and family circumstances. In addition, and alarming, is undercurrent tones alluding to continuing practice of the policy of institutionalisation that family carers were afraid and annoyed with.

For example, this study noted the challenges accessing formal supports for those requiring assistance with day-to-day issues such as dealing with home help services, welfare agencies, managing income security payments, or making health care decisions are poorly developed to-date. Confusion in relation to consent processes, de-congregation approaches and community resources all alluded to by family carers in this study appear ‘in flux’.
Therefore, this study calls for the need to understand, as our National Carers Strategy (Department of Health 2012) suggests, the informal family carers ‘de-facto’ position on par to that of an ‘Assisted’, ‘co-decision-making’ or ‘decision-making representatives’. An appreciation of this ‘relationship’ engaging in meaningful physical social and emotional ‘processes’ for facilitating engagement and resources to aiding personal development, inclusive of decision making experiences, for those living with PIMD is warranted. A relationship garnered and grows over the years, to facilitate moving forward.

This leads to the next discussion point that is, conceptualising ‘support in decision making’ and discussing the experiences of this group of family carers in conjunction with changing policy and legislation.

5.2 Conceptualising ‘Supporting decision-making’

While, supporting persons living with PIMD, in decision-making has been described as ‘the hard cases’ (Flynn and Arstein-Kerslake 2014a) this study found the considerations described by family carers were person-centred, individualised and underpinned by a compassionate engaging commitment.

That is in the face of historical perceptions and attitudes of profoundly disabled people as disparaging and challenging to dismantle evident in philosophical debates of personhood (Hogg 1999; Hogg 2007) and presenting the bespoke approaches to self-determination (Turnbull and Turnbull 2000; Werner et al. 2012). Such understandings challenge legal, medical and civil understandings of this group of people and the support they require.

Therefore, while there are many fundamental changes to come, the main success associated with Article 12 of the UN CRPD is its disputing long-standing notions that profoundly disabled people lack capacity to make decisions, based solely on the grounds of intellectual impairment. This cultural shift, influencing a changing trajectory of much discourse, has many implications yet to be realised.

The UN Committee on the CRPD (the UN Committee) 30, in its first General Comment made in 2014, defined legal and mental capacity as follows:
“Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.’

From an Irish perspective, a significant development in Irish capacity legislation was the introduction of the Assisted Decision Making (Capacity) Act (2015) which will have substantial implications for persons, living with PIMD, their families and professionals who support. The Act reforms Ireland’s Capacity legislation which has been in place since the 1870’s by establishing a modern statutory framework to support decision-making by adults who have difficulty in making decisions without help. It will repeal the Marriage of Lunatics Act 1811 and the Lunacy Regulation (Ireland) Act 1871.

Findings of this study concur with the thinking underpinning the 2015 Act that understanding capacity to make decisions and consideration of abilities to engage and understand from the ‘all or nothing status’ approach to a more ‘flexible functional definition’ is required when supporting persons, living with PIMD, in decision-making. Therefore, like family carers the 2015 Act views capacity in relation to the matter in question and only at the time in question. Acknowledging that a person found to lack decision-making capacity in one matter, will not necessarily mean that s/he also lacks capacity in another matter.

The Act recognises that mental capacity can fluctuate in certain cases. Therefore, to exercise rights and duties, the Assisted Decision-Making (Capacity) Act outlines Decision-Making Support Options to be made available when required. The Act proposes three types of decision-making support options to respond to the range of support needs that people may have in relation to decision-making capacity.
With each of the three decision-making support options decisions can be made on personal welfare, property and finance or a combination of both. These supports are classified as:

- **Assisted decision-making**: a person may appoint a decision-making assistant – typically a family member or carer – through a formal decision-making assistance agreement to support him or her to access information or to understand, make and express decisions. Decision-making responsibility remains with the person. The decision-making assistant will be supervised by the Director of the Decision Support Service.

- **Co-decision-making**: a person can appoint a trusted family member or friend as a co-decision-maker to make decisions jointly with him or her under a co-decision-making agreement. Decision-making responsibility is shared jointly between the person and the co-decision-maker. The co-decision-maker will be supervised by the Director of the Decision Support Service.

- **Decision-making representative**: for the small minority of people who are not able to make decisions even with help, the Act provides for the Circuit Court to appoint a decision-making representative. A decision-making representative will make decisions on behalf of the person but must abide by the guiding principles and must reflect the person’s will and preferences where possible. The functions of decision-making representatives will be as limited in scope and duration as is reasonably practicable (Assisted Decision Making (Capacity) Act 2015).

In this study, family carers presently by ‘de-facto’ operate as ‘Assisted, co-decision-making and decision-making representatives’ for their sons and daughters explicit in the substantive category ‘Framing Representation’ and the subthemes ‘Validating choices’ noting ‘Considering son/daughter ways’ asserting claims derived from ‘knowing their sons and daughters’.

However, into the future in the RoI, family carers will need to establish ‘a formal decision-making assistance agreement’. This futuristic approach will require an appointment by the Circuit Court, and monitored by the Decision Support Services situated in The Mental Health Commission, a legal contract between supporters and supported, primarily on personal welfare (including healthcare) and or property and affairs, or both.
The provisions of the Act will be commenced on a phased basis now that the ROI has ratified the UN CRPD as of 19th April 2018. The challenges are substantial. Not least of these challenges is the need to emphasise the principles of respect and autonomy with beneficence, to result in support that is at all times consistent with the person’s values and is effective, humane and consistent with human dignity.

Challenges with new legislation are inevitable, and in particular with the Assisted Decision-Making (Capacity) Act 2015 which seeks a major re-haul to ‘systematise’ many of the principles which already define ‘good practice’ be that in law, health, education or social care, but will be placed on a more explicit footing with this Act. Therefore, in comparison to our UK, Australian, Canadian, USA and other European counterparts we have much to advance in the area of supporting decision-making, but our framework in the legal context appears to marry that of other jurisdictions.

The 2015 Act now places the criterion of ‘will and preferences’ of all persons with challenges in decision-making at the heart of decision making in relations to ‘personal welfare’ (including healthcare) and ‘property and affairs’. A claim that this ‘new’ direction reflects the re-interpretation of experiences of disabled people and their families formulated chiefly by those having such experiences rather than the professionals (UN 2006; Department of Health 2009; Denzin and Lincoln 2011; HSE 2011; Munhall 2011; HSE 2012).

Family carers in this study describe their experiences in supporting the self-determination of persons, living with PIMD, in the ordinary everyday activities in addition to the bigger lifestyle choices that people make, built on relational, interactional and inference processes. Responding to these experiences, questions of how the law systematises and operationalises the official lawful ‘supports’ to exercise legal capacity ‘the key to accessing meaningful participation in society’ is now upon us.
In this regard, the Assisted Decision Making (Capacity) Act 2015 finds ‘capacity’ to mean ‘decision-making capacity and shall be construed in accordance with section 3’. Section 3 of the act, refers to a ‘Person’s capacity to be construed functionally’.

Capacity to be ‘construed functionally’ means a person shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time. While a critique of the UN CRPD is ‘its non-consequential character’ (Dawson 2015) this new RoI legislation recognises element of nature and consequences of the decision to be supported. Therefore, the act identifies a person to lack the capacity to make a decision if he or she is unable—

(a) to understand the information relevant to the decision
(b) to retain that information long enough to make a voluntary choice
(c) to use or weigh that information as part of the process of making the decision or
(d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party

Section 3(3) of the Act outlines that

‘a person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means)’

Assisted Decision Making Act page 15

The line ‘appropriate to his or her circumstances’ demonstrates the legislators responses to advocates calls for alternative and augmentative approaches to communication. However, the notions of capacity as the rational construct requiring independent ‘understanding’, ‘retaining’, ‘using or weighing information’ and ‘communicating’ is evident throughout the Act and creates tensions with notions of relationality which family carers feel are core to supporting persons, living with PIMD, in decision-making.
It is from this point onwards that the 2015 Act demonstrates the embodiment of theories of cognition and rational decision-making arguably to the neglect of relational notions of consent, autonomy, decision-making and dignity (Gilligan and Attanucci 1996; Kittay 2011; Noddings 2013). Family carers in this study offer a different insight into the communication abilities of persons, living with PIMD. The social constructivist interpretivist relocates emphasis on transmission and transaction models of communication, emphasising the need for a continuous and highly intricate relational and interactional processes required to support persons, living with PIMD, in decision-making. This interactional approach considers physical and psychological contexts.

The physical context includes the environmental factors in communication encounters. The psychological context includes the mental and emotional factors in communication encounters. This knowledge, reflected in the daily successes and challenges that this group of family carers spoke to in creating, establishing and overseeing opportunities and supporting persons, living with PIMD, to articulate their life wishes, choices and preferences is challenging. The relational and interactional perspective described by family carers emphasises the importance in developing meaningful interactions, in time and over time, to enhance mechanisms to assist persons, living with PIMD, develop engagement in the milieu of life, most often reflective of alternative, augmentative and bespoke communication strategies.

Family carers view this relational and interactional perspective as fundamental to all support strategies. This claim found in family carers experiences attuned to checking for signs of assent and dissent, their sons and daughters comfort zones and their discomfort zones, and ease to make a decision accepting of theirs sons and daughter’s acceptance or refusal of interventions. Family carers accepting at times for the need to guess, estimate or guesstimate (an estimate based on a mixture of guesswork and calculation) and represent their sons and daughters when their sons and daughters communication intent challenges understanding.
This dissertation places emphasis on understanding ‘appropriate to his or her circumstances’ in decision-making requiring the extensive and intensive actions and resources to aid decision-making abilities. As such, family carers have asserted how the socio-economic perspective aids implementation and operationalising the concept supporting decision-making.

This study aligns with the work of Carney, an imminent Australian scholar with a legal background, whose analogy ‘Glacial-To-Steady Progress’ refers to the understanding and implementation of supporting decision-making strategies internationally. Carney suggests characterising the ‘supporting decision-making’ arm of Article 12 as a socio-economic right as opposed to a civil right, which does not permit progressive realisation. ‘Building their sons and daughters personal development’ reflects family carers overall mission in supporting their sons and daughters, and while doing so, themselves develop personally as reflected in the findings ‘Interactional Guesstimating: Growing confidence with uncertainty’. As a socio-economic right support in decision making therefore would view capacity in building personal development and associated significant resourcing implications (Carney 2017a).

Although supporting in decision-making in the CRPD is only about ensuring equal access to agency as legal capacity, most support in decision-making programs to date offer a much wider spectrum of supports for greater agency in decision-making, so viewing support in decision-making purely as a ‘civil and political right’ is not persuasive (Carney 2017a). This study concurs with Carneys view that until the issues of resources are established and realised than the ideology of support in decision-making may never be realised. So in terms of embedding the philosophy of Article 12 of the UN CRPD this study recognises how family carers commitment and ability to interact and relate to people, living with PIMD, facilitates understanding and aids processing of information ‘appropriate to his or her circumstances’.
In this vein, viewing support in decision-making as ‘building personal development’ in socio-economic rights perspective, similar to health or education, therefore has the potential of imposing ‘positive’ liberties (i.e. claims on the state for expenditure or access to resources and therefore realised progressively). Whereas civil rights, are often realised in a ‘negative’ or protective way, such as in describing civil rights to privacy or autonomy as the ‘right to be left alone’ (simply guaranteed by the state against interference with enjoyment) (Carney 2017b). The parallel exemplar demonstrating understanding of the term ‘intellectual disability’ through socio-economic cultural viewpoints as advocated by the AAIDD may very well support this view.

Moving on from resources, an important facet to implementation are models of practice, which the next discussion point address.

