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| Authors              | Jingwa, Ndemazia Asonglefack                                                                                                                                                                                                                                                   |
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**University College Cork, Ireland**  
Coláiste na hOllscoile Corcaigh

Ollscoil na hÉireann, Corcaigh  
**National University of Ireland, Cork**



**Responding to Black African Immigrant Parents  
of Children with Disabilities in Irish Early  
Intervention Services: Parental Experiences and  
Professional Perspectives in the Search for  
Culturally Competent Practice**

Thesis presented by

**Ndemazia Asongleack Jingwa**

for the degree of

**Doctor of Philosophy in Social Work**

**University College Cork**

**SCHOOL OF APPLIED SOCIAL STUDIES**

Head of School: Professor Máire Leane

Supervisors: Dr Eleanor Bantry White and Dr Claire Edwards

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## **List of Acronyms**

|        |                                                               |
|--------|---------------------------------------------------------------|
| AON    | Assessment of Need                                            |
| ASD    | Autism spectrum disorder                                      |
| CDNT   | Children's Disability Network Teams                           |
| CNS    | Clinical Nurse Specialist                                     |
| CRPD   | Convention on the Rights of Persons with Disabilities         |
| CRT    | Critical Race Theory                                          |
| HSE    | Health Service Executive                                      |
| ID     | Intellectual Disability                                       |
| NDA    | National Disability Authority                                 |
| OCO    | Ombudsman for Children's Office                               |
| OHCHR  | Office of the High Commissioner for Human Rights              |
| OT     | Occupational Therapist                                        |
| PDS    | Progressing Disability Services for Children and Young People |
| PHN    | Public Health Nurse                                           |
| Physio | Physiotherapist                                               |
| SLT    | Speech and Language Therapists                                |
| SREC   | Social Research Ethics Committee                              |
| SW     | Social Worker                                                 |
| UCC    | University College Cork                                       |
| UK     | United Kingdom                                                |
| UNCRC  | United Nation's Convention on the Rights of the Child         |

UNCRPD    United Nations Convention on the Rights of Persons with Disabilities

UNHCR    United Nations High Commissioner for Refugees

USA        United States of America

## Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property.

Signed: Asong

Date: 3<sup>rd</sup> August 2023

Ndemazia Asongleack Jingwa

## **Dedication**

In loving memory of my beloved sweet mother, Mrs. Atabong Helen Nguika Fualefok, who sadly passed away at the start of my PhD journey (23/12/2016). Her legacy of hard work, patience, perseverance, open mindedness, and a positive outlook on life, saw me through. May God continue to rest her precious soul.

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I owe immense gratitude to all parents and professionals who participated in this research and shared their experiences. Without them, this write up would not have been meaningful.

I am very grateful to Dr Fiachra Ó'Súilleabháin for his encouragement and optimism; the panel of reviewers throughout my PhD journey for constructively discussing aspects of this research work with me; Mary McNutt and Dr Alastair Christie for taking time off their busy schedules to diligently read through my draft thesis, discuss parts of my written work and provide insightful feedback; and Dr Anna Kingston for sharing her research work with me. I also appreciate my fellow course mates for their moral support.

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A special thank you goes to my dear father, Mr. Fualefoc Ndemazia Richard (Pa Fuandegh), whose dream it has always been for me to study to the highest possible academic level; my amazing mother-in-law, Mrs. Awung Anastasia Nkenganyi; my siblings (especially Mrs. Ndemazia Emehlem Folifac), in-laws, extended family members (especially Prof. and Mrs. Folefoc Gabriel and Mary) and friends (especially our ‘Cork family’), who were a great source of encouragement and support during this tough journey. I pray for God’s continuous blessings on our dedicated friend, Rev. Fr. Cormac Breathnach, an enduring source of calm amidst the storms.

Above everything, I owe all to God Almighty for his continuous merciful guidance and protection over me and my family.

## **Abstract**

There has been growing concern in recent years about how health and social care services in Ireland can respond appropriately to the needs of an increasingly diverse population. Internationally, literature demonstrates that immigrant families experience significant discrimination and racism in many areas of their life, including access to services, but we know less about these experiences in the Irish context.

This research explores how black African immigrant parents of children with disabilities (from Nigeria, Cameroon and South Africa) in Ireland understand and experience accessing and engaging with Early Intervention Services; and how health and social care professionals respond to and engage with these families. It also explores the barriers and challenges experienced by families and indeed professionals, and specifically interrogates the concept of cultural competence in terms of its potential to offer a route to culturally responsive professional practice.

The research took a qualitative approach based on constructionism. It used semi-structured audio-taped interviews to explore the experiences of ten parents and ten professionals. Purposive sampling was utilised. Interviews were transcribed, anonymised, coded and analysed through an inductive thematic analytic approach.

Research findings indicate that parental service experiences are influenced by their cultural perceptions of disability and expectations for their child with a disability. While findings reveal parent appreciation for services being provided for their child, they also reveal tension and ambivalence in parent-professional relationships. The complexities of intersecting identities, compounded by unfamiliarity with the health care system, and other structural challenges are seen as influencing parental interaction with services.

In conclusion, the research suggests that the concept of cultural competence in its current form is inadequate to respond effectively to the needs of African immigrant families, and that professionals do not feel adequately equipped and supported to engage in culturally competent practice. Drawing on insights from intersectionality theory, the research proposes a synergistic relationship between cultural competence and intersectionality to create the process of intersectional cultural competence.

# Chapter One

## Introduction

### 1.0 Introduction

Ireland used to be a country characterised by emigration but has since the 1990s become a destination for many immigrants from different parts of the world, including Africa. According to Curry *et al.* (2010), immigration is one of the biggest demographic changes affecting Irish society since the famine. Ireland is now more culturally diverse and home to a number of minority ethnic groups like the Traveller community, asylum seekers, refugees, migrant workers and their families. Addressing the increasing diversity of Irish society has posed some challenges, especially in terms of integrating immigrants at an individual and group/societal level (Immigrant Council of Ireland, 2016; Aquino and Buczkowska, 2022).

With the increasingly culturally diverse population of Ireland, there is growing emphasis on the delivery of culturally sensitive health and social care services to service users from diverse ethnic backgrounds, who have different intersecting identities. This thesis addresses the experiences of one such group, namely black African immigrant families (henceforth referred to as ‘African immigrant families/parents’) of children with disabilities from Nigeria, Cameroon and South Africa. A significant body of literature is available on the experiences of immigrant families in relation to adapting to unfamiliar cultural environments (Lonergan, 2009; Maatta, 2017; O’Connor and Ciribuco, 2017; Pierce, 2003; Simon, 2001; Ngadaonye, 2012; Mac Éinrí, 2007; Wijekoon *et al.*, 2021) but limited literature exists on the experiences of immigrant families of children with disabilities living in Europe and North America (Albright, 1997; King *et al.*, 2013; Swift *et al.*, 2020). This creates the need for research to generate knowledge that will educate policy makers on how best to meet the needs of immigrant families of children with disabilities and increase “awareness of and sensitivity towards immigrant families who have children with disabilities” (Albright, 1997, p. 1).

Findings from research in other countries like Canada and the United States of America (USA), which are home to large numbers of African immigrant families of children with disabilities, suggest that disability services are not provided in a culturally appropriate manner to these families (Lindsay *et al.*, 2012; Lindsay *et al.*, 2014). This research aims to address the gap in the Irish context by exploring the experiences of African immigrant parents of children with

disabilities living in Ireland and availing of Irish Early Intervention Services<sup>1</sup> (henceforth referred to as ‘Early Intervention Services’). It also aims to explore how professionals work with these families in relation to their child with a disability and to possibly inspire more research in this area to influence policy development.

In addition, this research investigates how cultural perceptions of African immigrant parents of children with disabilities affect the way they approach and relate to Early Intervention Services in Ireland. It also investigates the extent to which the concept of cultural competence might be helpful in understanding how professionals working in Early Intervention Services (Social Workers, Speech and Language Therapists, Physiotherapists, Occupational Therapists, Psychologists and Clinical Nurse Specialists originally from Ireland, Romania and India) understand and work with African immigrant parents of children with disabilities. The presence of migrants, with complex intersecting identities, demands a new way of thinking about services and questions if cultural competence is fit for purpose. This research seeks to expand the concept of cultural competence by looking at potential synergies between cultural competence and intersectionality. The introduction of the concept of intersectionality to the cultural competence discourse is suggested as one way of advancing our understanding of how Early Intervention Services respond to African immigrant parents.

Given the broad range of disabilities that exist, this research focuses on developmental disabilities<sup>2</sup> in children from birth to six years old. I focus on developmental disabilities because Irish Early Intervention Services aim to support children with complex developmental needs aged 0 to 6 years and their families, in accessing resources that would maximise the child’s abilities (Gardiner and French, 2011). Meanwhile, this research focuses on Early Intervention Services because Early Intervention Teams are the first ports of call for children with disabilities and thus, crucial to determining outcomes that will stretch into adulthood (Gardiner and French, 2011). I focus on parental cultural attitudes because the role of a parent in the life of a child is significant and vital to the development of that child, and parental

---

<sup>1</sup> Irish Early Intervention Services are community-based teams of professionals who assess and support children up to the age of six, who may have delayed development or disabilities. These teams offer speech and language therapy, physiotherapy, psychology, occupational therapy and social work services. They work with existing services to make sure the child’s needs are met (HSE, 2013).

<sup>2</sup> Developmental disabilities include conditions arising from cognitive and/or physical impairments, identified in childhood and often lasting throughout the lifetime of an individual. Examples of these impairments include Down Syndrome, intellectual disabilities, cerebral palsy, autism spectrum disorders, language and learning disorders, hearing loss and vision impairment (May Institute, 2010)

perceptions and experiences of disability services may influence the quality of outcomes for their child. I also focus on immigrant parents of children with disabilities to gain more insight into their experiences with Irish Early Intervention Services, given their intersecting identities of migrant, parent of a child with a disability, and ethnic minority, amongst others.

This chapter is structured around four sections. In section one, I explain the rationale for this research. This is followed by an exploration of the research context, which includes a discussion of the experience of being a migrant, policy developments in the area of disability and children's services, and in particular, Early Intervention Services. Section three addresses the research questions and methodology, whilst the final section provides a summary of the thesis chapters.

### **1.1 Rationale for Research**

I grew up in Cameroon (West Africa) where I associated disability with witchcraft or retribution for past sins based on the dominant negative perceptions of disability, although this is currently changing. Due to this negative perception of disability, I was apprehensive about undertaking a disability placement in my Master of Social Work course in 2014. However, despite my misgivings, my work placement in a disability setting served as an eye opener for me, giving me a more humane view of disability, which positively challenged some of the stereotypes I grew up with. This experience made me realise that disability is perceived differently by different cultures. Working with parents of children with disabilities and seeing the psycho-emotional impact of a child's disability on parents and other family members, caused me to wonder what parents of children with disabilities experienced on a day-to-day basis and what could be done by service providers to support them on this uncertain journey.

The above experience and subsequent questions led me to write my Masters dissertation on the challenges and rewards of parenting a child with a disability. During my Masters research, I realised that, while some parents either blame themselves or the healthcare system for their child's disability and focus mostly on the challenges of their child's disability (unmet expectations, social isolation, extra demands/relationship conflict), other parents accommodate their child's disability better, by focusing on rewards (positive changes in parental perceptions and attitudes and deeper emotional connection in relationships than before the birth of their child with a disability) (Barnett *et al.*, 2003; Buckley, 2002).

On questioning the above reactions, I came to understand that people's perceptions and values are often influenced by their cultural orientation. This ignited my interest in conducting this research to educate myself on the cultural perceptions of disability held by African immigrant parents of children with disabilities living in Ireland (from predominantly black African countries), and how these perceptions affect their approach to and engagement with services. It also made me keen to know how healthcare professionals in Early Intervention Services engaged with people from different cultural backgrounds, what policies informed their practice and what could be done to enhance the experiences of these service users.

## **1.2 Research context**

### ***1.2.1 Being a Migrant in Ireland***

Despite Ireland's growing diversity, little or no analysis has been undertaken of the experiences of people from minority ethnic communities living with disabilities within an Irish context. Many Irish studies have reviewed disability and migration separately rather than examining the intersection between disability, migration and other socio-economic factors and the impact on socio-emotional outcomes for children with both disability and migrant backgrounds (Swift *et al.*, 2020). Limited research into the integration experiences of migrants in Ireland (McGinnity *et al.*, 2020) may be attributed to the fact that the people of Ireland were predominantly white up till about three decades ago (Gilligan and Curry, 2010). As stated by O'Connor and Ciribuco (2017, p.5), "migrants can often be perceived as homogeneous blocks of people, a threatening mass; the telling of stories can individualise the migrant experience and help achieve greater societal understanding of the migrant situation". This has led to calls in recent years for more attention to be given to difference and diversity among people with disabilities (O'Connor and Ciribuco, 2017). More recently, a small number of Irish studies have emerged, with some of them focusing on the intersection between ethnic minority status and childhood disability in relation to Irish child protection and welfare, and the impact of converging identities such as gender, ethnicity and disability on parenting capacity assessment for disabled children in Ireland (Flynn, 2020, 2021).

Integration is an on-going issue, as some migrants may be settled in one area but poorly so in another area. For example, an immigrant may be well settled in employment but poorly so in community life, leading to feelings of isolation, which in turn impacts on their health and wellbeing (Coakley and Mac Einri, 2007). Research shows that racism and discrimination are

the main barriers hindering the integration experience of immigrants in Ireland, with African/black people at a higher disadvantage in terms of sourcing jobs, and in workplaces for those in employment (Watt, 2008; McGinnity *et al.*, 2020; Dalikeni, 2022). Many African immigrants have expressed feelings of non-integration in Irish society, while a few have reported positive integration experiences since coming to Ireland (Curry *et al.*, 2010). It should be noted that migrants' experiences differ from one another, as even migrants from the same country have different integration and settlement experiences. Some African migrants who reported negative experiences acknowledged that their life was better in Ireland than in their country of origin, expressing the wish to remain in Ireland (Ngadaonye, 2012).

### ***1.2.2 Disability and Children's Services: Policy Context and Service Development***

Historically, in Ireland, disability was considered and dealt with from a medical model perspective and located in the policy area of health. Before the Industrial Revolution of the mid-18<sup>th</sup> to 19<sup>th</sup> centuries, people with disabilities in Western societies were segregated from the rest of society (Quin and Redmond, 2003). In Ireland, disability services for children from the 18<sup>th</sup> century were largely provided through residential homes and special schools by religious orders and voluntary bodies (Harvey, 2007). It was only in the 1940s that there emerged the concept of a Universal National Health Service (Harvey, 2007), but Ireland still does not have a national health service and has never really had one in the same way as some other states like the United Kingdom (UK). The Public Health Nursing service was introduced in 1966, with Public Health Nurses (PHNs) given the mandate to attend "to the public health care of children from infancy to the end of the school going period" (Department of Health and Children, Circular No. 27/66, para 7). Disability services had an unstructured and uncoordinated historical evolution, in addition to a lack of uniformity in service provision across communities, given that different organisations had different philosophies of care (Carroll *et al.*, 2013).

In the 1990s there emerged a focus on disability based on equality. A key watershed moment was the establishment, in November 1993, of a Commission on the Status of People with Disabilities, which articulated for the first time an understanding of people with disabilities' lives in terms of citizenship rights/human rights and focused its concerns on the principles of maximising participation and enabling disabled people's independence and autonomy. The Commission's report recommended the establishment of the National Disability Authority

(NDA) to conduct and commission research on disability issues, and this was established on 12<sup>th</sup> June 2000 on foot of the National Disability Authority Act 1999. The creation of the NDA was accompanied by a government decision for services for people with disability to be mainstreamed. The publishing of the NDA (2002) Annual Report highlighted the need for a National Disability Strategy to ensure a coordinated approach towards addressing disability policy issues across many departments. This was followed by the establishment of the Disability Bill 2004 and subsequently the Disability Act 2005, with one of its aims being to progress accessibility of services (NDA, 2019).

Part Two of the Disability Act (2005), which came into force in 2007, provides children from birth to five with the statutory right to an independent Assessment of Need (AON) within a specified time frame and a Service Statement outlining the required services. An Assessment Officer, employed by the Health Service Executive (HSE) oversees the co-ordination of the assessment process. However, despite the progression of disability policy towards a rights-based approach, the implementation of the Act has not been as effective as expected (De Wispelaere and Walsh, 2007), not least due to long waiting lists for assessment and families battling to secure resources for their child with a disability (Moloney *et al.*, 2021; Ombudsman for Children's Office, 2020). The Act has also been criticised for not being rights-based, as whilst it guarantees a right to an assessment, it does not provide for a right to services or resources that may be needed following the assessment (De Wispelaere and Walsh, 2007; Moloney *et al.*, 2021; Ombudsman for Children's Office, 2020). The above deficits in the implementation of the Disability Act contravenes Article 7 of the Convention on the Rights of Persons with Disabilities (CRPD) which requires State Parties (including Ireland) to uphold the human rights of children with disabilities, their fundamental freedoms on an equal basis with other children, and foreground their best interests (UNCRPD, 2006). It does not also respect the human rights-based approach to disability recommendation of the United Nation's Convention on the Rights of the Child (UNCRC) Committee. Meanwhile, the Disability Act's definition of disability which focuses more on productivity and participation is more adult oriented than child oriented due to its failure to account for children and their needs. This has led to calls for a review of the Act with particular attention to its definition of disability (Section 2), ensuring a multidisciplinary, holistic and needs-based approach to Assessment of Needs in the best interest of the child (Section 7) (Ombudsman for Children's Office, 2020).

### ***1.2.3 The Emergence of Early Intervention Services***

The first six years of a child's life are crucial in terms of the development of foundational skills (UNICEF, 2012). Many early childhood intervention support services began as research units in universities (for example, Syracuse University in the United States and Macquarie University in Australia), while others were developed out of organisations helping older children. Early childhood intervention originally developed as a support and educational system for very young children (aged birth to six years) who had been victims of, or were at high risk of, child abuse and/or neglect, as well as children with developmental delays or disabilities (Guralnick, 2001). However, some states and regions, including Ireland, have chosen to focus these services on children with developmental disabilities or delays. For the purpose of this research, Early Childhood Intervention (Early Intervention Services) will be discussed in terms of children with developmental disabilities or delays.

Irish Early Intervention Services have developed as funded by the HSE, but delivered predominantly by voluntary sector providers, as well as the HSE. Early Intervention Services are aimed at supporting families of children (from birth to six years) with intellectual/developmental disabilities in accessing resources that maximise the child's physical, cognitive, and social/emotional development. Early Intervention Teams usually comprises of a Clinical Psychologist, Social Worker, Physiotherapist, Speech and Language Therapist, and an Occupational Therapist (HSE, 2013). This service is located within the family systems theory framework which recognises the enhancement of family well-being through family-centred practice (HSE, 2013). Family involvement is very important to the effective intervention of disability services, given that children spend most of their time with their families, with parents playing the role of gatekeepers to children accessing services and reinforcing recommended therapies through activities at home. Service provision for children with disabilities, formerly criticised for its inclination towards the medical<sup>3</sup> model and expert

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<sup>3</sup> The medical model sees disability as a personal tragedy rather than a structural issue. It sees the child or adult with a disability as deficient by focusing on what they cannot do. The personal tragedy approach is often reinforced in the care of children with disabilities (Bricher, 2000), as medical professionals often focus on the child's disability rather than on the needs, concerns and problems of the child and their parents. The treatment of symptoms rather than the concerns, needs and difficulties of the child with a disability and their family can be seen as a form of social oppression (Oliver, 1996). This can lead to disempowerment as it can cause parental dependence on medical expertise and the view of extended family members as de-skilled (Middleton, 1999), leading to a mismatch between the goals of parents and professionals.

approach, has sought to embrace the bio-psychosocial model<sup>4</sup> as its guiding model in family centred practice (HSE, 2021; Carroll *et al.*, 2013; Foran and Sweeney, 2010; Dunst, *et al.*, 2007). This reflects the influence of the social model<sup>5</sup> of disability and systems theory while recognising the importance of partnership and strengths-based models in sustaining individual and family wellbeing (Carroll *et al.*, 2013). However, it should be noted that service delivery is not the sole determinant of outcomes, but also the intersection of contextual factors such as family cultural background, availability of community support, family functioning and parental stress levels (Devery, 2018). The earlier a child is assessed, the higher the chances of influencing positive outcomes throughout the person's life (Guralnick, 2011, Ombudsman for Children's Office, 2020).