5.3 Models of Supporting Decision-Making
Empirically derived theories of supporting profoundly disabled persons in decision-making are lacking in the current body of literature. As stated in Chapter Two since 2006, the rise in papers exploring the concept, construct and approaches to supporting decision-making has risen. These papers primarily originate from Ireland, the United Kingdom, Australia, Canada and the United States of America. The general thrust of these papers reflect the origin and theoretical significance of supporting decision-making for people with disabilities, and their supporters (Bach and Kerzner 2010; Werner et al. 2012; Gooding 2013; Browning et al. 2014; Carney 2014; Lashewicz et al. 2014; The Office of the Public Advocate 2014; Watson 2016; Bigby et al. 2017). Research commencing the evidence base to these claims are also emerging (Bigby et al. 2017; Watson et al. 2017) in which this dissertation adds to.
These discussion and research papers call for a principled approach to supporting decision-making in lieu of past derogatory and inhuman institutional practices, historical eugenic programmes and dismissive and negative attitudes to those with severe impairments and alluded to by some family carers in this study. Therefore, models of supporting decision-making have a place in implementing and aiding operationalising of support, in addition to implementing supporting decision-making practices.

We propose a model of supporting decision-making grounded in family carers’ experiences that moves understanding of support beyond the simplistic view of ‘communication of needs and wishes as matter of fact’ or a ‘matter of entitlement’. Moreover, this approach conceptualises supporting decision-making as asserting value and meaning associated with the uniqueness and ways of expression(s) of the profoundly disabled individual. This approach referred to ‘Interactional Guesstimating’ a model of supporting profoundly disabled people in decision-making.

Findings evoke what Gilligan and Attanucci call the ‘care perspective’, which organises the relationship between self and other in terms of care and attachment rather than solely justice and equality (Gilligan and Attanucci 1996). Gilligan and Attanucci’s claim that people's perspectives change when confronted by real dilemmas from their own lives, rather than hypothetical moral dilemmas, because they then have to consider in their answers what they do, rather than just responding abstractly according to some high-sounding principle. Family carers in this study relate to this claim.

This model founded in a social constructionist approach centres on ways of ‘knowing the person’ and viewing trusting and respectful relationships as pivotal in asserting the life choices of people, living with PIMD. Therefore, ‘Interactional Guesstimating’ as a model of supporting decision-making embraced family carers’ sense of ‘commitment’, ‘relationality’ and the centrality of a ‘care-for philosophy’ in human existence. Drawing on the findings of this study, and presented in Chapter one, Figure 1.4 is revisited here.
Presented below (Figure 1-4) ‘Interactional Guesstimating’ model of supporting persons, living with PIMD, in decision-making presents the cyclical and individual nature of support required by persons, living with PIMD, in decision-making.

![Interactional Guesstimating model](image)

Figure 1.1 ‘Interactional Guesstimating’ model of supporting persons, living with PIMD, in decision-making

Drawing on family carers’ experiences the ‘Interactional Guesstimating’ model of supporting persons, living with PIMD, in decision-making is presented. This model, founded in family carers’ experiences of supporting persons, living with PIMD, in decision-making, recognises that with care, commitment and intensive interaction ascertaining the value and meaning associated with the uniqueness and ways of expression(s) of the profoundly disabled individual supporters are in a position to assert meaning to the supported intent, wishes and preferences.
In addition, at times, supporters must offer an explanation that they think (guess or estimate) could or would be the disabled persons will or preference. This can challenge rational notions of the independent nature in decision-making. In a similar vein, Kittay (2011) challenges notions of independent rights and independent living as sole predictors in the route to making choices in life. As a mother of a profoundly disabled woman, Kittay’s experience has aided her philosophical debates and her ideas of ‘shaping a world’ that will accept her daughter, Sesha, who Kittay recognises

‘will never walk the halls of academe but when what happens within these halls has the potential to affect her, then I as an academic have an obligation to socialize academe to accept my daughter. Such ‘care’ may seem to be far from the daily care that her fully dependent body requires, and it may appear to be far-fetched to call this ‘care’, but it is part and parcel of that labor of love that we do as parents, especially parents of disabled children-more so in the case of those who are so disabled that they cannot speak for themselves, a defining condition for those who are severely disabled’ Kittay pg. 398 in Kittay and Carlson 2010

Therefore, like Kittay, this social constructivist perspective ‘Interactional Guesstimating’ espouses care and commitment contributing to the civil and ethical obligations of examining and responding to experiences beyond the relationship, but wider afield.

‘Interactional Guesstimating’ as a model of support decision-making (concept) commensurate with shaping a world in which support in decision-making (action) is conceptualised as multi-dimensional and continuous, characterised by both humanist and instrumentalist facets. This interlocking of humanistic and instrumental visions of supporting decision-making necessitates individualised and personalised approaches requiring intense physical social emotional and economic resources as seen in this study.

The broad approach to support in the milieu of life underpins ‘Interactional Guesstimating’ consisting of three main cyclical interrelated components summarised as
Synthesis and Discussion

a) ‘SFS’ interface - Sensing a Union, Framing Representation and Steering Affairs. This interface stresses the need for

- Establishing connections and a closeness between supporter and supported created through seeing, hearing, touching and feeling; facilitating understanding from interaction (Sensing a Union) to aid ‘knowing a person’
- Establishing or postulating representation of an others perspective and signification’ in which the supporter ascertains, asserts or at times postulates, guesses or estimates the wishes will and preference of the supported (Framing Representation)
- Assisting in maintaining the individual’s dignity through guiding actions (Steering Affairs)

b) The kinds of decisions they face, and when they face them ‘related to personal circumstances’ addresses contextual factors noting:

- intrinsic factors (e.g. love, values and living strategies, education and personal attributes)
- and extrinsic factors (e.g. law, policies and professional support)

c) Triggers that initiate supporter questioning and reflection(s), for example, decision-making in times of receiving a diagnosis, supporting periods of illness, supporting educational and recreational opportunities/discrimination in addition to financial and housing arrangements, in addition to the ethics within choice making and options.

The ‘Interactional Guesstimating’ model of supporting persons, living with PIMD, in decision-making’ therefore, considers the nature of relations as contributing to general decision-making support. Therefore, supporters are in a position to assert meaning to their sons and daughters’ choice making claiming

- ‘For sure’ category of wishes, will and preferences known to the supporter
- ‘Think so’ category of wishes, will and preferences based on ‘knowing the person’
• Guesses and estimates of wishes, will and preferences not known to the supporter but proffered based on ‘knowing the person’

This model therefore aids implementing a functional approach in supporting another when exercising capacity in decision-making. That is recognising and responding to decision-making is time specific, context specific and issue specific. In this manner, supporters can assist the profoundly disabled persons participation as fully as possible in decisions recognising that in complex or grave decision-making matters supporters are required to draw on the experience of ‘Knowing the person’ and the value and meaning associated with their uniqueness and ways of expression to aid in asserting choices.

The model of supporting decision-making that emerged in this study shares similarities with the models proposed by both Back and Kerzner (2010), Flynn, and Arstein-Kerslake (2014). The two models ‘Maximising Decision Making Abilities’ by Back and Kerzner (2010) and ‘Enabling Conditions’ (built on the work of the Back and Kerzner 2010) by Flynn and Arstein-Kerslake (2014) describe theoretical approaches to supporting decision-making outlined in Chapter Two aligning philosophically with ‘Interactional Guesstimating’ in that relational aspects feature predominantly in all three models.

All three models premise that all persons are capable of making decisions, recognising time specific, issue specific and context specific factors. Back and Kerzner (2010) and Flynn and Arstein-Kerslake (2014) emphasis on individual rights and autonomy of the disabled person refers to supporting decision-making addressing legal capacity and the right to support for the exercise of legal capacity independently of supporters rights or input. ‘Interactional Guesstimating’ as a model of supporting persons, living with PIMD, in decision-making diverges from Back and Kerzner (2010) and Flynn and Arstein-Kerslake (2014) models whose emphasis on the role of supporter primarily lies in the role of transmitting or transactions reporting the ‘individualistic perspective’ of the supported.
'Interactional Guesstimating’ views ‘relationality’ in the representative role, as central to the construction of the profoundly disabled person’s needs wishes and preferences, in which, the profoundly disabled person’s individuality comes to be represented. This interactional perspective encompasses negotiations of individualism, social and environmental considerations presenting an ‘interdependent nature of being’ in effecting general decision-making in addition to exercising legal capacity.

The rich and endearing narratives underpinning this model of supporting decision-making therefore challenge both the stoic disposition often associated with persons, living with PIMD, and claims reticent of representatives asserting claims of ‘knowing the person’ in a way that supports needs and attempts to ‘draw out’ and at times guesstimate the wishes, will and preferences of the person.

Therefore, two main features of the model ‘Interactional Guesstimating’ are:

- The model ‘Interactional Guesstimating’ supporting persons, living with PIMD, in decision-making presents understanding of who the disabled person is, recognising the moral agent and decision maker they are in their ‘interdependent nature of being’
- Recognising the functional approach to decision-making support attempts to ‘draw out’ the wishes, will and preferences of the person require guesstimates and estimates when supporters experience uncertainty or do not know the persons preferences.

This model developed to aid support persons living with PIMD in decision-making the support process described is conceptually applicable more broadly to others. We all require support at different points in our lives, however, requiring support is certain for an identifiable cohort of people, in which the relevance of the findings of this study may be relevant, such as those with acquired brain injury, psychosocial or mental disabilities and advanced dementia.
5.4 Chapter Conclusion

The discussion presented an appraisal of the ‘de-facto’ role that family members find themselves, in times of new legislation, changing ideology and culture of practice. This exposed philosophical views related to independent and relational notions in supporting profoundly disabled person to express will and preference highlighting legal ethical and practical perspectives. The call to value family carers ‘de-facto’ position on par to that of an ‘Assisted’, ‘co-decision-making’ or ‘decision-making representatives’ was presented to accredit family carers meaningful physical social and emotional ‘processes’ for facilitating engagement and resources aiding their sons and daughters personal development, inclusive of decision making experiences.

This study finds that current literature and models relate to supporting decision-making are abstract and present a simplified approach to the concept undervaluing the complex physical, emotional and social process required in support. The model ‘Interactional Guesstimating’ is proposed and grounded in family carers experiences of ‘Sensing a union’, ‘Framing representation’ and ‘Steering affairs’ reflecting physical, social and emotional elements required in ‘relational’ notions of support, and resources, to progressively realise the ideology purported by the UN CRPD and aid policy makers in establishing future directions, as yet to be realised.

The next chapter of the dissertation draws the research dissertation to a close.
6 Chapter Six Reflections, Recommendations and Conclusion

This chapter at a glance …

- Specifies how the research adds to existing knowledge
- Considers alternative explanations of the findings
- Acknowledge the study’s limitations
- Identifies recommendations and potential contributions for policy, practice and research
- Concludes the dissertation

As stated in Chapter One, this research drew from family carers experiences of supporting persons, living with PIMD in decision-making recognising the interplay of ‘Becoming and being a family carer’ ‘Understanding PIMD’ and ‘Supporting decision-making’ as mutually reinforcing concepts located within individual, social, and cultural environs. Therefore, in drawing this research dissertation to a close, this final chapter summarises the knowledge claims associated with this dissertation.

Like Whiting (2014) this study acknowledges the scant evidence establishing family carers circumstances (Whiting 2014) in addition to their roles and responsibilities supporting persons, living with PIMD, and this work provides valuable knowledge of their understandings. In this study, family carers have detailed vividly how supporting persons, living with PIMD, requires extensive scope and intensive interaction; therefore, the scope, time commitment, and complexity of the caregiving role make it unique.

The responsibilities of providing complex personal and intimate care at home in addition to seeking, co-ordinating and follow up services falls to family carers in which no single health care, disability support service or social service is charged with assisting this group of family carers’. Therefore, additional duties of navigating bureaucratic mazes and managerial skills required by family carers in their role as supporter arises in which family carers receive minimal recognition.
Reflections, Recommendations and Conclusion

This research dissertation acknowledges the insights, sensitivity and acumen that family carers possess. This study challenges the narrow definition of ‘family carer’ adopted by policy makers and services highlighting the intense and extensive nature of the job in addition to the interdependent nature of the relationships. Findings of this study contribute to highlighting the need for professional, social and political systems to acquire a greater depth of understanding and empathy for the needs of family carers, and family units as a whole, than what they have at present in addition to providing understanding of their experiences and circumstances.

6.1 What this research adds

This study developed a substantive theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ of family carers experiences supporting persons, living with PIMD, in decision-making presenting the main categories, ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering affairs’ and the inherent relationship between them. The theory provides a conceptual rendering of the data that furthers understanding of the studied experience. Theorising entailed engaging with family carers and the studied phenomenon and constructing abstract understandings about and within these experiences (Charmaz 2006, p130). The developed theory, upon my own interpretation of the studied phenomenon, is substantive in that it furthers understanding of family carers’ experience of supporting, persons, living with PIMD, in decision-making.

Contrary to the dehumanising and institutionalisation of vulnerable people, in favour of promoting self-determination, control, and autonomy in fostering independence ‘supporting decision-making’ has much to offer all people. ‘Supporting decision-making’ offered as an alternative to guardianship and capacity assessment makes the assumption that all people have the capability to self-determinate and that with the right support the will and preference of the supported can be yielded. Heralded as a liberator supporting decision-making as is causing a flurry in radically changing a culture of over-protection into ‘positive risk’, guardianship into ‘decision-making supporters’ and care to rights.
Affirmation of rights, in legislative and in general terms, is most often regarded as an independent person exercising their individual human, social economic and cultural rights, as outlined by legislators in their country, having many implications for those with difficulties such as severe learning and communication difficulties. In looking at family carers experiences, reconciling the roles and rights of family carers and the rights of their sons and daughters challenges the general (and strong) terms in which rights are upheld and affirmed.

In offering support, family carers come to value the cumulative and embedded ‘ways of knowing’ in seeing the uniqueness and ways of expression in which their sons and daughters assert meaning and outline their preferences. Family carers also note the challenges their sons and daughters present with in relation to comprehension and expression of ways, in which, family carers come to realise that longitudinal and relational aspects developing ‘knowing the person’ and eliciting ‘ways of expression’ play out. Family carers came to question notions of ‘exercising’ independent rights affirming relational and interdependent tenets challenging traditional approaches to rights validation.

Philosophically, ‘Interactional Guesstimating: Growing confidence with uncertainty’ places as its central thesis the view that supporting persons, living with PIMD, is a personal and emotive endeavour underpinned by commitment to a process of physical, social and emotional interaction facilitating development. Uncovering family carers’ perceptions of the intrinsic and extrinsic factors that influence the categories ‘Sensing a Union’, ‘Framing Representation’ and ‘Steering affairs’ play a part in the role of support. Emphasising the ‘relational’ and ‘interdependent nature of being’ as core to supporting profoundly disabled person’s family carers sharing of experiences has facilitated understanding of the concept supporting decision-making beyond the textual analysis of Article 12 UN CRPD.
The grounded theoretical portrayal of family carers’ experiences shows how family carers in the ‘taking up’ of a relationship with their sons and daughters and actioning the civic responsibilities of ‘support’ promote the uniqueness and ways of expression of the supported in addition to their own personal development. Not an easy accomplishment. Commitment, engagement, moving between ‘knowing and not knowing’ and questioning self together aid the process in supporting another.

Presenting a model ‘Interactional Guesstimating’ supporting persons, living with PIMD, in decision-making based on the substantive theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ serves to present a unifying and accessible understanding for families, staff, and other professionals in the multi-disciplinary team to develop guidance to optimise approaches in working with persons, living with PIMD, in decision-making.

This theory and subsequent model will be open to criticism and re-interpretation. This is expected and welcomed. A grounded theory cannot cover all identified phenomena. Its implications need to provide openings for others to join the conversation. In this regard, I note Lincoln and Denzin

‘The end of a work such as this should signal neither a conclusion nor a final word, but rather a punctuation in time that marks a stop merely to take a breath’ (Lincoln and Denzin 2005, p1115).

6.2 Trustworthiness of Study Findings

Criteria to judge constructivist grounded theory proposed by Charmaz (2006) relates to four principles namely credibility, originality, resonance and usefulness (Appendix 12) each now discussed.
6.2.1 Credibility

For credibility, to identify the value of the study, Charmaz (2006) recommends ‘immersion’ by the researcher in the research setting and the research topic. In order to achieve the recommended ‘immersion’ to the study setting and topic, I actively engaged and included ‘The Organisation’ and family carers in each stage of the research process, such as the preparation of the research question, the information sheet and consent forms, the Carers group facilitated in ‘The Organisation’ in addition to the planning and recruiting of participants. The data collection was gradual and carried out over three years. This prolonged engagement with the participants and the research setting facilitated me to develop a rapport and insight with family carers concerns and lives and helped me to interpret and shape the data analysis.

In line with a grounded theory approach, the findings of the study are not absolute truths but my interpretation and understanding of the data (Wuest 2012). In other words, the findings are not real facts but are constructed truths. The extent of viability and defensibility of the study findings depends on my presentation of them to a relevant audience in a way that is meaningful (Denzin and Lincoln 2011). Furthermore, the research process followed rigorous, detailed and thorough strategies to capture family carers’ experiences. Listening, reading and rereading transcripts of conversational interviews parallel to the family carers group were important ways of getting closer to family carers' perceptions and gaining confidence in the overall credibility emerging findings of the study.

The audio recordings of the interviews, detailed transcripts, observations and memos during the research process facilitated its dependability and reliability. During the presentation of the study findings, each category, supported with family carers’ words and connotations, made explicit detailed understanding of family carers’ experiences.
6.2.2 Originality

The original contribution of this study is the co-construction of the theory of ‘Interactional Guesstimating: Growing confidence with uncertainty’ and the proposed model of supporting decision-making ‘Interactional Guesstimating’.

The findings from this study add to the body of work that is gradually building in the area of supporting decision-making and family care practice. The work also contributes to the methodological knowledge related to including family carers in a research process. The social and theoretical significance of the study findings offers insight to current service providers, policy makers and importantly to the major contribution of family carers. This constructed theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ sheds light on the intensive and extensive contribution of family carers supporting their sons and daughters in decision-making. Other studies have explored decision-making and paid carers’ perspectives. By including family carers, this work offers a new dimension and a deeper understanding of the realities of supporting persons, living with PIMD, from the family carer perspective. To the best of our knowledge, the first to explore family carers’ contributions, from their perspectives, in the RoI context.

A visual presentation of the theory was presented in Chapter Four illustrates important concepts and relationships between categories. Chapter Five presented ‘Interactional Guesstimating’ as a model of support decision-making (concept) commensurate with shaping a world in which support in decision-making (action) is conceptualised as multi-dimensional and continuous, characterised by both humanist and instrumentalist facets. This interlocking of humanistic and instrumental visions of supporting decision-making necessitates individualised and personalised approaches requiring intense physical social emotional and economic resources as seen in this study.
Furthermore, information provided in the appendices adds further transparency to the research process. These processes help the reader to make an independent assessment of the claims made and to determine whether to agree with these because there is enough evidence provided to allow this (Charmaz 2006).

6.2.3 Resonance

The core message and understanding gleamed from this group of family carers will be understandable to other family carers in similar situations, in addition to healthcare professionals such as RNID’s and RGN’s who work at the point of support and care for people requiring intensive and extensive support needs. Such people living with other cognitive impairments such as dementia, acquired brain injury in addition to those who care and support other intellectually disabled individuals and their family carers or paid supporters may see echoes of their own situations.

6.2.4 Usefulness

The theorising of this work can inform and develop further understanding useful to all support personal be that healthcare, education or law. Nursing practice, particularly the discipline of Intellectual Disability Nursing may gain increased insight from this grounded theory having the possibility of influencing care provided to the people they serve and recognise the family carer as expert in their own right.

The usefulness of a theory relates to the ability for the interpretations to be used in the everyday world. The results of this study offer insights with implications for further theory development, practice and future research and discussed below. These insights come not only from the theorising that emerged from the study but also from the process involved in coming to this theorising, through the framing of the study, the interviews, and the process of making meaning of family carers experience.
Ongoing discussions and future endeavours with ‘The Organisation’ are continuing based upon conducting this research, so in that regard, the process and outcome has served well. The usefulness of this theory, may be best known in time, and the contributions and implications in relation to research, practice and policy are suggested to further aid family carers in their care and support endeavours.

6.3 Further Research

Supporting decision-making approaches aspire that all people be known as masters of their own lives, with a life plan, pathway, a life story or narrative. ‘Education, training and further research’ to address the fundamental aspects to deliver this aspiration are thus warranted. The shallow evidence base around how best to hear the preferences of people with complex support needs (Cairns et al. 2014; Brown et al. 2016) requires input and exemplars from those who support most. Family carers therefore, must be included in all ‘education, training and further research’ going forward.

In conducting this research, I have come to realise the potential and exciting nature that supporting decision-making has to offer, and this research is a beginning with many pathways to develop further down the line. From a family carer perspective, it would be worth considering further studies that focus on how different ages of family carers, gender, social contexts and associated demographic such as employment in more depth. In addition, factors that influence how supporting decision-making operates explicated in more-depth. Factors that may need further review are the composition of the family household (i.e. who lives with the family carer and their contributions), range of supports available noting regional distribution, and age of supported.

To utilise the grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ specific recommendations for policy and practice are now outlined.
6.3.1 Specific Recommendations for policy

In theory, all people, who require decision-making aid, can avail of supports under the 2015 Act. While it is likely that a decision-making assistant will be sufficient for most, it is not at all clear how many will require greater levels of support or how many Circuit Court hearings will be needed. In the RoI preparations are being made and specialist judges trained, much will depend on the development of regulations, codes of practice and—most of all—broader training in relation to the new legislation. This qualitative research is therefore timely and may be useful to policymakers because it describes the settings in which policies require implementation.

- This study challenges the narrow definition of ‘family carer’ adopted by policy makers and services highlighting the intense and extensive nature of the job in addition to the interdependent nature of the relationships. The commitment, intensity and required knowledge base demonstrates the acumen and competence required-consideration of remuneration fitting for such a role required
- The grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ will challenge perspectives in the discussions of supporting decision-making when the extrinsic factors associated with the socio-economic policies involved in supporting people in decision-making are acknowledged
- The due regard and recognition of family carer contributions in our society, warrants further considerations. Family carers in this study remind us how much we can learn from and with them to assist and serve them as professionals, educators and researchers.
- Aligned with the previous recommendations, traditional interpretations of ‘profound intellectual disability’ to move beyond rational and cognitive portrayals noting the interpretative perspective valuing the nature of their being and lives to be acknowledged in policy frameworks
• Consideration of ‘Circles of Support and Accountability’ programme, for family carers. Originally established in the restorative justice field in Canada and launched in Dublin last year. The programme holds the following principles, Voluntary participation (training provided) based on informed consent, Inclusion, Problem-solving, Equality, Accountability and support and Safety. Support in this fashion to family carers may serve to reduce their social, informational and a peer network providing practical assistance and solution focused strategies.

• Reducing the bureaucratic mazes that family carers navigate the Citizens Information advice requires considerably attention beyond that of ‘Carers Allowance’.

• Home Care Package (s) schemes n the ROI not established in law, is an administrative scheme, with no automatic right to the scheme or avail of services under the scheme. This requires urgent attention in lieu of family carers’ findings.

• Custodial policies of ‘support’ should not be enforced on the grounds of ‘available services’ as opposed to home care supports

• Due to the high nature of support required, resources need to be available, often immediately, therefore, a system that recognises ‘high priority’ to this group of family carers would be beneficial

The grounded theory ‘Interactional Guesstimating: Growing confidence with uncertainty’ will challenge perspectives in the discussions of supporting decision-making when interactional and relational aspect are regarded. In that vein the ‘Recognised Supported and Empowered’ vision of our Family Carers Strategy requires some specific mention in the recommendations:
• In the RoI’s Carers Strategy, ‘Recognised Supported and Empowered’ accepted at a cost-neutral strategy in 2012 as a token of recognition for family carers work when the country was in financial crisis may be seen as the starting point. In Budget 2018, dedicated funding for the next National Carers’ Strategy 2018-2022, and going forward, to address the serious issues and concerns faced by family carers called reflecting the everyday recurring costs and support needs that family carers face in relation to the care and support they provided. This study provides testament to this call

• Re-sculpting power relations between carers and professional and social welfare services requiring
  o Evidence of displacing the deficit-based language and bio-medical lens that currently characterises encounters between professionals and family carers
  o Humanist perspectives acknowledged
  o The more nuanced knowledge and understandings that family carers have of both their own needs and the needs of the person they support to be acknowledged and regarded

Specific recommendations, as a first step, may aid in operationalising the attributes of supporting decision-making

• Implementing the proposed ‘Interactional Guesstimating’ model of supporting decision-making into an instrument for the purposes of evaluation of existing or planned arrangements considered.