Children with disabilities' needs and services cut across government departments such as the Department of Health, the Department of Children, Equality, Disability, Integration and Youth Affairs (formerly known as the Department of Children and Youth Affairs), the National Educational Welfare Board (NEWB), and the Family Support Agency (FSA). However, there is no standardised way of monitoring and evaluating the quality of Early Intervention Services (Carroll *et al.*, 2013), given the lack of a universal national policy for Early Intervention services in Ireland. While there are some very good services in place for children with disabilities and their families, some large gaps are evident. A key issue is lack of geographical consistency in services - due to the ad hoc nature in which they emerged. For example, children

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<sup>4</sup> The medical and social models of disability are often portrayed as opposites and incomparable, but the World Health Organisation (WHO) has devised a model known as the bio-psycho-social model, which is a merger of the two models and takes into consideration the biological, psychological and social aspects of the concept of disability (World Health Organization, 2002). The WHO has also devised framework known as the International Classification of Functioning (ICF), which portrays disability as "a universal human experience where anyone can experience limitations of their functioning in society because of a health problem and societal barriers" (World Health Organization, 2002, in Honey-Arcement, 2016, p.8).

<sup>5</sup> The social model, which was pioneered by the Union of the Physically Impaired Against Segregation (UPIAS) (Finkelstein, 1980; Oliver, 1990; Oliver, 2009; Oliver and Campbell, 2013), and internationally driven through the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was ratified by Ireland in March 2018 (Banks *et al.*, 2018), is focused on the social and environmental barriers excluding people with disabilities from society. Though against the medical model of disability, the social model acknowledges the need for medical care (Dare and O'Donovan, 2002). This model has shifted disability debates from the biomedical point of view to issues of citizenship and politics (Brett, 2002). Rather than seeing disability as an individual problem, this model sees disability as socially constructed and views the individual in the context of their environment. The social model sees disability as a form of oppression created by social and physical barriers that marginalise people with impairments. This model sees society as the problem rather than the child or adult with a disability, because society excludes children and adults with disabilities from mainstream life through the erection of barriers like discrimination, rejection, poor social organisation and negative attitudes (Case, 2001; Brett, 2002; Sherry, 2017).

with an intellectual disability could be catered for by services in a locality, but not children with a physical disability (HSE, 2020).

Thus, the Department of Children and Youth Affairs developed a National Early Years Strategy, with a focus on universalising the provision of Early Intervention Services. Meanwhile, the HSE pointed out the need to reconfigure disability services for children (HSE, 2010b), and launched ‘Progressing Disability Services for Children and Young People’ (PDS), a national programme in partnership with the Department of Health and Children, non-government agencies, and the Department of Education and Skills (Carroll *et al.*, 2013). This programme was launched in 2011, with the aim of providing geographically based services, which are both timely and accessible for children with disabilities and their families, and which provide a singular pathway for assessment and intervention in the context of the primary care model. Services are based on a child’s needs rather than on their diagnosis, and it is intended that families, health services and schools work together to support children in developing their potential (Health Service Executive Reference Group Report, 2009; HSE, 2011; HSE, 2020).

PDS is currently being rolled out across Ireland, with the formation of Children’s Disability Network Teams (CDNTs) comprising a team of health and social care professionals providing services for a specific geographical area, based on the child’s home address. This is in line with two main objectives of the Sláinte Care Report (2017), a cross government agreement on a ten-year programme for Irish health and social care services to provide most of the care at or as close to home as possible and to create an integrated system of care with healthcare professionals working closely together. In addition, the implementation of the National Access Policy encourages close collaboration between Disability and Primary Care staff, while the HSE’s Primary Care, Disability, Child and Adolescent Health Joint Working Protocol (2017) encourages close collaboration between staff across three health service areas to facilitate service access to children with disabilities (HSE, 2020). Meanwhile, in March 2020, the National Clinical Programme for People with Disability (NCPPD) was established by the HSE, aimed at supporting the provision of evidence-based and context appropriate assessments, interventions and supports for people with disabilities within a rights-based and social model of disability (<https://www.hse.ie/eng/about/who/cspd/ncps/disability/>).

The needs of children with disabilities have been acknowledged in several other parallel developments. One such example is the National Best Practice Guidelines for Informing Families of their Child’s Disability. In 2007, significant consultation and research, endorsed

by parent and family organisations of children with disabilities, professionals from community, hospital and disability service settings and educational institutions, led to the development of National Best Practice Guidelines for Informing Families of their Child's Disability by the National Federation of Voluntary Bodies. This project aimed at ensuring less distress for families receiving news of their child's diagnosis and improving the sensitive delivery of such information to families by professionals through guidance, support, education and training for all professionals involved (National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, 2007).

#### ***1.2.4 Positioning Parents in Early Intervention Services***

Children with disabilities have historically been classified as silent and voiceless people, whose rights were in the hands of their adult caregivers, thus denying them the right to make choices (Corker and Davis, 2000). The focus of this research on parental and professional perspectives does not capture the views of the child with a disability (Shakespeare *et al.*, 1999). However, it is important to contextualise children's experiences in line with the functioning and processes of the family (Dale, 1996).

Research shows that people with learning disabilities, especially children, rely on the continuous support of care givers like parents and family members, who act as gatekeepers for access to services and are active in therapeutic interventions (Bradley, 1992; Case, 2000; Case, 2001; Brett, 2002; Danesco, 1997; Kingsley and Mailloux, 2013). This validates the need to elicit the perspectives/experiences of parents of children with disabilities as a means of understanding the experiences of these children, given the advocacy and responsibility rights of parents for their child with a disability (Kiernan, 1999).

From the perspective of this research, in situations where a child is finding it difficult to communicate due to their age or level of ability, the parents are the key means to unlocking their child's personal background and experiences and providing important insights into the child's situation. This offers a context within which the child's experiences and actions can be understood (Spiegle and Van Den Pol, 1993). Involving parents, by carefully listening to them and effectively communicating specialist information, may go a long way to strengthen parents to support their child at home and improve intervention outcomes for the child with a disability. These help in building parental confidence and self-esteem which has a positive knock-on effect on the outcomes for the child with a disability (Case, 2001). It is on this premise that this

research is based, given its focus on children aged between 0 and 6 years, who by virtue of their young age and/or disability, may not be able to fully articulate their experiences, thus necessitating contact with their parents.

While there is significant value in family-centred interventions (involving the family in interventions for their child), there is a lack of clarity in relation to ways of identifying the needs and strengths of families, supports that could be beneficial to families and how to involve families from diverse socio-economic backgrounds (Albright, 1997; Kingsley and Mailloux, 2013). Although there has been interest in supporting parents of children with disabilities, this is not often visible in the quality and availability of resources (Kelley and Lambert, 1992; Moloney *et al.*, 2021). Service delivery is more in line with dominant culture and values (Dalikeni, 2021). This means that families from different cultural backgrounds, like immigrant families, may end up receiving culturally inadequate and insensitive services. It should be noted that migration causes changes in family life patterns and may result in the loss or breakdown of their traditional family support systems (Albright, 1997). This highlights the need for professionals to collaborate with families, based on their culture and values within the wider socio-cultural structure, to ensure successful family centred intervention (Arfa *et al.*, 2020).

### **1.2.5 Parent-Professional Partnerships**

The cultural orientation of parents plays a significant role in shaping their attitudes towards disability, especially in relation to service expectations, family roles, and positive expectations for the child with a disability (Schuman, 2000). The way in which professionals portray disability, cultural meanings attached to disability and their impact, and choices presented to people with disabilities and their families can have a great influence on shaping parental responses to a child's disability (Wilgosh and Scorgie, 2006). Differences in culture and the fact that many immigrants may not have adequate knowledge of the health system of their country of residence, requires the development of strategies by professionals to effectively address the needs of service users. Hurdle (2002) suggests that one of the main ways to achieve cultural competence is through the empowerment of service users in terms of problem identification and solutions.

Hodge and Runswick-Cole (2008) in their study of parent-professional relationships within special needs education settings, see parent-professional partnership as an ideal resource to have within disability settings, but point out that this partnership can be highly problematic in

practice and a source of conflict and stress for both parents and professionals. Hodge and Runswick-Cole's (2008) UK study shows that despite the recognition of complementary expertise being seen as a way forward in parent-professional partnership (Armstrong, 1995), parents' expertise is not always sought and many barriers to partnership working are often found at the level of individual parent-professional relationships. Parents often feel disempowered and vulnerable in the face of professional knowledge being privileged over their intimate knowledge of their child, with some professionals focusing more on the child's impairment rather than getting to know the child (Todd and Jones, 2003; Hodge, 2005, 2006; Woodcock and Tregaskis, 2006; Runswick-Cole, 2007). This unequal balance of power causes parents to fear offending the professional, as this could not only jeopardise access to services for their child but also confirm the parents' position as deviant, maladjusted, difficult or inadequate in the eyes of professionals (Murray, 2000). Research shows professionals as preferring to remain secure within their 'expert' position (Hodge, 2006; Runswick-Cole, 2007), while evidence from Hodge and Runswick-Cole's (2008) study suggests that parental 'expert' opinions are still dismissed by professionals on the grounds of parents' emotional involvement with their child. This may cause parents to be under pressure to acquiesce with professionals' decisions even when interventions seem inappropriate for their child, to compromise against their instincts, and to alter their behaviours and parenting styles in order to meet what they deem to be professional expectations. Meanwhile, Dalikeni's (2021, 2022) study of interactions between asylum seeking families of African origin and social workers within the Irish social care and child protection system, reveals conflicting cultural perceptions in relation to acceptable child rearing practices, issues of racism and discrimination, unequal power relations and mutual mistrust.