• Personal support requires commitment, engagement and sensing. Legal frameworks, codes of conduct(s) and professional discourses need to assert value in these processes

• Time to ‘know the person’ is required, therefore, paid supporters and professionals in this domain require allocating time to engage in knowing the person

• Re-sculpting power relations between family carers and professionals including social welfare services requiring
o Evidence of displacing the deficit-based language and bio-medical lens that currently characterises encounters between professionals and family carers

o Humanist perspectives acknowledged

o The more nuanced knowledge and understandings that family carers have of both their own needs and the needs of the person they support to be acknowledged and regarded

The relevance of this study’s findings to international groups is worth noting, particularly in those jurisdictions where current policy and legislation in relation to supported decision-making is being considered, under review or does not yet exist. As of 3rd April 2019, the Conventions has 162 Signatories, and 177 Parties [see here]. This means that over 162 countries have agreed to abide and implement the philosophy and obligations of the Convention. The ambiguity and uncertainty surrounding Article 12 is reflected in the majority of reservations, for example, the Canadian reservation ‘To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.’

The Polish reservation in relation to Article 12 states that Poland ‘will interpret Article 12 of the Convention in a way allowing the application of the incapacitation, in the circumstances and in the manner set forth in the domestic law, as a measure indicated in Article 12.4, when a person suffering from a mental illness, mental disability or other mental disorder is unable to control his or her conduct’. In England and Wales, the Mental Capacity Act (MCA) 2005 designed to ‘protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment’, currently under review, is criticised for permitting substitute decision-makers to act with the ‘best interests’ approach are considering the application of ‘will and preference’ approaches.
Noting the reservations made by many of the signatories primarily relate to Article 12 and the interpretation of the concept of ‘legal capacity’ the model ‘Interactional Guesstimating’ has the potential to aid a realist approach to realising supporting decision-making and article 12. The model ‘Interactional Guesstimating’ offers a humanistic, familial community-based approach to the provision of support to profoundly intellectually disabled persons that recognises arrangements to include formal and informal support at the macro, meso and micro levels such as support agreements, advocacy and future planning.

‘Interactional Guesstimating’ acknowledges the ambiguity and challenges in supporting persons, living with PIMD, in decision-making, and there is no quick fix solution. Aguilar’s ‘Report of the Special Rapporteur on the rights of persons with disabilities’ published in March 2018, (UN 2018) reports on international activities related to the right of persons with disabilities to equal recognition before the law. The Special Rapporteur analysed the responses to a questionnaire sent to Member States, national human rights institutions, agencies of the United Nations system, civil society organisations and persons with disabilities and their representative organisations. She received 40 responses. She also relied on information gathered during an expert meeting on supporting the autonomy and independence of older persons with disabilities, which took place in New York in October 2017 (UN 2018).

Aguilar’s report identified that the majority of supported decision-making schemes reviewed for 2017 concentrated on a specific group of persons with disabilities (mild to moderate). While some pilot projects have attempted to include a diverse range of participants, the diversity of the disability community requires a response to a very broad range of support needs and specific groups, for example family carers, may be in the best position to define those support needs. Furthermore, persons with a high level of support needs, including those with severe cognitive impairments, non-verbal communication and/or complex needs were usually excluded from such schemes (UN 2018).
This study demonstrates that people, living with PIMD, assert their uniqueness in trusted relationships and their ways of expression(s) often bespoke and non-traditional. Therefore, the ‘one size fits all’ approach to supported decision-making mechanisms purported by individualistic notions of autonomy are ineffective if not discriminatory to this cohort. Similar to Aguilar’s contention (UN 2018-theme: legal capacity reform and supported decision-making B: 55) providing access to a broad range of support arrangements seems better than developing a single model of supported decision-making. The cyclical nature of ‘Interactional Guesstimating’ aims to meet this broad range of supports. This research is one element addressing this gap, and from this perspective offers the following recommendations:

- Discussing this research and the proposed model at the IASSIDD in Athens (2018) demonstrated the challenges implementing this ‘change of policy’ particularly for persons, living with PIMD. The international audience at this conference, representing all continents, shows the diversity of cultures, practices and laws affecting the rights of persons, living with intellectual disabilities, and the challenges of implementing support at the macro, meso and micro levels.

- Continued discussions at an international level with audiences beyond the legal professions, such as IASSIDD thus warranted.

- The development of legal frameworks, in all countries, recognising both informal and formal support arrangements.

- Findings of this study contribute to understanding legal capacity as per assessment aligned to supports both formal and informal. Therefore, understanding profoundly intellectually disabled person’s engagement in decision-making- ‘Interactional Guesstimating’ as a model can contribute to the UN CRPD philosophy and therefore support its successful implementation.
6.3.2 Specific Recommendations for practice

In the 22nd century, family carers may well look back at the beginning of the 21st century in RoI and see this time as beginning recognition for their role and contribution in advancing understanding of the significant role that family carers play in the lives of those they support, and in relation to this study, those living with a PIMD. The actions of family carers as supporters detailed promoting intimate and personal care, household tasks, providing emotional support, and performing health and medical tasks, 24/7 days. In addition, advocating and ‘delivering on’ for their sons and daughter’s needs, values, and preferences in multiple forums inclusive of home, community and in particular health, educational, financial, leisure and specialist settings, functioning in an ambiguous capacity, with legal ramifications, as a supporter in decision maker in changing times.

Professionals and society need a greater depth of understanding and empathy for the needs of family carers than they have at present (Chadwick et al. 2013; James 2013). Despite changes in societal inclusion of disabled people family carers experiences of negative attitudes continue to hamper acceptance and certainly appear to contribute to the experiences of discrimination and health inequalities experienced by their sons and daughters. Practitioners should be aware that parents of children and adult dependents, living with PIMD, spend the longest time of all carer groups, supporting and caring their children and adult dependents. This study in conjunction with data from the national Census 2016 (Central Statistics Office 2018) correlates this finding.

While attempts to change these attitudes have met with some degree of success further work is required. Therefore, professional interventions should recognise the real dilemmas that family carers face and consider in their answers what to do, rather than just responding abstractly or bureaucratically, such as

- Value and appreciation of family carers experiences in ‘knowing the person’ acknowledged and respected in delivering on this support
- Focused educational and learning resources to individual circumstance
• Develop effective meaning-focused coping strategies for family carers themselves shown to increase positive emotions

• The assessment and provision of care to meet the psychosocial needs of family carers is a key consideration for future work

• Challenges in this research with regard to the existence and sustainability of ‘natural supports’ were evident. Focused strategies to develop these natural supports would be beneficial, including firstly, education of children in local schools, where they meet their local community and known to the community.

• Legislation needs to acknowledge this diversity in supported decision-making regimes. However, there is little recognition of peer support in legislation, despite its potential to assist persons with disabilities in exercising their legal capacity. Legislation needs to consider the recognition of formal and informal peer and familial support in these regimes.

• Support parents in the ‘hands-on’ assistance required, over the 24 hour day, not just the 9-5 business hours

• In reducing professional dominance practitioners require re-orientating of services/practices for example:
  o Were family carers perspective accounted for
  o Practitioners and services to conduct regular audits (or employ an independent auditor) of family carers experiences in relation to interactions with the service
  o Take family carers seriously
6.4 Alternative explanations of the findings

This dissertation while acknowledging the difficulties that can be involved in determining a person's will and preferences may provide arguments that sustain notions that people, living with PIMD, are unable to express their will and preferences, despite receiving adequate support. In medical and technical terms, there may be a truth to this understanding. Family carers have clearly stated the purpose of functional, interpretivist approaches in ascertaining will and preferences. Therefore family carers’ arguments of representing the person’s uniqueness and ways of expression, via assisting, and representing their sons and daughters is well founded. Albeit at times guesstimating.

In asking the question, is this research helpful to the target population, I considered and to this end, the writing style and argumentation of this theory serves to assist family carers and their organisations, so written in a manner that is relatable to them. Some may find this style simplistic and long-winded. The writing style deliberately aimed to move beyond ‘text’, and a product, but serve the essence of what writing can do and generate new thinking. In that regard, bringing the essence of family carers’ commitment, engagement and workings to this dissertation, articulating their wisdom and central role in supporting another.

Different theoretical and methodological lenses could lead to different interpretations. In this study, the constructivist interpretivist stance taken serves to illuminate experiences of the interactional and relational aspects of supporting person, living with PIMD, in decision-making. This approach served well. However, as with every research approach strengths and limitations exist now detailed.
6.5 **Strengths and Limitations of the study**

This co-constructed ground theory has numerous strengths and limitations listed below.

*Strengths*

This study was able to address some of the limitations of prior research by using a qualitative approach, avoiding the deficit perspective so common in family carer studies, and using data collected directly from family carers rather than relying on professional reports. It provided an in-depth look at a complex experiences and facilitated family carers’ to express and share their words, thoughts and ideas. Therefore, a strength of the study relates to the chosen methodology, which listened to family carers.

Data collected from a small number of family carers cannot be generalised to a larger population. While this was not the intention from the onset of the study, what has emerged is how the findings can be transferable to other settings. For example, supporting those with other cognitive impairments and decision-making challenges. In addition, it would be worth pursuing if this model in supporting decision-making were utilised in developing parenting approaches. Would there be any benefit to child development and positive outcomes re self-esteem and confidence building. Therefore, child workers, along with educators, nurses, GP’s and social care workers may be interested in this model of supporting decision-making.

‘Not being listened to’ a recurrent theme in professional, political and social arenas for many family carers and particularly those supporting intellectually disabled people. The silence of this population’s voices experienced, among other ways, through the attitudes toward services for persons with intellectual disabilities and their families have focused on the importance of the role of ‘experts’ and minimised the role of the personal experiences of those most affected by the situation (Mansell 2010).
Family carers in this study have been listened to, heard and in promoting their words, ideas and understandings, their ‘voice’ recognised. This dissertation and subsequent publications give voice to their experiences (Ryan (2018a) and Ryan and Coughlan (2018b)). Presentation at conferences have communicated their important viewpoint (Ryan and Coughlan 2018a, Ryan 2018b) in addition to further dissemination plans to continue to articulate their important contribution to knowledge.

Healthy debate on ideas and social change is important, and another strength of the study relates to the findings, grounded and realistic interpretations that family carers shared providing detailed information to explain the complexities surrounding supporting persons, living with PIMD, in decision-making. In this study the subtleties and complexities about family carers being and becoming is powerful and compelling than perhaps I would have achieved from a quantitative data set or missed by a positivistic enquiry.

Many previous studies framed their research ‘on’ this group of family carers prior to the UN CRPD (2006) proliferation of a changing paradigm. Prior to the 20th century, in the RoI, similar to many European counterparts and some countries today, offered a range of institutions in ‘response’ and as a matter of social policy to a range of problems faced by ‘Irish society’ including public asylums, mother and baby homes, country homes, reformatories and industrial schools, special schools and residential homes. Most residents held in these places of ‘coercive confinement’ involuntarily, or failed to provide consent. This study accentuates the political, social and economic circumstances affecting family carers supporting profoundly disabled persons. Their lives, environment and personal circumstances reflected in the data illuminated family carers’ current role, identity and experiences as well as a holistic view of family carers’ experiences in supporting their sons and daughters in decision-making.
Therefore, moving into the 21st century this study in offering a model of supporting decision-making that promotes a ‘progressive’ humanist response to supporting profoundly disabled the ‘first generation’ of the UN CRPD (2006) going forward. Addressing civil, political social economic and cultural rights collectively to meet this aim.