However, studies conducted by Hodge (2006) and Runswick-Cole (2007) reveal that some parents experience positive parent-professional partnerships (Hodge, 2006; Runswick-Cole, 2007). These positive experiences happen when parents feel listened to, professionals are seen as helpful and are more interested in getting to know the child rather than the child's 'disability' (Woodcock and Tregaskis, 2006; Hodge and Runswick-Cole, 2008). Thus, successful parent-professional partnership is characterised by professionals not always having to get it right but being "perceived by parents as trying to do so and by taking on board the parents' expertise" (Hodge and Runswick-Cole, 2008, p.645). This highlights open-mindedness, willingness to accommodate new perspectives, and free thinking as effective parent-professional partnership characteristics (Hodge and Runswick-Cole, 2008).

While parent-professional partnerships may be an aspiration, in the context of immigrant parents and families, there may be several barriers that circumscribe this partnership building. Healthcare professions are often built on Eurocentric views and dominated by white middle class values involving autonomy and independence (Pon, 2009). These values can sometimes conflict with non-Western cultures, for example those involving collective family identity, thus creating challenges in the provision of care in terms of priorities and expectations. When service providers working with immigrant families from different cultural backgrounds are not aware of the understanding of and attitudes towards disability across different immigrant groups, it creates a barrier for immigrant families who access and utilise these services (Fellin *et al.*, 2013).

Findings by Lindsay *et al.* (2014b), in a study on the provision of culturally sensitive care in a paediatric rehabilitation setting in Canada, indicate that when professionals acknowledge their own biases and assumptions and learn about the perspectives of the families they work with and what is important for them (by listening to them, developing an understanding of their cultural background and views about disability, and learning about what it means for them to live within a different cultural environment – cultural translation), it goes a long way to make trust, rapport building and advocacy more engaging and more relevant for immigrant families of children with disabilities (Condon and Mytton, 2019). In addition, the investment of time in long term relationships with immigrant parents of children with disabilities could encourage parents to have open and honest discussions with professionals in relation to their experiences and concerns for their child. This is because of the stigma attached to having a child with a disability in some cultures (including some African cultures), which may be a source of shame for parents. However, the prioritisation of tasks by organisations and bureaucratic barriers, where policy often gets lost in large organisations, giving priority to administrative tasks and specialisation, may require a worker to work solely at an individual level rather than at a family level (Harrison and Turner, 2011). Although the individual cultural skills of professionals are important, of more importance is the availability of resources to ensure the continuity of such in-depth interactions, as invested in by the organisation (Lo, 2010).

### **1.3 Research Questions and Methodology**

Cultural perceptions of disability affect the ways in which people with disabilities approach and respond to services. This means that professionals are now more challenged than ever before, to be culturally sensitive in order to provide effective intervention and try to ensure

positive outcomes. The main question raised in this research concerns whether access to, and experience of, Early Intervention Services equitably translates to African immigrant families. To answer this question, the following sub-questions constitute the core of this research:

- 1) How do African immigrant parents of children with disabilities socially construct and understand disability?
- 2) How do African immigrant parents of children with disabilities perceive and experience Irish Early Intervention Services in terms of access and utilisation?
- 3) What are some of the facilitators and challenges in developing Early Intervention Services which are accessible and responsive to African immigrant parents of children with disabilities?
- 4) To what extent is the concept of cultural competence useful in helping us to understand how Early Intervention Services and professionals respond to immigrant parents of children with disabilities; and how can the concept of intersectionality contribute in strengthening the cultural competence discourse and practice?
- 5) How might African immigrant families of children with disabilities' access to and utilisation of Irish Early Intervention Services be improved?

This qualitative research is based on an interpretivist approach to gain in-depth insight into the lived experiences of some African immigrant parents of children with disabilities<sup>6</sup> and professionals. The research does not seek generalisability to all African parents of children with disabilities but seeks to have some relevance for African parents by shedding light on the experiences of parents who participated in this research (Levitt *et al.*, 2018). For wider relevance and value, this research sheds light on the processes and factors that shape how people construct/make sense of their experience.

The research makes use of both primary and secondary data sources through semi-structured individual interviews of ten African parents of children with disabilities and ten healthcare professionals, including Social Workers, Occupational Therapists, Physiotherapists, Speech and Language Therapists, Psychologists and Clinical Nurses. Research participants were based

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<sup>6</sup> Including those who came into Ireland as asylum seekers, through family reunification, with work permits and refugee with professional/academic qualifications, amongst others.

in two Irish counties. Data analysis, based on Braun and Clarke's (2006; Terry *et al.*, 2017) thematic analysis framework, was applied to this research as explained in Chapter Four.

## **1.4 Outline of the Thesis**

In *Chapter Two*, I seek to contextualise and position my research by bringing together literature which enables an interrogation of migrant parent identities in the context of parenting a child with a disability. To theorise migrant parent identities, the concept of intersectionality is suggested as a helpful starting point in relation to recognising and identifying different identity markers that could intersect with historically perpetuated inequalities to influence service outcomes for immigrant families of children with disabilities (Bešić, 2020).

*Chapter Three* explores the ways in which professionals respond to immigrant parents of children with disabilities, with cultural competence being mooted as a key approach in addressing the challenges faced by African immigrant parents living in Ireland and availing of Early Intervention Services. This chapter seeks to explore how the concept of cultural competence is understood, what some of its critiques and limitations are, and how it could be useful in addressing the challenges faced by African immigrant parents of children with disabilities. The chapter also conceptually connects cultural competence and intersectionality.

*Chapter Four* outlines the methodological approach taken in this research. It discusses theoretical underpinnings in relation to ontological assumptions and the epistemological approach; methodology which encompasses sample selection, data collection, including discussion of the interview process; ethical considerations; and data analysis.

*Chapter Five* begins the exploration of findings from interviews with parents and healthcare professionals working in Early Intervention Services. It focuses specifically on how African immigrant parents of children with disabilities living in Ireland construct and understand their child's disability, based on their experiences both in countries of origin and in Ireland. It also discusses the impact this has on them in relation to their support networks and engagement with Early Intervention Services. As will be seen in this chapter, making sense of impairment and disability in general, and their child's disability in particular, reflects the coming together of a diverse range of influences and perceptions which are often held in tension.

*Chapter Six* connects parents' constructions and understandings of disability and parenting identities to their access and utilisation experiences within Irish Early Intervention Services. While parents express gratitude for services in the context of limited expectations, some parents report experiences of racism and being discriminated against in their interactions with services. Parental experiences of discrimination, both direct and indirect, is one of the main themes that cut across the narrative in this chapter.

*Chapter Seven* presents findings on professionals' knowledge, understanding and practice of cultural competence in Irish Early Intervention Services, implications for African immigrant parental responses to services in relation to their child with a disability; and implications for professional practice within Early Intervention Services.

*Chapter Eight* provides a summation of what the data analysis found in response to the research questions and outlines the research work's contribution to theoretical knowledge. It also makes recommendations for the improvement of the experience of service access and utilisation for African immigrant families, based on analysed data and reviewed literature; and outlines areas for further research.

## Chapter Two

### Disability, Migrant Parent Identities and Intersectionality

#### 2.0 Introduction

In this chapter, I seek to contextualise and position my research by bringing together literature which enables an interrogation of migrant parent identities in the context of parenting a child with a disability. There is some limited literature primarily from Canada, the USA and UK (United Kingdom) on the challenges faced by immigrant parents of children with disabilities, notably in relation to cultural perceptions of disability influencing families' approaches to and engagement with available services (Welterlin and LaRue, 2007; Kediye *et al.*, 2009; King *et al.*, 2011; Lindsay *et al.*, 2012; Munroe *et al.*, 2016; Arfa *et al.*, 2020). However, only a few studies have explored immigrant experiences of parenting a child with a disability with a focus on how race, class, gender, socio-economic status and disability intersect to affect their experiences (Lee and Zhu, 2020; Gillborn, 2015). To theorise migrant parent identities, I suggest that the concept of intersectionality (as discussed in Section 2.3) is a helpful starting point, given that parent participants come from different cultures with different perceptions of disability, belong to an ethnic minority group, have no history of the system and no knowledge of available services.

Debates in the literature suggest that having a child with a disability can be challenging for parents due to multiple socio-cultural barriers (Jarrett *et al.*, 2014). These challenges are both psycho-emotional and structural (Thomas, 2004) and are experienced in the form of stereotypes and prejudices, limited availability of services for their child with a disability, difficulties in accessing these services, strained family relationships, social exclusion and financial problems (Albright, 1997; Jennings *et al.*, 2014). Despite the above challenges, parents often describe their child with a disability in positive terms, challenging the idea of their child's disability as a defining feature of the child, or associated with negative ideas of dependency (Jarrett *et al.*, 2014).