The emergent model of supporting decision making ‘Interactional Guesstimating’ presented emphasises the relational components focused on commitment, engagement and a humanist interpersonal spirit co-existing with the physical and technical component(s) involving the differential evocation and reinforcement of the profoundly disabled persons wishes, will and preferences.

6.5.1 Limitations

Research on supporting decision making, as the dissertation outlines, is in its infancy stage of development. Agreement in the literature of the nebulous concept supporting decision-making is and the lack of prior research studies on family carers’ experiences supports using an exploratory research design. However, the findings are tentative and the small sample with self-selection and snowballing sampling process may reflect those family carers who expressed interest in the study having felt more comfortable discussing their experiences.

Family carers with more negative or mixed feelings about supporting their sons and daughters in decision-making, or perhaps little feelings on the matter, may be more hesitant to express those thoughts to a researcher and as a result may not have responded to the invitation. Despite efforts to recruit a diverse sample, there was minimal diversity among participants. Certain voices are absent for example family carers not fluent in English, family carers of minority ethnic origins, and while fathers were included, the majority of family carers were mothers.
This constructivist grounded theory study represented the researcher’s interpretation of a reality situated in a certain time and place. The theory co-constructed with family carers acknowledges there may be other interpretations of reality and other realities to interpret. Nevertheless, the aim of the current researcher is to put the account before members of the scientific community and have them decide.

While a strength of the study noted as the grounded theory approach, an opposite limitation must also be the character of grounded theory with its learnability difficult and minimal direction in relation to its flexible approaches. Challenges in annual progressions stating the need for conceptual frameworks to be explicit early in in the research process were difficult to defend on a first grounded theory. From this, it became clear how important research supervision is in the context of this method, but clearly highlighted the contentious nature and understanding that grounded theory brings to academic discourse.

6.6 Reflections

Initially the rationale for this study evolved from reflecting on practice and discussing anticipated consequences of major changes in public policy, legislation in addition to the re-organisation of disability and health care services. This commenced the acute awareness of my initial ignorance to family carers’ experiences summarised in a reflective journal as that of a romantic impression suggesting joyous and virtuous aspects of familial heroes. Like the flipping of a coin, tossed and turned in air, landing upside down, my worldview has changed.

The ‘conversational interviews’ and the ‘carers group’ facilitated family carers’ voice in a manner that noted ‘what they wanted to say’. This was important to this group of participants, which it would be fair to say, have little voice in our history, research and society in general core to grounded theory approaches. The essence of this approach yielded much in-depth and fecund data, presented with strong emotions of their individual situations.
As my insight developed further and listening to family carers’ assertions, I came to realise the hard graft of family carers’ experiences is most often unrecognised and at times taken for granted. Witnessing the enormity of their situations in a vacuum of primary and community services shocked me. Saddened me in my role in health and education. The feeling ‘we are leaving them down badly’ transpired.

Writing about family carers’ experiences, illuminating tacit and silent ways was tricky. Wanting to bring their intense commitment and understanding to this dissertation, I did not want to present a negative view of the person they supported, as this I believed would have been disingenuous to their trust in me. I queried at times was I over stretching my personal beliefs of disability to the analysis, which the co-construction viewpoints allows, I wanted their experiences to be the mainstay. Reflections and supervision contributed to this tension. I needed to demonstrate understanding of family carers’ very personal experiences and circumstances, which was complex therefore, at times may be hard for readers to grasp. I believe this stems from family carers’ conceptualisation of ‘profound disability’ and ‘support’ to be dissimilar to many professionals, and we have much to learn from their interpretations.

The actions of this group of family carers in supporting their sons and daughters in decision-making has challenged traditional notions of ‘profound disability’ and ‘capacity’ beyond the scientific or technical matter. Family carers sharing of experiences has raised many questions, moving beyond textual understanding recognising how family carers in supporting another take into account the person’s uniqueness and ways of expression in addition to the consequences of the decision being made, bringing us to the nub of a controversy.
Family carers’ conceptualisation of ‘support’, given the high level of knowledge and the significant level of care they provide, challenges professionals understanding of their role and responsibilities, inclusive of supporting decision-making. When family carers aid their sons and daughters to engage in decision-making claims of quality of life and authority come to play. Family carers recognise that when their sons and daughters do not comprehend decisions, then family carers render action mindful of the uniqueness and ways of expression in addition to the consequences. Family carers challenge professionals’ responses as often dismissing the uniqueness of the persons, and their circumstances inclusive of the family support, and note how professionals in the main consider the scientific, professional requirements or technical and legal matters. This is not surprising.

Developing insight into family carers ‘care perspective’ brought the essence of love and humanity, the core of their relationship, to the forefront and a realisation for myself, as a professional and important to instil in student nurses, the importance of recognising these factors. Often berated, as over protective and paternalistic, yet without family carer interventions where would people, living with a PIMD, be? Systematic changes require seeing all perspectives. Family carers tacit and acquired knowledge, skill and competence challenges professionals in areas of which professionals generally have little understanding, therefore, being open to challenges and listen and work with family carers who ‘knows the person’ must replace ‘the professional knows best’ approach.

This dissertation gives voice to this group of family carers. The 24/7 decision-making support requires personal knowledge of another, found in sensing a union, aids them in offering support with the informal every day decisions, through framing representation and steering affairs. Distinguishing between formal decision-making (personal welfare –including healthcare and financial affairs) and informal decision-making (arguably personal welfare, including healthcare and financial affairs, in addition to decisions surrounding the milieu of life) may not be helpful if the philosophy of supporting decision-making is to be realised.
Are the rights to autonomy, physical and mental integrity, and generally to be free of interference by agents of the state to prevail over social and economic rights yielding positive entitlements such as full social inclusion and participation, the highest attainable standard of health, and a minimum standard of living? What happens when those rights conflict? Civil rights protect individuals’ freedom from infringement by governments, social organisations and private individuals. The enjoyment of all human rights are interlinked, however, without enforcement of the economic social and cultural aspects to support in decision-making requiring high levels of investment such as financial, personal, and creative thinking, realisation of the ideology of supporting decision-making for all (not just those that get heard) may remain an elusive ideology.

This inquiry has unearthed the ethical, legal and practical elements within the concept ‘supporting decision-making’. In supporting persons, living with PIMD, in decision-making these family carers realistic and first hand experiences depict the line between two seemingly incompatible obligations of the state – to respect individual autonomy and to protect the interests of people who are vulnerable (Dawson 2015).

Civil, social, economic and cultural rights all need to be realised. These family carer’s claims of the need for humanist and instrumentalist approaches to support in decision-making bring a realistic interpretation of Article 12 of the UN CRPD, and can offer understanding aiding a humanist perspective to advance strategies following the introduction of the Assisted Decision Making (Capacity) Act 2015 in Ireland.
6.7 **Dissertation Conclusion**

Proper recognition of the extent of family carers’ caregiving roles and commitments by professionals, service providers, policymakers and stakeholders is long overdue. The examples given in this dissertation show that family carers work intensely and extensively to make sure that their sons and daughters are valued and given the services, they need. We owe it to these family carers to give them recognition, listen to what they have to say, involve them in decisions, which affect their lives and provide them with services, which help them to deal with their role. I hope this dissertation study will have some utility in emphasising this commitment.

‘Interactional Guesstimating: growing confidence with uncertainty’ builds a comprehensive account of family carers’ experiences in supporting their sons and daughters in decision-making. In this study, family carers demonstrated that in such a relationship, embedded aspects of the iterative interplay between the family carer and the person they support requires family carers to provide an extension of oneself and movement into another person's world to aid in seeing their sons or daughters viewpoints, understandings and values. Challenging as this is, there are times when success is clear, sometimes, there is no knowing. This level of interaction and connecting by its very nature established on the human and personal level is intense, garnered over time. Emphasising the ‘relational’ and ‘interdependent nature of being’ as core to supporting profoundly disabled person’s family carers sharing of experiences has facilitated understanding of the concept supporting decision-making beyond the textual analysis of Article 12 UN CRPD.

Emphasising the personal and interpersonal relationships as central to support challenges legal notions of support. Civil liberties and human rights appear to dominate discourse in the area of supporting decision-making aiming to empower disabled people; this dissertation throws new light on these discussions. This group of family carers bound by a duty and ethic of care demonstrate vividly the complexities of proffering the will and preference that profoundly disabled person.
Appendix 1 Listening to Carers
The centre manager invited me to attend a forum for Carers in March 2012 ‘Listening to Carers Forum’ in a Hotel in the Mid-West area, hosted by the Executive Group of the Organisation, in preparation for their submission to the Department of Health (DoH) on the upcoming Carers Strategy. This was an eye opening experience into carers’ realities. The following field notes ‘Listening to Carers’ reflects my growing insight;

This field note concerns attendance at the ‘Listening to Carers’ forum at the XX Hotel, ‘Mid-West Region’

Mainly older carers in attendance (approximately 60 carers) of Irish nationality with the exception of one Indian couple. Noticeably when carers enter the room a familiarity amongst carers and a closeness shown in their greetings, looking at each other and a warm nodding of welcoming. Some carers were there for the first time and appeared more anxious, straight into asking questions for example, ‘where can you get the respite?’ and their stories flow automatically from them.

A sense of security and solidarity is created automatically and the older carers relay their experiences and advice prior to the forum officially commencing. The CEO opens the forum, outlining the plan for the day and informing the group of the intentions to guide the discussion, yet to hear all opinions and comments. In all, eight discussion areas including Social inclusion, financial supports and health matters. I noted how structured the agenda is and whose agenda it is................The CEO asks the group to formulate into six focus groups choosing one matter individually. Each group then provided feedback after a half hour discussion. The introduction was very detailed, and the CEO outlined where he saw the vision of the ‘The Organisation’ under the different headings. Were the caregivers being railroaded? One carer commented on how ‘The Organisation’ is funded by the HSE and therefore is it really independent or acting as a buffer for the HSE and policy makers?

The politics of caring was immediately apparent with the discussions around outlining a vision for supporting carers around finance health employment and social inclusion. The eligibility for the carers grant, respite care grants, income up to 15 hours a week were all freely discussed. I questioned what has this to do with caring, and the ethics of paying for informal care at home. The debate regarding the saving to the economy was described as €4 billion a year and how carers need to be recognised for their contribution clearly articulated. As an outsider looking in I was conscious of the emotions in the room and of the genuine recall carers were describing of their experiences.

XX described caring for his wife as ‘something I never signed up for but in sickness and in health’ it was the way he said it too, the tone jolly yet sad.
XX described her stress of caring for her two elderly parents, juggling childcare and coping with the sibling conflicts of managing the care and associated challenges for her parents. Prime example of who should get the carers allowance, and the medical card? Should all siblings or the ‘named’ carer and if they are all helping? And XX, the ‘if only Heineken did a XX’ the carer who has experience, common sense, looked at herself in caring, her abilities her challenges her struggles, her needs. And yes she likes to talk and feels it important to talk and attend meetings such as this forum as it helps ‘to get things off your chest’. She described a choking incident at home where she had to literally throw her husband out of the chair on to the grass to help with his breathing. Not knowing what to do, she didn’t press the panic button as she thought she’d have to wait all day. All ended well, but she ‘wasn’t right for the day, a feeling of uneasiness’. If training like CPR or manual handling was there to meet her individual needs it would be helpful. She didn’t think to ring ‘The Organisation’, not knowing what could they really do for her then?

Yet any ‘formal carer’ (that is health care professional) that would go into a home would have to have training in these areas. Her son has OPPD and the difficulty is compounded that ‘it’s easier do it yourself’ and therefore she has no home help or carers’. ‘They’re a bit awkward’. Her daughter helps out, and took the day off work to ‘mind the two as she said you could do with the day out’ to attend forum.

And then Ms A, who previously cared for her mother and now her son. Manager introduced her to me, and explained my research which ‘she was happy to do anything if it helps in any way’. We exchanged numbers and arranged to meet the following Thursday.