The experience of parenting a child with a disability is complex and diverse, based on a combination of multiple factors such as type of impairment, race, gender, socio-economic class and cultural perceptions of disability (Annamma *et al.*, 2013; Liasidou, 2013). A case in point is the focus of this research, the experience of African immigrant parents of children with disabilities living in Ireland and availing of Irish Early Intervention Services. Migration brings

significant change in the lives of those involved, with mixed effects. Positively, migrants may experience a better livelihood, but on the other hand, they can experience social isolation and the challenges of navigating a new social, cultural, economic and political system (Lee and Zhu, 2020). A diagnosis of disability can compound the challenges for immigrant families in relation to coming to terms with the child's disability (based on socio-cultural perceptions), learning how to parent that child and at the same time struggling to navigate the new system they find themselves in (King *et al.*, 2011). Looking at the above factors from an intersectional lens has potential to shed light on the holistic needs and experiences of immigrant parents who are parenting a child with a disability.

Theorising migrant parents of children with disabilities requires us to explore several separate, but interrelated bodies of literature. Given that a central aim of this thesis is to explore how understandings of disability shape parents' experiences, I first address understandings of disability and culturally specific understandings of disability. I then go on to explore literatures which engage with the experience of parenting a child with a disability. In addition, I explore the concept of intersectionality in order to provide an understanding of the complexities involved in different identity intersections and consequences for immigrant parents in relation to experiences of social exclusion and discrimination. Finally, I explore intersections with literature which focus on migrant parent experiences.

## **2.1 Disability as a Social Construction**

There are diverse understandings of disability. Disability is defined by society and given meaning by culture (Gillborn, 2015). This gives rise to different cultural perspectives of disability around the world, which shape the kind of services provided to people with disabilities (Murphy, 1990). Perceptions of disability have historically been linked to karma or moral failing, divine punishment, and biological deficit (Shakespeare, 2006). Historically, in different parts of the world, people with disabilities have been marginalised, and relatives with a disability often seen as a 'shame' on the family and sometimes cast aside, left to die or even killed (especially in places where daily life is a survival battle leading to the rejection of those unable to fully contribute to the society) (Dare and O'Donovan, 2002).

The dominant narratives in relation to disability within many African societies are largely negative (Baker and Imafidon, 2020). Historically, the dominant view of disability in many parts of Nigerian society, for example, is that it is a curse from God, the result of offending the

ancestral deity, bad luck, witchcraft, punishment for adultery, punishment for insulting or fighting with an elder (which is a societal taboo), and many others (Onwuegbu, 1977; Abang, 1992; Eskay, 2009; Baker and Imafidon, 2020). Historically, in Botswana, a child's disability is attributed to God's will, witchcraft, anger of ancestors or breaking of a taboo (Ingstad, 1988). It is important to bear in mind that perceptions of disability may vary within the same cultural group. It is also to be noted that different rights and statuses may be attributed to people with different kinds of disability. For example, a community may include blind people but exclude people with intellectual disabilities (Groce, 2005). Meanwhile, disability in later life may be seen as divine punishment of the person with a disability or their community. Some children born with a disability may not always be seen as innocent victims, but as evil spirits and thus shunned by people from fear of being bewitched or contaminated (Groce, 2005). Although Ireland has come a long way in terms of accepting and integrating people with disabilities (NDA, 2017), given their history of socially isolating and excluding people with disabilities (Dare and O'Donovan, 2002), more needs to be done to achieve full integration and inclusion especially of people with invisible disabilities within Irish society.

Although modern science has explained impairment in terms of viruses, genetic disorders and accidents, the idea of blame is still prevalent in some cultures and often resurfaces in a more "scientific" form, as both lay people and professionals often question if a disabled new-born's mother drank, smoked or took drugs (Groce, 2005; Tang, 2008). Thus, ways are often sought to determine if the person with a disability is responsible for his/her condition or if someone else is responsible. This perception may have a negative impact on identity formation by causing parents of children with disabilities to experience feelings of guilt or self-blame, which could limit their level of interaction with their community and healthcare services (Jewell and Blackmore, 2004). The concept of intersectionality is useful here in terms of appreciating how people with disabilities and their families experience marginalisation based on societal perceptions. This is especially important as parents grieve the loss of their 'hoped for' or 'normal' child (Moses, 1988), struggle to come to terms cognitively and emotionally with their child's diagnosis, while wrestling with initial reactions of self-blame, self-pity, fear, disbelief and anxiety over their child's future.

Stigma is seen as one of the main catalysts of social exclusion and social isolation which has a very damaging emotional impact on parents of children with disabilities (Green, 2003; Green, 2007), leading to "profound feelings of 'otherness'" (Jarrett *et al.*, 2014, p.197). Green's (2003)

study of 81 mothers of children with disabilities in Florida, for example, found that stigma adds to the mothers' burden of care.

## **2.2 Parenting a Child with a Disability**

There is an established and growing body of literature which explores the experiences of parenting a child with a disability. This is a diverse literature from across disciplines which reflect different understandings of disability and impairment. Historical narratives of disability and parenting a disabled child have tended to focus on the challenges and psychological impacts (Jewell and Blackmore, 2004; Mackey and Goddard, 2006; Urdang, 2008). However, Thomas (1999a, 2004) seeks to elaborate the tensions in the role and bring more social-relational understandings of disability to the fore. In seeking to make sense of the parenting role in disability, I suggest that social-relational understandings can be helpful in this regard. In response to social model debates and criticisms, a social relational model of disability<sup>7</sup>, encompassing the psycho-emotional and structural dimensions of disability was proposed by Carol Thomas (1999a, 2004) based on adult women's experiences of disability. The social-relational model of disability was a way of further developing the social model of disability. This model draws a distinction between impairment and disability and is further adapted by Reeve (2002) to discuss the power relations between people with disabilities and people without disabilities, ways in which psycho-emotional dimensions of disability can be challenged by people with disabilities, the subjectivity of psycho-emotional disability experiences and its connection to identity. Although, the social relational model, with a focus on the psycho-emotional dimension of disability, has been criticised for leaning towards the 'personal tragedy' model of disability, it highlights key dimensions of the lived experiences of

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<sup>7</sup> The social model's definition of disability as a consequence of socio-structural barriers rather than an individual problem, has been criticised for overlooking the physical and intellectual restrictions of impairment and illness experienced by people with disabilities, the cultural dimensions of disability and for not paying attention to individual experiences of oppression with emotional ramifications (Thomas, 1999, 2004; Reeve, 2002). Thomas (2004, p. 27), sees disability as "a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision". This means that "people are disabled both by social barriers and by their bodies" (Thomas, 2004, p. 27).

Thomas' (2012) emphasis on the impact of impairment on a person, "impairment effects" (not socially imposed restrictions) and on the exclusion experienced by people with impairments due to social and cultural barriers, "disablism", has raised a huge debate within disability studies (Ferrie and Watson, 2015, P. 1). It however encourages disability discourses to engage with both the embodied experience of living with impairment and the social oppression of people with impairments to fully capture the experiences of people with disabilities (Thomas, 1999). This brings together ideas of medical sociology and disability studies without pitting one against the other.

people with disabilities in relation to oppression and highlights the possibility of resisting such forms of oppression (Thomas, 2004).

The stigma and societal oppression attached to disability in some cultures has psycho-emotional consequences for parents of children with disabilities, leading to a loss of opportunities and experiences (Reeve, 2002). This warrants an exploration of the psycho-emotional dimension of disability which focuses on the internal (feelings of worthlessness) and external (not being given opportunities) experiences of oppression by people with disabilities and their families, caused by inadequate societal acceptance of people with disabilities (Thomas, 2004). Service responses to the needs of families of children with disabilities will be more effective if prejudicial ideas and distorted understandings of families are cast aside to give room for the real-life experiences of families to come to light (Jarrett *et al.*, 2014).

In caring for their child with a disability, parents often tend to change or abandon their career plans to fully carry out their duties as primary care givers due to the extra needs of their child and the lack of services. Parental sacrifices are often found in the areas of employment, health, education, community life (Petriwskyj *et al.*, 2017), with fathers often ending up as the main breadwinners for the family in two parent (heterosexual) households, while mothers give up their work and career plans to become full time carers (Hope and Oppenheimer, 1997; McKeown, 2001). This phenomenon of fathers as breadwinners and mothers as home makers is not new to Irish society, with its history of strong Catholic Church influence (Inglis, 1998).

Parents of children with disabilities have multiple intersecting identities, which are sometimes held in tension. These identities include, but are not limited to carer, parent and person (Petriwskyj *et al.*, 2017). Parents have often described the parent-carer role as dominating and overwhelming other aspects of their self-identity (Beresford *et al.*, 2007; Holland and Blood, 2008; Todd and Shearn, 1996a; Shearn and Todd, 2000). The responses of society to families of children with disabilities “can add to the burden of care, stigmatize non-disabled family members and impact a family’s ability to present themselves as ‘normal’ or ‘competent’” (Jarrett *et al.*, 2014, p.198). This negatively affects family members’ identities and those of mothers and may limit their ability to promote their child’s wellbeing in the face of existing socio-cultural barriers (Jarrett *et al.*, 2014). Petriwskyj *et al.*, (2017) criticise the combination of parent-carer roles by some literature, which portray parents mostly as carers without recognising parents as the separate entities that they are, denying parents their full identity. Revision of identity is an ongoing process as the child grows and transitions from one growth

stage to another, thus necessitating an understanding of the roles and identities of parents beyond the parent-carer to better support them plan for their child with a disability throughout the life course (Petriwskyj *et al.*, 2017).

African immigrant families often come from cultures in which disability is stigmatised. This stigma is not only attached to the individual with a disability but also to their family members. In the case of children with disabilities, parents find themselves on the front line, dealing with this stigma and associated psycho-emotional challenges (feeling less valued, misunderstood), in addition to structural barriers (Birenbaum, 1992; Darling, 1979; Green *et al.*, 2005). Immigrant experiences of stigma in relation to disability before arriving in Ireland may make them reluctant to ask for services in Ireland and prevent them from adequately advocating for their child with a disability (Darling, 1979; Kediye *et al.*, 2009).