Field notes 6-1 ‘Listening to Carers’

This field note immediately highlights the intensity of caring across the lifespan, the diversity of carers and the physical social financial and emotional needs of carers in addition to the person(s) they support.
Appendix 2 International Summer Schools NUIG

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<tr>
<th>Date: Course/Seminar/Learning: Thoughts and Comments</th>
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<td><strong>18th-23rd June 2012; Fourth International Summer School on disability law &amp; policy Convention on the Rights of Persons with a Disability (NUIG)</strong></td>
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This was amazing, 29 countries in all represented, the 4th summer school in Disability Law and Policy, aimed at law students, but opened up to all, so interesting where to start, 20 PhD students there from DREAM (Disability Rights Expanding Accessible Markets or DREAM is a training network for early stage researchers stemming from the EU Marie Curie Initial Training Network Funding Programme. The primary aim of DREAM is to professionally develop and educate the next generation of disability policy researchers and entrepreneurs to assist the EU and its Member States in their efforts to implement the UN CRPD at EU and Member State levels. This will involve exploring options for European Union disability law and policy reform in light of the United Nations Convention on the Rights of Persons with Disabilities (2006).

Meeting
- Prof Gerard Quinn lead in the Research Centre NUIG
- Janet Lord, Harvard Law School Project on Disability; BlueLaw International; University of Maryland Francis King Carey School of Law
- Professor Theresia Degener, Member of the UN Committee on the Rights of Persons with Disabilities,
- Professor Rosemary Kayess, University of New South Wales (Sydney).

Date: Course/Seminar/Learning: Thoughts and Comments

All visiting lecturers/guests stayed around for the full week, open to chatting/discussing/debating. Talks were insightful and fundamental to all was the importance of personhood, while the main aim of the school was to explore article 12 (capacity) and importance of article 19 (living arrangements) had to be included in most of the presentations. It brought the convention to life for me; Moot court was interesting; I surprised myself in how I could apply reasonable adjustments, safeguard mechanisms and protection as enhancing rights, even if I was on the opposite side!! Which is apparently the one you should go on to get real experience, good for the law students, good for me.

17th-21st June 2013  Fifth International Summer School on disability law & policy Convention on the Rights of Persons with a Disability (NUIG)

This year the focus on Voice & Choice was evident; One day – VOICE (Article 12 UN CRPD) - given over to the challenge in restoring voice by reforming out-dated legal incapacity laws. Innovation around the world was explained and there will be an in-depth discussion about the complexity of reform and successful advocacy strategies.

Meet Janet and Rosemary again this year, and their passion and enthusiasm for ‘passing on to the next generations’ the necessity for this convention is admirably.

Part of another day – CHOICE (Article 19 UN CRPD) –focused on giving people with disabilities power over their own lives in terms of their living arrangements and community connectedness. Important strategies – including legal strategies – for achieving community living was explored. These two elements – Voice & Choice – are connected and the many lines of connexion was explored – including the degree to which community living is itself a form of support to enable people exercise their legal capacity.
Appendix 3 Initial Contact

From: Name Centre Manager [organisation@organisation.com]
Sent: 01 June 2011 23:00
To: Ruth Ryan
Subject: Re: Chat

Hi Ruth
Thanks for the email. I have been thinking about this and without wanting to pass you from pillar to post, I feel the best person for you to talk to is Name Social Policy Officer who is based in our Head Office in XX. She deals with our research and policy development etc and I feel she would be more able to help you on this. Her number is 0xx xxxxxxx
Best of luck,
Name Centre manager

Name Centre Manager
Organisation
0xx xxxxxxxx
----- Original Message -----
From: ‘Ruth Ryan’ <Ruth.Ryan@ul.ie>
To: organisation@organisation.com
Sent: Wednesday, 1 June, 2011 4:37:34 PM
Subject: Chat

Hi Centre Manager,

I spoke to (administrator) in the office this afternoon, who said the best way to catch you would be to email. Let me introduce myself, my name is Ruth Ryan, I am presently working in the Department of Nursing and Midwifery here in the University of Limerick as a Lecturer on the BSc. Nursing (Intellectual Disability) programme and would be interested in chatting to yourself.

I hope to undertake further study (PhD level) and as part of that would involve research in the area of intellectual disabilities I would like to include carers and individuals with a disability from the very beginning, that is at the design stage etc. hence before I go any further I think it appropriate to contact your organisation to get a sense of the realities of this approach, the perspective of carers/parents and most importantly aspects of research they deem most appropriate. I am particularly interested in ‘How persons with profound intellectual disabilities engage in decision making with the support of their carers’

As I said this is very preliminary and I am open to comments and suggestions you may have to offer, I would appreciate if you could take the time to consider this, and perhaps contact me to chat, my mobile number is 08X XXXXXXXX (personal mobile).

Kind Regards
Ruth

Ruth Ryan/ Ruth Ui Riain
Department of Nursing and Midwifery/ An Roinn Altranais agus Cnáimhseachais
Faculty of Education and Health Sciences / Dámh an Oideachais agus na nEolaiochtaí
Sláinte
University of Limerick/ Ollscoil Luimnigh
Guthán / Phone: + 353 61 234216 / 086 6094454
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Facs / Fax: + 353 61 234216
Gréasán / Web: www.nm.ul.ie
Appendix 4 Brief Research Proposal
Extracted from original research proposal to supervisor and presented to ‘Social Policy Officer’ and ‘Centre Manager’ of the Organisation in October 2011

Introduction
A report commissioned by MENCAP in the United Kingdom (U.K.) (2004) ‘People with profound and multiple learning disabilities: A review of research about their lives’ conducted by Dr. Steven Carnaby described eleven themes form the research literature that were pertinent to the lives and wellbeing of this group and their families. The eleven themes were: Service design and quality of life, Choice and decision-making, Communication, meeting personal needs - Therapeutic interventions, Sensory needs, Staff training and staffing issues, Parent and carer issues, Mental health and wellbeing, Challenging behaviour, Physical health, Personal relationships and sexuality. A comprehensive and meaningful report, which was one of the first reviews to address from the perspective of persons with profound intellectual and multiple disabilities (PIMD) and their families the concerns, challenges and opportunities in their daily lives.

Of particular concern and importance, underpinning each and every theme described by Carnaby (2004) is the concept of choice and how choice is addressed. An analysis of how people with PIMD are offered choices throughout their day would help to outline both the ways in which decision-making needs to be approached and the range of settings in which it can be considered. Following from this a review of how decisions are made on behalf of people which may range from everyday decisions about what to eat, through to discussions about compatibility of potential housemates would. There is no doubt that this group of people require support in most activities yet there is little evidence to support the experiences of parents/family carers in offering this support. Literature has demonstrated how services and professional engage in support, and this has led to many professions developing specialist posts for example nursing in intellectual disability with much of the research conducted from an international perspective. However, the experience from the so called ‘exert group’ the parents/family carers, is scantily described in the literature.

This project aims to explore the experience of family caregivers when involving people with PMLD in decision-making

Main objectives of the proposed study are to:
• hear the stories of family caregivers
• gain insight and understanding of the success and challenges that family caregivers have when supporting PMLD
• engage in a participatory process with participants
• consider the process of gaining this insight
• develop an explanatory theory

Ethical Considerations: Reviewing moral responsibilities in proposed research. Ethical approval will be sought from the University’s EHS Ethics Committee
Data Collection: 1) Individual Interviews:
Consideration to the ethical principles at each stage of the research process is required. All research can be potentially harmful to participants and researchers and while this proposed research is not testing new drugs through invasive procedures naturalistic enquiries that seek evidence about sensitive topics such as supporting decision-making in persons with a PIMD may lead to inadvertent emotional stress to individuals and therefore informed consent will be obtained. This will be facilitated by means of an ‘Information Sheet’ containing the following; aim and objectives of study, proposed time of interview, rights of participant in addition to maintaining confidentiality, data protection, right to withdraw, potential benefits, potential harms.

Data Collection: 2) Group Sessions:
Information Sheet containing the following; aim and objectives of study, proposed times and commitment required, rights of participant, mutual benefit. Informed consent containing info regarding the following: confidentiality, data protection, right to withdraw, potential benefits, potential harms. Ground Rules of group, will be established the beginning of group mindful of group dynamics, interactions and confidentiality issues

Data Analysis:
Iterative process, which will occur simultaneously to data collection.
Appendix 5 Gatekeepers Agreement

-----Original Message-----
From: Name Social Policy Officer of the Organisation
[mailto:name@organisation.com]

Sent: 25 October 2011 10:36
To: Ruth Ryan
Subject: Re: Research Proposal

Hi Ruth,

I'm more than happy to help where I can. Things are a bit crazy in here at the minute but I'm available to have a chat on Monday if you would like to give me a call then.

Regards,

Name; Social Policy Officer
The Organisation
Address
Tel: 0xx xxxxxxx

Follow up-Telephone conversation;

- Welcoming nature of research
- Access to Organisation granted; to liaise with Centre Manager from here on in who can assist with recruitment and highlighted possible challenges and supports for participants (review provision of care for individual with PIMD if carer for interviews/carers group, expenses of travel)
Appendix 6 Ethical Approval

From: Anne.O'Brien
Sent: 05 March 2012 13:19
To: Ruth Ryan
Cc: Barry Coughlan
Subject: EHS29021282

Dear Ruth, Barry

Thank you for your Research Ethics application which was recently reviewed by the Education & Health Sciences Research Ethics Committee. The recommendation of the Committee is outlined below:

Project Title: EHS29021282 Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PTMD) in decision-making and consultation
Principal Investigator: Ruth Ryan
Other Investigators: Barry Coughlan
Recommendation: Please reapply through Chair’s Action taking the following points into consideration:

EHSREC recommends that audio tapes must be destroyed once the transcription is complete. The transcripts must also be made anonymous.

Yours Sincerely

Anne O’Brien
Administrator, Education & Health Sciences
Research Ethics Committee

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From: Anne.O'Brien
Sent: 13 March 2012 09:29
To: Ruth Ryan, Barry.Coughlan
Subject: EHS29021282

Dear Ruth, Barry

Thank you for your amended Research Ethics application which was recently reviewed by the Education & Health Sciences Research Ethics Committee. The recommendation of the Committee is outlined below:

Project Title: EHS29021282 Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PTMD) in decision-making and consultation
Principal Investigator: Ruth Ryan
Other Investigators: Barry Coughlan
Recommendation: Approved

Yours Sincerely

Anne O’Brien
Administrator, Education & Health Sciences
Research Ethics Committee
Study Information Sheet

Study Title: Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PIMD) in decision-making.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish. Feel free to contact me if there is anything that is not clear or if you would like more information. Thank you for reading this.

Background to researcher Ruth Ryan:

Originally trained as a nurse in the area of Intellectual Disability and qualified in 1995 as a Registered Nurse (RNID) Ruth worked in the Daughters of Charity Services, here in Ireland and in Romania between the years 1996 – 2004. In November 2004 Ruth commenced work as a lecturer in the Department of Nursing and Midwifery in the University of Limerick and is presently conducting this research as part requirement for the Doctor of Philosophy degree under the supervision of Dr. Barry Coughlan.

The purpose of the study:

People with a PIMD have been described as the most vulnerable among society having a profound intellectual disability associated to a motor and/or sensorial disability, causing a restriction of autonomy as well as perception, expression and relating capacities. This research aims to focus on how carers support people with PIMD and how these interactions promote choice and self-determination for the person with a PIMD. In a period in Ireland where the deinstitutionalisation and community integration agenda is to the forefront it is anticipated that this study will contribute to existing discussions and body of knowledge supporting carers and professionals in empowering persons with a PIMD in how persons with a PIMD can be supported to make meaningful choices and elicit decision making strategies within that support.

Why have you been chosen?

You have been chosen as a prospective participant in this research project because you are directly involved with the care of a person with a PIMD and familiar with the concerns and challenges of caring for an individual at home.

Do you have to take part?
It is up to you to decide whether or not to take part. Your participation is voluntary. If you decide to take part you will be asked to sign an ‘Informed Consent Form’. If you decide to take part in the study you are free to withdraw at any time without giving a reason.