### **2.2.1 Psycho-Emotional Disablism**

The psycho-emotional dimension of disability looks at disability through the lens of power inequality, with some groups of people (for example, people without disabilities) having the power to exclude those with disabilities (Thomas, 2004) and people with disabilities experiencing more discrimination than those without disabilities (Banks *et al.*, 2018). Thomas (2004) is arguing here that oppressive social reactions to people with disability within families, communities, education, welfare and health services impact on the sense of self, identity and self-esteem of people with disabilities. Thomas (1999, 2004) focuses on the individual with a disability and does not discuss the psycho-emotional dimensions of disability in relation to families of people with disabilities. However, looking at the focus of this research on parenting a child with a disability, parents of children with disabilities are by extension emotionally affected by existing barriers. Some of these socio-structural barriers and their points of intersection in relation to identities and inequalities are linked to psychological effects of discrimination, exclusion and prejudice (Reeve, 2002) and are a cause of psychological stress to families (Blacher *et al.*, 2005; Emerson and Hatton, 2007; Emerson *et al.*, 2004).

A study involving twelve mothers of children with disabilities (Jarrett *et al.*, 2014), based on Thomas' (1999, 2004) understanding of the social model of disability, highlights family members' experience of prejudice associated with the presence of a person with impairment in their family. This prejudice negatively impacts on family life, as parents find it hard to accept

society's perception of their child's disability, the inferiority status allocated to their child and themselves and inequality experienced in relation to social interaction with others. Thus, the stigmatisation of children with disabilities impacts on their parents and close relatives (Birenbaum, 1992; Darling, 1979; Gray, 1993; McKeever and Miller, 2004; Green *et al.*, 2005). This is referred to as 'courtesy stigma' by Goffman (1963, in Jarrett *et al.*, 2014) in relation to the devaluing of a person with a disability being extended to their family members and friends especially when their personhood is called into question by dominant norms (Landsman, 2005).

Psycho-emotional dimensions of disability can be manifest through feelings of shame, frustration and the acceptance and internalisation of certain societal expectations (internalised oppression) (Reeve, 2002; David and Derthick, 2014). Internalised oppression acts to exclude people with disabilities and their families in addition to structural barriers. In the words of Morris (1991, p. 25), "it is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility". Thus, extending the social relational understanding of disability to encompass both psycho-emotional and structural dimensions of disability (Thomas, 1999a), opens discussions in relation to internalised oppression and other emotional challenges experienced by people with disabilities and their families due to inadequate societal acceptance. Internalised oppression is powerful in shaping what people can be and who they believe they are, thus impacting on what they can do (Thomas, 2004). Prejudice undermines identity and self-esteem (Jarrett *et al.*, 2014). In the case of immigrant parents of children with disabilities, an intersection of the above challenges could negatively affect their approach to, engagement with services and level of advocacy for their child.

Although parents of children with disabilities sometimes benefit from family and community support, they may also experience social isolation from family and friends. This may be due to cultural perceptions of disability, lack of understanding of the child's disability or lack of acceptance of the child with a disability (Jewell and Blackmore, 2004). These aggravate parental grief, leaving them with feelings of powerlessness and vulnerability (Smith *et al.*, 2006). Parents attribute the bulk of their stress to social and political factors such as stigmatisation, judgmental attitudes, rejection by friends and family, public policy and law rather than to caring for their child with a disability (Turnbull *et al.*, 1993; Jennings *et al.*, 2014).

While there have been some positive changes on the part of governments, healthcare professionals and some parts of the society in relation to social inclusion, stigma reduction, provision of emotional, financial and practical support to families of children with disabilities (Woodgate, 2008), not enough attention seems to be paid to parental views on the type of support they need to effectively support their child (Barnett *et al.*, 2003). Professional support to parents should ideally start at the time of diagnosis, as this is likely a point of confusion for parents and greatly determines the attitude of parents towards their child and professionals going forward (Healy, 2015). This support may take the form of compassionate relay of the child's diagnosis while expressing hope for both the child and parents, sensitively seeking to understand the meaning of a child's diagnosis for the family and how they could be supported (Healy, 2015).

Though the challenges are many and some profound, as parents get to know their child, some of these negative feelings begin to give way to the discovery of inner strengths and resilience built on hope. Some parents cope with their child's diagnosis by "updating, rebuilding, and replacing the hopes and expectations they had prior to their child's birth with the realities of their child's actual prognosis" (Barnett *et al.*, 2003, p. 186), thus facilitating their ability to sensitively respond to their child's needs. While many scholars have generally focused on the challenges of raising a child with a disability, more recent research has explored the rewards of parenting a child with a disability without minimising the challenges (Buckley, 2002; Jennings *et al.*, 2014; Jarrett *et al.*, 2014). Having a child with a disability has been known to change some parental perceptions and attitudes towards disability, causing them to be less judgemental, less self-focused, more compassionate, tolerant and accepting of people with disabilities. It has also been known to provide a strong sense of meaning to some mothers (Jennings *et al.*, 2014), more patience, the learning of new skills as they care for their child, becoming more assertive, and improvement of family cohesion and adaptation to stressful situations (Buckley, 2002; Jarrett *et al.*, 2014). Meanwhile, Ryan and Runswick-Cole (2008) reject medicalised understandings which associate parenting a disabled child with notions of grief and loss and encourage more attention to be paid to special competence gained by parents from complex caring roles such as advocating, mediating and negotiating on their child's behalf.

However, it is important to note that from time to time, parents may experience emotional setbacks such as frustration and anger due to their child's disability, inappropriate treatment

from professionals and social rejection, even after adjusting to their child's diagnosis (Healy, 2015). Thus, unlike other parents, parents of children with disabilities may need extra support for longer periods (Sheldon and MacDonald, 2009). This is especially true for African immigrant parents who often depend on the extended family for support and may have lost this resource because of transitioning from one geographical location and societal structure to another (Thomas, 1995; Condon *et al.*, 2020).

In negotiating and responding to the stigma attached to parenting a child with a disability, some parents advocate for and inform people about their child's condition; some try to hide their child's disability to avoid having to challenge the socio-structural barriers; while others are less able to fight off the prejudices due to their own negative attitudes towards disability (Neely-Barnes *et al.*, 2010). The effect of disablism on the psycho-emotional wellbeing of individuals with a disability and their family members requires social change to address the harm caused in addition to other disablism harms (Jarrett *et al.*, 2014). While Jarrett *et al.* (2014) focuses on the psycho-emotional dimension of disability without explicitly connecting it to an intersectional approach, Ryan and Runswick-Cole (2008) mention that other factors such as the economic and social environment intersect each family's experiences. This brings us to the concept of intersectionality, which I discuss in the next section.

### **2.3 An Intersectional Approach**

Intersectionality has its roots in Critical Race Theory (CRT), which also directly applies to this research in relation to the identity of African immigrant parents of children with disabilities and how professionals engage with them. This is especially so, given the particular focus of many CRT scholars on the experiences of black people and their challenge of common assumptions that serve dominant group interests (Tate, 1997). One key perspective of CRT is its understanding of 'race' as being socially constructed and 'racial difference' as "invented, perpetuated, and reinforced by society" (Gillborn, 2015, p. 278). Racism is thus understood as subtle (hidden beneath a veneer of normality), complex and flexible; manifesting in diverse ways (depending on the context), with minority groups subjected to diverse and changing stereotypes. 'Whiteness', as an identity, is considered to be socially constructed and malleable because it refers to a set of beliefs, assumptions and practices that place white people's interests and perspectives at the centre of what is considered to be the norm, thereby constantly reinforcing the power of white interests and identifications (Ladson Billings and Tate, 1995). This shapes the world in the interest of white people (Ansley, 1997). While emphasising how

contemporary society is shaped by racism, many CRT scholars also set out “to explore how raced inequities are shaped by processes that also reflect, and are influenced by, other dimensions of identity and social structure” (Gillborn, 2015, p. 278). CRT focuses on social justice and respect of a person’s dignity and worth.

Intersectionality also has its roots in black feminism (Lee and Zhu, 2020). It was first introduced by Kimberle Crenshaw (1989, 1991), an American critical race theorist, as a tool to explore the different overlapping forms of discrimination experienced by African American women due to a combination of factors such as race, class, and gender. Crenshaw (1989) used the concept of intersectionality to highlight the many ways in which the multiple dimensions of black (African American) women’s employment experiences were shaped by the interaction of race and gender. This portrayed anti-discrimination legislation in the USA as failing to protect black women making claims against an employer. These women were asked to choose between race and gender, despite the discrimination they faced being a result of both dimensions, that is, being black and being a woman, and the same level of discrimination not experienced by black men or white women. Crenshaw argued that the full experience of racism and sexism experienced by black women could not be fully captured if race or gender dimensions were viewed separately. It also highlights differences within groups in relation to discrimination.

In addition, Crenshaw (1991) used the concept of intersectionality to analyse different dimensions of male violence against women in the form of battering and rape and how intersecting patterns of racism and sexism affected the experiences of black women, with these experiences not being discussed within feminism or antiracism. Crenshaw (1991) categorises intersectionality into two dimensions: structural and political intersectionality. Structural intersectionality reflects how the convergence of identity statuses marginalizes individuals. An example cited by Crenshaw focuses on how race and gender combine to make for qualitatively different experiences for black women of domestic violence, rape and remedial reform from those of white women. This is specifically so in rape counselling whereby the convergence of race, gender and economic status makes it difficult for black women to access necessary assistance if resource allocation is in line with the need standards of women who are economically and racially privileged (Shields, 2008). If we are to apply these ideas, it is the aim of this research to find out how race/ethnicity, culture, disability, class/socio-economic

status and gender intersect to affect the quality of experiences of African immigrant parents of children with disabilities availing of Irish Early Intervention Services.