**What will happen to you if you take part?**

You will be asked to meet with Ruth for approximately one to two hours. This meeting will be scheduled at times and locations that are convenient for you. With your permission the meeting will be audio recorded to allow for recall of important information. Ruth will transcribe verbatim the conversation and provide you with a transcript of the interview to review verify and provide comments.

**Will there be possible benefits in taking part?**

As such there are no direct benefits from you taking part in this interview with Ruth, however you may benefit from knowing that your participation in this study will contribute to the body of knowledge around supporting persons with a PIMD by eliciting how persons with a PIMD can be supported to make meaningful choices and elicit decision making strategies within that support. At the end of the research I will forward a summary of the findings and hope to conduct local and regional seminars with the ‘The Organisation’ to share this information.

**What are the possible disadvantages and risks of taking part?**

There are no anticipated risks related to this study. The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life. It has received Ethics Committee Approval and will be supervised throughout. Participation is voluntary and you will have the right to withdraw at any time. Post interview you will have the opportunity to ensure that the discussions accurately reflect the views expressed.

**Confidentiality and Anonymity**

All information collected during the course of the research will be kept strictly confidential to Ruth. All researched data will be anonymised and stored securely within a locked filing cabinet in the researchers’ place of work. Access will be restricted to Ruth, Ruth’s’ supervisor who will check on the accuracy of the transcription and interpretation of findings. The tape recording will be destroyed after it has been transcribed and at the end of the study the transcripts will be shredded. After the interview you will have an opportunity to review the findings of the analysis and state your support, objections or further contributions. This can be done in person, telephone or email of your choosing.

**What will happen at the end of the study?**

The results of the study will be written up and made available to you in summary format. It will be also accessible via the publication of a thesis bound for the library in the University of Limerick. It is anticipated that aspects of the report may be offered for publication both locally and nationally via journals and conferences.

In addition local and regional seminars with the ‘The Organisation’ to share this information will be organised. No one participating in the study will be identified in any report or publication.
If you are having difficulty in understanding any aspect of this information sheet what should you do?

If you are having difficulty in understanding the information in this information sheet, please telephone me on 086 6094454 or email Ruth.Ryan@ul.ie and I will endeavour to provide the appropriate assistance.

Contacts for Further Information

If you have any questions related to this study, please address your questions to the following people:

Dr. Barry Coughlan
Tel: 061-234345
Email: Barry.Coughlan@ul.ie

Or alternatively

Email: Chairperson of the Education and Health Sciences Research Ethics Committee, ehsresearchethics@ul.ie or to Anne O'Brien, who is providing administrative support to the committee. (anne.obrien@ul.ie).

Tel: 061- 202022

Thank you for taking the time to read this information sheet and considering taking part in this study. The information sheet is yours to keep and a signed copy of the consent form will be given to you should you agree to take part in the study.

Sincerely,

Ruth Ryan
Doctoral Candidate, Department of Nursing and Midwifery
Faculty of Education and Health Sciences
University of Limerick
Appendix 8 Informed Consent Form-Interview

Consent Form Interview

Individual Interview

Informed Consent Form

Study Title: Exploring family caregivers' experiences of involving people with profound intellectual and multiple disabilities (PIMD) in decision-making and consultation.

Name of Researcher: Ruth Ryan

I confirm that I have read and understand the information sheet dated March 2012 for the above study and have had the opportunity to ask questions.

I understand that I may withdraw this consent at any time by advising the researcher and I understand that my participation is voluntary and I am free to withdraw at any time.

I understand that the interviews are to facilitate the collection of information with the understanding that all the information I provide will be held in confidence and I will not be identified in the thesis, summary report or publications.

I agree that excerpts from the interviews may be included in the thesis and/or publication to come from this research, with the understanding that the quotations will be anonymous.

I understand and agree that the interviews and the subsequent transcripts and summaries, may be examined by individuals approved by the University of Limerick during the course of this study.

I agree to take part in this research

Name of Participant:

Signature: _____________________________ Date: _____________________
Appendix 9 Poster for Recruitment

Do you care for a person with a profound intellectual and multiple disability (PIMD) at home?

Would you consider being part of some research?

WHAT IS THE STUDY?

• Looks at how carers support decision making with persons with PIMD?
• Meet with researcher Ruth Ryan for one to two hours to talk
• Confidentiality assured

WHO SHOULD TAKE PART?

• Carers of people who live with persons with a PIMD
• Parents and siblings of persons with PIMD that support them on a regular basis

More Information can be accessed from

Ruth Ryan is a student of the University of Limerick and conducting this research as part requirement for her Doctor of Philosophy degree under the supervision of Dr. Barry Coughlan. Contact Ruth at 086 6094454 if you have any questions or queries or if you are interested in finding out more about this research. This study has received Ethical Approval from the Faculty of Education and Health Science Research Ethics Committee (EHSREC) on the 13th March 2012.
Appendix 10 Simpson and Repper (2011) Collaborative Approaches
Family carers have experience of providing support for people in all kinds of distress over varying time scales and with differing caring roles. This experience may be helpful to guide research from early planning right through implementation to dissemination. Examples below derived from Simpson and Repper (2011).

Early planning (pre-protocol work): Inviting carers to early planning meetings raises awareness among the research team about the experience of living with varying levels of disturbance, distress, unpredictability the impact this has on the lives of family members and close friends, upon relationships with these people – both positive and negative. This helps to shape the research question and determine the scope of the study. It is not always practical to include the perspective of family carers in the research, but the decision to exclude them needs to be justified rather than merely an oversight.

Ethical considerations: One of the key reasons for actively promoting and supporting patient and public involvement in research lies in its potential to result in more ethical research. That is, more relevant and meaningful to the people it is trying to help, more sensitive to their needs and more accessible (Staley, 2009). The presence of family carers introduces a different perspective on every aspect of research, raising new questions: what impact does this issue have on family members and informal care givers; how can their views be incorporated, what is their experience of this, would they understand what this information sheet is saying?

Designing information sheets: Removing jargon, abbreviations, wording that might seem insensitive. Advising on procedures for accessing family carers: Seeking alternatives to recruitment through service users or statutory mental health services. For example, recruiting family carers through local self-help groups, advertisements and national groups like Rethink or Mind.
Designing interview schedules for use with carers: Ensuring that questions are clear, meaningful relevant and reflect the priorities and interests of carers. Or participating in the selection of measurement tools from a range of standardised measures. Undertaking interviews with other family carers or with staff: Although there appears to be little evidence that carer interviewers are more accessible to other carers, or that interviewees are more likely to speak to them freely, this is more likely to be due to lack of involvement than lack of impact. Reminding the team about carer specific issues: For example the difficulties of speaking in private if living with the person they care about; the importance of offering separate interviews for different carers as they may have different roles and different opinions.

**Data analysis:** Involving carers in qualitative data analysis can ensure that interpretation is not conducted through a biased professional or managerial lens. Family carers may well bring a different interpretation to the text and it is important to test this through rigorous analytic procedures. For example, Allam et al (2004) recount the experience of analysing transcripts in a group with service users and carers. One man spoke of his practice of locking his wife in her room at night. Service users were horrified by the level of control he exerted, family carer researchers interpreted this as a measure of anxiety he felt about his wife harming herself during the night. This was a clear reminder that the research team had to stick closely to the words of the interviewee and avoid reacting emotionally.

**Dissemination:** It can be useful to consult carers about the most appropriate mechanisms to reach a family carer audience so that research has as wide an impact as possible. This will include writing a summary of the research suitable for a lay audience, writing papers in local magazines, circulars and newsletters; presenting the results in various, research, service and voluntary sector settings both local and national.
Appendix 11 Carers Group Meeting Documentation

November 2012

Carers Group Meeting Information Sheet

Study Title: Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PIMD) in decision-making.

Background to researcher Ruth Ryan:

Originally trained as a nurse in the area of Intellectual Disability I qualified in 1995 and worked in the Daughters of Charity Services, here in Ireland and in Romania and in 2004 commenced work as a lecturer in the Department of Nursing and Midwifery in the University of Limerick. I am presently conducting this research as part requirement for the Doctor of Philosophy degree under the supervision of Dr. Barry Coughlan.

The purpose of the Carers Group Meeting:

The group is about meeting other carers who are in a similar situation to yourself in a group of no more than six, and engaging in dialogue discussion and reflection about your experiences of involving people with PIMD in decision-making and consultation. Group situations have demonstrated positive effects of working together and will be facilitated by Ruth Ryan. The focus of the group will be to explore your experiences to date. An evaluation of the group will occur at the last session.

Why have you been chosen?

You have been chosen as a prospective participant in Carers Group Meeting because you are directly involved with the care of a person with a PIMD and familiar with the concerns and challenges of caring for an individual at home.

Do you have to take part?

Your participation is voluntary and therefore up to you to decide whether or not to take part. If you choose to you should know that a commitment to attend six sessions and participate and explore your experiences of involving people with PIMD in decision making and consultation is required. This can be done through discussion, or other means you think relevant, writings, poetry, and imaginary.

What will happen to you if you take part?
If you decide to take part you will be asked to sign a ‘Confidential Agreement’ to maintain confidential of the group. You will be asked to attend six sessions which may be audio taped (with agreement) and take place in the ‘The Organisation’, Street name, City Name.

Dates and times will be organised to suit participants with the first meeting on November the 28th at 7pm 2012

Venue: ‘The Organisation’, Street name, City Name

**Will there be possible benefits in taking part?**

You may benefit from participation in that you will be directly hearing the success stories of other carers and can associate with and perhaps relate too. Group and partnership forums have proven to be successful and with a focus on positive interactions and successes provide an opportunity to develop new skills and knowledge in a friendly caring and relaxed environment.

**What are the possible disadvantages and risks of taking part?**

There are no anticipated risks related to this study. The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life. It has received Ethics Committee Approval and will be supervised throughout. Participation is voluntary and you will have the right to withdraw at any time. Post meetings you will have the opportunity to ensure that the discussions and reflections of the meetings accurately reflect the views expressed. This can be arranged via email or telephone.

**Confidentiality and Anonymity**

You will be asked to sign a ‘Confidential Agreement’ to maintain confidential of the group. All researched data will be anonymised and stored securely within a locked filing cabinet in the researchers’ place of work. Access will be restricted to Ruth, Ruth’s’ supervisor who will check on the accuracy of the transcription and interpretation of findings. The tape recording will be destroyed after it has been transcribed and at the end of the study the transcripts will be shredded. After the meetings you will have an opportunity to review the findings of the analysis and state your support, objections or further contributions. This can be done in person, telephone or email.

**What will happen at the end of the study?**

The results of the study will be written up and made available to you in summary format. It will be also accessible via the publication of a thesis bound for the library in the University of Limerick. It is anticipated that aspects of the report may be offered for publication both locally and nationally via journals and conferences. No one participating in the study will be identified in any report or publication.

If you are having difficulty in understanding any aspect of this information sheet what should you do?
If you are having difficulty in understanding the information in this information sheet, please telephone me on **private, mobile number** and I will endeavour to provide the appropriate assistance.

Contacts for Further Information

If you have any questions related to this study, please address your questions to the following people:

Dr. Barry Coughlan  
Tel: 061-xxxxxx  
Email: Barry.Coughlan@ul.ie

**Or alternatively**

Email: Chairperson of the Education and Health Sciences Research Ethics Committee, ehsresearchethics@ul.ie or to Anne O'Brien, who is providing administrative support to the committee. (anne.obrien@ul.ie).

Tel: 061- 202022

Thank you for taking the time to read this information sheet and considering taking part in this study. The information sheet is yours to keep and a signed copy of the consent form will be given to you should you agree to take part in the study.

*Sincerely,*

*Ruth Ryan*  
Doctoral Candidate, Department of Nursing and Midwifery  
Faculty of Education and Health Sciences  
University of Limerick
Carers Group Meeting Informed Consent Form

**Study Title:** Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PIMD) in decision-making and consultation.

Name of Researcher: Ruth Ryan

I confirm that I have read and understand the information sheet dated November 2012 for the above study and have had the opportunity to ask questions.

I understand that the Carers Group Meetings are to facilitate the collection of information with the understanding that all the information will be held in confidence and I will not be identified in the thesis, summary report or publications.