Meanwhile, political intersectionality looks at the different goals and needs of groups from which an individual draws their identity. An example provided by Crenshaw is in relation to black women splitting their political energies between race and gender social action agendas, which when viewed in isolation may not adequately address the most pressing needs or specific concerns of black women (Shields, 2008). Unlike other theories that view discrimination from a single identity marker perspective, intersectionality decries the ‘single-axis-framework’ which portrays race, gender and other identity markers as ‘mutually exclusive’ categories and experiences while asserting that they all interact simultaneously with each other to “create a whole that is different from the component identities” (Bešić, 2020, p. 114). This means that an individual has multiple identities which contribute to their perception of self and society’s perception of them. An African immigrant parent of a child with a disability, for example, is simultaneously an African, an immigrant and a parent of a child with a disability. These identities connect to affect how they are perceived within society (Crenshaw, 1991). While different aspects of a person’s identity can be explored in isolation from the other(s), doing so does not provide a full understanding of the complexities involved in such interactions and a rationale for reflection, resistance and change of oppressive and discriminative social structures and relations (Liasidou, 2013; Gillborn, 2015; hooks, 2015).

Intersectionality moves beyond the argument that individuals have intersecting identities to explain how the concept of ‘difference’ (Minda, 1995) leads to the exclusion of some groups and the privileging of others. This connects intersectionality to the discourse of power relations of oppression and subordination based on race, gender, class, (dis) ability, language abilities and national origins as social disadvantage sources (García and Ortiz, 2013). It should be noted that these categories in themselves are not problematic. It is rather the meaning that they carry, as construed by the society based on dominant social, economic and political arrangements. In such cases, privilege is tied to the social, cultural, and financial capital of certain groups (Green *et al.*, 2005, Pease, 2010). As envisaged by Crenshaw and other CRT activists, intersectionality has two core elements. Firstly, intersectionality has an empirical basis in relation to seeking a fuller analysis of social problems, to better understand the processes that create and sustain social inequities. Secondly, intersectionality has a core activist component, which connects to

the earliest roots of CRT as a movement of engaged legal scholars, in its aim to resist and change the status quo by promoting coalitions between different groups (Gillborn, 2015).

This concept, although mainly used in gender studies, is being adapted by scholars from other fields, including education, social work, psychology, and sociology (Jiménez-Castellanos and García, 2017). In the field of sociology, the concept has been adapted to shed light on the experience of multiple forms of oppression by certain groups of people by virtue of their social, cultural, religious, ethnic and ability affiliations (Liasidou, 2013). In the domain of education, intersectionality has been used to highlight the marginalisation and discrimination of students at individual and institutional levels, resulting in the creation of socio-educational stratification, contrary to the tenets of inclusive education (Hancock, 2007; Gillborn, 2015). Although intersectionality is applied differently, depending on the research context, one thread that cuts across all definitions is that “social identities which serve as organizing features of social relations, mutually constitute, reinforce, and naturalize one another” (Shields, 2008, p. 302; Collins, 1990; Crenshaw, 1991; Nakano Glenn, 1999). This creates both opportunity and oppression for the person concerned (Baca Zinn and Thornton Dill, 1996). Thus, experiences of privilege or oppression are not exclusive to a single intersectional position (Baca Zinn and Thornton Dill, 1996; Choo and Ferree, 2010; McCall, 2005). According to Bowleg (2012), qualitatively distinct experiences are created by systems of inequality, with the belonging of an individual to multiple subordinate categories creating opportunities for personal growth and expansion due to the acquisition of resilience. Thus, Bowleg (2012) sees social location as changing the nature of experience rather than the degree of oppression (Warner and Shields, 2013).

However, intersectionality has been critiqued by some scholars for lacking a defined intersectional methodology; not sufficiently addressing the social construction of identity categories; and the problematic use of categories within the application of intersectionality (Choo and Ferree, 2010; Duong, 2012; Prins, 2006; Robertson and Sgoutas, 2012; Nash, 2008). Despite the above criticisms, intersectionality has been recognised as disrupting cumulative approaches to identity and problematising social categorisation processes through strategically deploying the experiences of marginalised subjects (Nash, 2008). Thus, an intersectional approach bypasses conventional analysis to focus on otherwise unrecognisable injuries by seeking a fuller analysis of social problems, more effective interventions and the promotion of a more inclusive coalitional advocacy (Gillborn, 2015). Given that social reality is constantly

being constructed by individuals in combination with other factors (Bourdieu, 1991), intersectionality should be viewed from a dynamic rather than from a static perspective to effectively capture ongoing changes. Meanwhile, from a more critical perspective, to understand the workings of racism, requires an appreciation of how race intersects with other oppression axes in different contexts and at different times, while finding “a balance between remaining sensitive to intersectional issues without being overwhelmed by them” (Gillborn, 2015, p. 279). Intersectionality is useful in this research in explaining how African immigrant parents of children with disabilities living in Ireland and availing of Early Intervention Services encounter different levels of exclusion because of how services address or fail to address their intersecting identities (Bešić, 2020).

## **2.4 Identities and Experiences of Being a Migrant Parent**

Although there is diverse literature on parenting a child with a disability, literature specifically exploring the experiences of migrant parents of children with disabilities is still an emerging field. Meanwhile, some parallels have been identified by literature in relation to being a member of a minority ethnic group and having a disability, with both groups experiencing some form of discrimination, oppression and social isolation which affect identity formation/reconstruction (Alston and Mngadi, 1992; Emery and Wiseman, 1987; Albright, 1997; Arfa *et al.*, 2020; Gillborn, 2015). Thus, in addition to the identities of carer, parent and person, immigrant parents are faced with multiple minority statuses of being an immigrant and being a parent of a child with a disability (Liasidou, 2013; Pierce, 2003; Jennings *et al.*, 2014). These intersecting identities of race, nationality and/or legal status within a country places immigrant families at a higher risk of experiencing multiple levels of exclusion and discrimination. They must constantly (re)negotiate their identities between two worlds: their ‘home’ (country of origin) and ‘host’ (country of residence) countries (Lee and Zhu, 2020). In this light, African immigrant parents in Ireland may have to negotiate different systems from the ones they are familiar with and are faced with uncertainty in relation to identifying with Irish cultural norms or those of countries of origin or how to integrate the two. Many immigrants continue to have family in their country of origin. It should be noted that “commonality of race does not produce commonality of self-identity” (Berry, 2010, p. 24). This is due to the diverse and heterogeneous nature of migrant groups, with varying dislocation and relocation journeys shaped by gender differences, arrival statuses, belonging politics and citizenship rights (Al-Ali and Koser, 2002; Ahmed *et al.*, 2003; Calavita, 2005; Spencer, 2003). The intersection of immigrant parenting experiences with less social support than non-

immigrants, racialisation and economic challenges, increases the support needs of immigrant parents in terms of information support (sometimes affected by language barriers), structural support in negotiating the social and medical system and transparency in public support systems (Jennings *et al.*, 2014; Byrne and De Tona, 2012; Simon *et al.*, 2015; Condon *et al.*, 2020).

Despite intersectionality's wide use in some social science fields such as social work, education and sociology, the intersections of disability, race, class and gender have only been explored in a limited number of studies despite commonalities between 'race' and 'disability' (Gillborn, 2015). Although the concept of 'race' is a contested one, 'race' is used daily to demarcate groups in relation to skin colour, physical appearance, culture, ethnicity and national origin, with racism being described as "conduct or words or practices which disadvantage or advantage people because of their colour, culture or ethnic origin" (Migrant Rights Centre Ireland, 2010, p.1; Curry *et al.*, 2010; Annamma *et al.*, 2013). When understood in conjunction with race, gender, socio-economic background and other social disadvantage indicators, the notion of disability is viewed from a lens that challenges oppressive and unequal practices within social structures and institutions.

An exploratory study by Lee and Zhu (2020) of the experiences of Asian immigrant mothers of children with autism spectrum disorder (ASD) living in Canada, highlights findings that may be of relevance to African immigrant parental experiences of raising a child with a disability in Ireland. Firstly, in terms of being immigrants, these mothers who came from different socio-cultural environments had to adapt to a new environment where they were a minority group and viewed as 'others' by mainstream society. There was pressure to integrate and adapt to the new environment. Secondly, Lee and Zhu (2020) found that being a parent of a child with a disability compounded the challenges faced by immigrant mothers, as they did not only have to break into the new system but also had to navigate their identity as parent of a child with a disability based on constructions and understandings in their countries of origin versus country of residence, in addition to facing the challenge of navigating this 'new system' to source support for their child. These mothers came face to face with a system that did not understand their perceptions and understandings of disability and that sought to impose their view of disability on them (Lee and Zhu, 2020). They found it hard to exercise their parental role of advocacy as they sought to find their feet in this new system, not just in relation to themselves but also their child with a disability. Looking at the above challenges through the theoretical

lens of intersectionality brings to light the full extent of the complexities being navigated by these mothers and how these intersected to affect their experiences. Thus, intersectionality relates to both personal experience (an individual's experience of their social sphere) and socio-structural dimensions (the social needs, resources or legal status of an individual that may advantage or marginalise them) (Shields, 2012).

Meanwhile, exploring the experiences of Somali immigrant mothers of children with ASD living in Canada, Kediye *et al.* (2009) highlights the challenges of raising a child in an unfamiliar environment with lack of traditional support mechanisms in the form of extended family members. This is compounded by “inflexible immigration policies” (Kediye *et al.*, 2009, p.215) which makes it almost impossible for parents to bring family members from countries of origin to support with caring for their child. In addition to lack of support, some immigrant parents feel judged by members of the public who do not know them, based on their child's behaviours and due to lack of knowledge of their child's condition (as the child may look ‘normal’ but exhibit challenging behaviour, as in the case of autism – invisible/hidden disabilities) and parental culture. This judgement could be in the form of looks or words laced with a tone of racism. Being conscious of their identity as a visible minority when navigating public spaces causes parents to desire withdrawal from public spaces.