I agree that excerpts from the meetings may be included in the thesis and/or publication to come from this research, with the understanding that the quotations will be anonymous.

I understand and agree that the Carer Group Meetings and the subsequent transcripts and summaries, may be examined by individuals approved by the University of Limerick, or other regulatory authorities during the course of this study.

I agree to take part in this research

Name of Participant:

Signature: __________________________________

Date: ______________________________________
November 2012

Carers Group Meeting ‘Confidential Agreement’

**Study Title:** Exploring family caregivers experiences of involving people with profound intellectual and multiple disabilities (PIMD) in decision-making and consultation.

This agreement is a contract for confidentiality among the members of the ‘Carers Group’ whose purpose is to meet other carers in a similar situation and engaging in dialogue discussion and reflection about personal experiences of involving people with PIMD in decision-making and consultation.

Every member of the group acknowledges the need to keep personal information shared in the group private. Any information shared by a group member with the group about him- or herself should be considered personal and private information.

In order to become a group member and maintain membership, each member must agree to protect this private information. Information gathered about other members of the group cannot be shared with anyone else.

If you agree with the above procedures, please sign below

<table>
<thead>
<tr>
<th>Signatures of Members</th>
<th>Date</th>
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<table>
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<tr>
<th>Signature of Facilitator</th>
<th>Date</th>
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Appendix 12 Memo’s
The memo ‘Developing intimacy’ demonstrates where the emergent concept ‘personalising care and support’ generated during the GT analysis process-

Memo; ‘Developing intimacy’
What is evident from family carers’ words and actions is the ‘enhanced emotional intimacy’ experienced between themselves and their sons and daughters. Family carers’ intimacy development is founded in family carers seeing first-hand the vulnerabilities and subjectivities and the making of personalities and feelings explicit, theirs and interpretations of their sons and daughters. Through time in addition to the physical and social actions of support (interventions) a sense of closeness and understanding of another facilitates a growing confidence within family carers in asserting preference and likes for their sons and daughters, thereby creating awareness of the other person and family carers action of ‘enforcing and reinforcing individualism’ (for their son or daughter). Such commitment demonstrates a closeness capturing the interpersonal processes whereby the dyad share important feelings and information. This closeness provides the impetus for family carers in this study to comprehend and communicate their sons and daughters’ intentions.

Through their (family carers) attempts of ‘personalising’ support feelings of ‘heightened intimacy’ place family carers in a position, moreover than others, to propose or suggest their sons and daughters wishes. I argue that the ‘sense of intimacy’ that family carers perceive is a core dimension when supporting their sons and daughters, living with PIMD, in decision-making. My reason for this argument, founded on analysis of roles highlights more than the mere list of tasks and interventions. Through passion and commitment in fulfilling such roles family carers demonstrate the contextual meaning of connecting and personalising in which intimacy matures’. Therefore, the relational aspect established through sensing this intimacy must feature in supporting persons, living with PIMD, in decision-making.

This is hard to translate into legal guidelines and UN conventions, perhaps related to a culture of individualism. ‘Relationalism’ challenges individualism as relationalism views the moral status of living beings as determined not by solely its particular characteristics (capacities) but by the relations’ it has with human beings. Well intentioned as they are (legal guidelines and UN conventions) at establishing and maintaining individual rights, they must not ignore the realities of the dyad’s relationalism perspective represented in this study.

Memo 3 ‘Developing intimacy’
This next memo reflects the process of constant comparison. A letter originally written by a father to his 11-year-old son, subsequently published and then read into the Dáil Eireann record by Fine Gael’s equality representative Mr David Stanton, was compared with the data in this study: the following memo emerged

<table>
<thead>
<tr>
<th>Memo—‘Letter to Matthew’ printed in ‘Irish Times’ 20th October 2004</th>
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<tbody>
<tr>
<td>Dear Matthew</td>
</tr>
<tr>
<td>I am writing this letter into the unknown. I know you will never</td>
</tr>
<tr>
<td>be able to read or understand it, yet it seems like the only thing</td>
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<tr>
<td>I can do just now. I lay you in your cot every night, not daring</td>
</tr>
<tr>
<td>to think of tomorrow, of our future, of your future. But tonight</td>
</tr>
<tr>
<td>it is different. I have just been at a meeting on the new Disability</td>
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<tr>
<td>Bill, and I am troubled more than I have been for a long time, yet</td>
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<tr>
<td>you still make me smile, as you have done, through dark days and</td>
</tr>
<tr>
<td>nights since you were born eleven years ago. Thank you for that.</td>
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<tr>
<td>I am truly at a loss as to why they won’t listen. How is it that</td>
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<tr>
<td>you scare them so much? Sure, you can’t walk or talk and you look</td>
</tr>
<tr>
<td>funny and I know it is hard for them to see you through the</td>
</tr>
<tr>
<td>distractions of what to them is not ‘normal’. But that’s no excuse.</td>
</tr>
<tr>
<td>We have been trying to show them for years that you are all there,</td>
</tr>
<tr>
<td>a whole person, different, but nonetheless a whole person, just</td>
</tr>
<tr>
<td>like them.</td>
</tr>
<tr>
<td>A few years ago they (the Government) sought to introduce a ‘Disability</td>
</tr>
<tr>
<td>Bill’, it was withdrawn, because it did not recognise you for the</td>
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<tr>
<td>citizen you are. The Government reacted, and for nearly two years</td>
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<tr>
<td>a consultation process ensued. There was hope, they were going to</td>
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<tr>
<td>listen to us, they were going to recognise that you have the right</td>
</tr>
<tr>
<td>to services to access your basic human rights. I am not talking</td>
</tr>
<tr>
<td>about an annual holiday to Lourdes, no, but rather the security</td>
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<tr>
<td>that the State would, as it does for all other citizens, do what</td>
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<tr>
<td>was necessary to allow you to live out a basic existence, free</td>
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<tr>
<td>from fear of being exploited, or worse, ignored, because the</td>
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<tr>
<td>money was needed for some other requirement of the State.</td>
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<tr>
<td>Tonight, Matthew, I learned that they have not listened. I felt</td>
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<tr>
<td>the slap in my face as real as if the hand that delivered it was</td>
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<tr>
<td>there. I despair. How can we leave you to these people when our</td>
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<tr>
<td>time is gone? I have been in the residential units of your future,</td>
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<tr>
<td>they exist today but a few miles from our house, grown adults</td>
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<tr>
<td>confined to quarters built for children, nothing to do all day,</td>
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<tr>
<td>except to go slowly mad. We thought that this Bill would cure all</td>
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<tr>
<td>that, but no, more of this crazy fear that you will bankrupt the</td>
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<tr>
<td>State, poor Mattie, if you only knew what a threat you are. Your</td>
</tr>
<tr>
<td>life is not to be facilitated without being shackled to ‘the</td>
</tr>
<tr>
<td>availability of resources’ or the grey notion of ‘practicability’.</td>
</tr>
<tr>
<td>We were not looking for money. We were looking for security. We</td>
</tr>
<tr>
<td>were not looking for everything now. We knew that it would take</td>
</tr>
<tr>
<td>time. A slap in the face, that’s what we got. This Bill, supposedly</td>
</tr>
<tr>
<td>the best thing to happen for people with disabilities since the</td>
</tr>
<tr>
<td>foundation of the state, is 80% to do with the state running away</td>
</tr>
<tr>
<td>and the balance a flawed attempt to give a little something.</td>
</tr>
<tr>
<td>Matthew, I know you can’t be angry, nor can you despair, you don’t</td>
</tr>
<tr>
<td>know how, but I do, ------I do, I am terrified that you will end up</td>
</tr>
<tr>
<td>in a ‘State’ (sic) of fear like so many before you. Sleep well,</td>
</tr>
<tr>
<td>my little man.</td>
</tr>
<tr>
<td>Tomorow we will try again Your Dad</td>
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</table>
While acknowledging the influences affecting family carers experiences this letter represents many of the very real concerns and fears; fears for their sons and daughters futures in social and political systems of today. It is hard to describe the emotion within me as I read these words and see within them the gravity of the situation for this family.

Having meet many families in similar situations over the past years; this letter written 10 years ago, has relevance today. Reading a letter, which was read into Dáil Éireann, the ‘House of Representatives’, in which a parent felt the physical assault of ‘the slap in my face’ acts as a reminder to healthcare workers and service providers of the hurt and emotion in the lives of these families. Writing a letter to the unknown, this is perhaps reflective of many family carers in this study. Their voices, letters and actions to the unknown. The data has similarities to Matthews’s father-participants in this study recognise feelings of despair and isolation coupled with the impact of national policies in their daily lives. Their experience in turning for help has been both positive and negative. Nearly all participants describe having ‘battled’ with the ‘availability of resources’ and their role in having to fight advocate and campaign for resources, for assistance in relation to time ‘hours’; either home help, night nurse, speech therapy to name a few resources.

For this group of family carers perhaps what are unique are the antagonist and often discriminating interactions they incur because of the many challenges with integration, for the very ordinary everyday needs such as school (mainstream verses special), play (playgrounds accessibility) and transport (accessibility of public and lack of assistance for school, occupational etc.). Family carers’ experiences mainly derive social cooperation from charities, family and friends. Evident in the data is the challenges generated in the economic downturn has significant ramifications for both the quality of community support services as well as the availability of services and supports to those at home. Family carers are thus guided by an ideology of normalisation and community integration at the meso and macro level: motives that guided deinstitutionalisation may be turned to a more cynical attempt to shift responsibility and avoid more expensive specialised services and supports affecting those at the micro level- justified in ‘fiscal conservatism’ and ‘value for money’ strategies.

Memo 4 ‘Letter To Matthew’
The sense of finding the ‘the right answer’ is very much a feature of family carers actions in ‘Framing Representation’. While writing this memo, an important focused code, ‘second guessing’, was constructed to explain a recurring process that was evident (but not yet named) in the first ten to twelve interviews.

**Memo ‘Second Guessing’**

Family carers have elicited the important aspect of representing preferences with the *combinatorial nature* of many domains, not a simply black and white answer. The data reveals family carers mental activities of assessing, observing, imagining, thinking constantly and mentally projecting ‘building a life like any’ (Mr. J) noting the emotive underpinnings. The data challenges ‘Back and Kernzer’ and ‘Flynn and Arstein-Kerslake’ views of the role of the supporter in the decision-making process as solely representative of the will and preferences of another. Flynn and Arstein-Kerslake 2014b contention ‘requires representatives making such decisions to do so in a way which attempts to draw out the imagined will and preferences of the person’ is problematic and overtly simplistic when listening and hearing to this group of family carers experiences.

I claim family carers action of ‘second guessing’ [required in the ‘not knowing] represents family carers actions of representing an others perspective and signification *in harmony with the person’s being*- illuminating family carers role as supporter in bringing forth and formalising one’s (persons, living with PIMD) purpose in addition to giving effect to one’s decision.

Memo 5 ‘Second Guessing’
Appendix 13 Criteria for Grounded Theory Studies

Credibility

- Has the researcher(s) achieved intimate familiarity with the setting or topic?
- Are the data sufficient to merit the researcher’s claims? Consider the range, number, and depth of observations contained in the data
- Has the researcher made systematic comparisons between observations and between categories?
- Do the categories cover a wide range of empirical observations?
- Are there strong logical links between the gathered data and the researcher’s argument and analysis?
- Has the researcher provided enough evidence for his or claims to allow the reader to form an independent assessment—and agree with the researcher’s claims?

Originality

- Are the categories fresh? Do they offer new insights?
- Does the analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significance of the work?
- How does the work challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?
- Has the researcher revealed liminal and taken-for-granted meanings?
- Has the researcher drawn links between larger collectivities and individual lives, when the data so indicate?
- Do the analytic interpretations make sense to members and offer them deeper insights about their lives and worlds?

Usefulness

- Does the analysis offer interpretations that people can use in their everyday worlds?
- Do the analytic categories speak to generic processes?
- Have these generic processes been examined for hidden social justice implications?
- Can the analysis spark further research in other substantive areas?
- How does the work contribute to making a better society?
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