The above experiences of Somali Canadian mothers have resonance with reported experiences of African immigrants in Ireland in relation to overt and covert exclusionary practices within Irish society (Coakley and Mac Einri, 2007). These include physical violence, discrimination in accessing public spaces, name calling and institutionalised racism (Coakley and Mac Einri, 2007). Many Africans feel that their differences rather than their abilities are being recognised and many have reported feeling evaluated by those around them and being made conscious of their skin colour, leading them to feel ‘different’ and not in control of their own space (Coakley and Mac Einri, 2007). Thus, migration experiences are never ending, as even the most settled migrants may sometimes experience the allocation of an ‘outsider’ status (Byrne and De Tona, 2012). The above ethnic minority status disadvantages, coupled with having a child with a disability, is tantamount to “double stigma” (Florian, 1987, in Albright, 1997, p.23). Misrecognition in relation to rendering a person invisible, devalued, or subject to disrespect by members of the dominant group may cause the person to develop an inferior sense of identity (Jarrett *et al.*, 2014). Thus, respect for human dignity and a person's cultural way of life is important in fostering a positive sense of identity for people (Pierce, 2003).

Some studies within educational settings in the USA, UK and Canada with a focus on racial segregation speak of the over representation of minority populations in intellectual disability settings, with behavioural, emotional and social difficulties (Gillborn, 2015; Hibel and Jasper, 2012). They also highlight the practice of minority populations being educated separately from mainstream more often than white students (Annamma *et al.*, 2013; Gillborn, 2015). Furthermore, a study by Annamma *et al.* (2013), based in the USA discusses segregation on economic grounds with more white children with disabilities than black children entering colleges based on the ability of their families to pay for such. While there is no study to prove this is the case in Ireland, looking at it from the perspective of parents of children with disabilities in Ireland, there is a parallel in relation to parents in Ireland often paying for private diagnosis and private therapy (Devery, 2018). This is done to ensure their child does not miss out while waiting for the HSE, which is often characterised by long waiting times and inadequate numbers of therapy sessions. Payment for private services is itself a classification tool, as parents who cannot afford private diagnosis and therapy, which are often very costly, are more likely to wait for the HSE, thus leading to less positive outcomes for their child. African immigrant families living in Ireland are known to possess less social and cultural capital and economic power, which affects their socio-economic status and health outcomes (Coakley and Mac Einri, 2007; Green *et al.*, 2005; Jayaweera and Quigley, 2010).

Many African immigrants travel to Ireland in a bid to engage in waged work, cater for their families and pay their way. However, this often proves difficult as African migrants often find it difficult to gain employment due to the difficulties in proving prior experience, the high cost of third level education and attaining an adequate level of English (Ngadaonye, 2012; Ní Chonaill, 2009; McGinnity *et al.*, 2020). Although some immigrants are unskilled, many of them are qualified, skilled and experienced but are unable to find work at an appropriate level. This may make many highly qualified individuals settle for minimum wage jobs, regardless of how qualified they are or where they gained their qualification. Meanwhile, for those who came as refugees the situation is worse, given the level of importance placed on qualifications and previous employment by employers, as most of these people would have fled their countries without adequate preparation and planning, leading to loss of documentary evidence of qualifications and previous experience, thus greatly limiting their potential in Ireland (Ngadaonye, 2012). Although structures are in place to handle such cases, people still feel disadvantaged (Coakley and Mac Einri, 2007; O'Connor and Ciribuco, 2017). In addition to lack of employment/underemployment, African immigrant parents experience the absence of

wider kin-based relations to draw on in relation to extended family members helping to care for children (Condon *et al.*, 2020) while mothers go to work. This is not helped by Ireland's restrictive family reunification policy (Loneragan, 2009), thus validating Collins' (1990) assertion that "social structures that create social positions ... shape oppression" (p. 492, in Annamma *et al.*, 2013, p.8).

#### **2.4.1 Policy Context in Relation to Migration and Disability**

Migration, an element of social and economic transformation, has often been seen as a problem in contemporary society, with many states developing a generally hostile attitude towards migrants/asylum seekers (OECD, 2018a; United Nations, Department of Economic and Social Affairs, Population Division, 2017; Castles, 2010). The intersection of migration and disability highlights issues of human rights and citizenship, especially in relation to the experience of people with disabilities and migrants of exclusion from cultural, economic, political and civic life (Burns, 2017). This intersection has been explored and debated by scholars within disability studies in relation to citizenship, ethnicity and identity with consideration to access to education, employment, health and social care (Albrecht *et al.*, 2009; Soldatic and Fiske, 2009; Soldatic, *et al.*, 2012).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) sets out international rights for people with disabilities, including the right to have access to services and family life for children with disabilities. While Ireland works within this framework, some of the national policies and law still have some way to go in terms of making those rights a reality, including rights to personal assistance services, education, employment, amongst others. In relation to migration law and policies, the Office of the United Nations High Commissioner for Refugees (UNHCR, 2010) encourages States to adapt relevant policies and programmes to incorporate the specific needs of migrants with disabilities and migrants in vulnerable situations in an accessible way by addressing direct and indirect discrimination and unequal treatment in relation to policies, law and practices. This includes providing targeted supports for migrant families to parent and access services for their children. It also encourages the consultation and inclusion of migrants in the development of relevant public policy and access to justice where human rights violations are experienced (OHCHR, 1996-2023).

In early 2017, Ireland published the Migrant Integration Strategy (2017-2020) based on the principles of equality and non-discrimination. The aim of this Strategy was to monitor the level

of integration of diverse groups, identify differences in outcomes between migrants and the native population, and determine areas where extra supports could be required to facilitate full migrant participation in Irish economy and society. It also aimed at providing information to policy makers and the public on integration outcomes and respond to policy challenges (OECD, 2018a). While the 2020 Monitoring Report on Integration found that migrants were generally integrating well in relation to indicators like employment, active citizenship, education, and social inclusion, it identified certain specific challenges persistently experienced by some groups. For example, it found that African nationals were the most disadvantaged non-Irish national group, with persistently high unemployment and underemployment rates, potentially due to a combination of time spent by those seeking protection in the asylum system (with no access to the labour market) and possibly the experience of discrimination and racism in the Irish labour market. The unemployment rate for Africans was 12percent by 2019 while that of Irish nationals was 5 percent (less than half the rate of African nationals). Despite the establishment of a new anti-racism committee for the development of an anti-racism strategy, there may still be required specific anti-racism and anti-discrimination measures to successfully address presenting issues (McGinnity *et al.*, 2020). An awareness of these challenges experienced by some African immigrant families, coupled with having a child with a disability, may be helpful in guiding policy and practice towards enhancing targeted and meaningful service provision to African immigrant families of children with disabilities. Meanwhile, increased global attention to intersectionality issues necessitates an enhanced link between disability and migration in future international dialogues, especially considering sparse data on migrant status and disability.

## **2.5 Conclusion**

People with disabilities do not exist in isolation, but as members of families and social units. Parents of children with disabilities occupy a liminal position as they are neither disabled nor otherwise. These parents are ‘allies’ of their child with a disability due to their experience both directly and by proxy of the discrimination and marginalisation faced by their child with a disability. They experience disablism even though not disabled themselves (Ryan and Runswick-Cole, 2008; Jennings *et al.*, 2014).

Parenting a child with a disability can be challenging and is even more so for immigrant parents with the intersection of factors like race and disability constituting their lived experiences. An intersectional analysis sheds light on how social and cultural factors interweave to produce

experiences of marginalisation, discrimination and oppression for certain groups of people like immigrant parents of children with disabilities (Liasidou, 2013). This approach points to the role of power hierarchy in the exclusion of some groups and the privileging of others based on society's perception of them (Nash, 2008), thus highlighting the importance of understanding the role of power in constructing the categories of exclusion and privilege throughout the history of migration. Being immigrants in a foreign land places African immigrant parents in a more vulnerable position than host country (white Irish) families of children with disabilities who have a history of the system, know where and whom to go to for necessary supports and the courage to do so, backed by informal support systems in place, unlike immigrant parents. This, therefore, could lead to the unconscious marginalisation of immigrant families by the system, as they approach services with less bargaining power than families from the dominant culture. It is therefore important to recognise how different identity markers could intersect with historically perpetuated inequalities (legacies of discrimination towards specific groups of people) within stratified societies to influence service outcomes for immigrant families of children with disabilities (Bešić, 2020).

Social identities then cannot be studied in isolation from one another nor separate from processes of inequality bound up in sexism, racism, ableism or classism (Warner and Shields, 2013). Focus on only one identity marker such as a child's disability by professionals may cause them to miss the bigger picture. The application of a 'single-axis framework' to exploring the experiences of immigrant parents of children with disabilities may simplify a complex situation and imply that Early Intervention Services exist in a vacuum and are neither influenced by the society nor by the occurring processes within the society. This will not do justice to culturally competent and anti-oppressive practice with immigrant families of children with disabilities. Thus, it is necessary for services to analyse all marginalising and exclusionary factors between and within different family groups. Failure to recognise differences within and between groups may cause families experiencing intersectional discrimination to become invisible or undeserved, based on their specific needs (Bešić, 2020; Shields, 2008).

In the words of Lee and Zhu (2020, p. 4), "it is worthwhile to pay attention to the process of how the minority identities of immigrant parents and their children are constructed as "others" when they are faced with a dominant culture". Cultural competence is seen as a practical way to address immigrant challenges (Lee and Zhu, 2020). The following chapter will focus on

exploring and critiquing ideas of cultural competence, while situating cultural competence within an intersectional frame.

# Chapter Three

## Exploring and Critiquing the Concept of Cultural Competence

### 3.0 Introduction

Cultural competence is a complex and contested concept aimed at improving the accessibility and effectiveness of services for people from minority ethnic/racial backgrounds. The emergence of the concept of culturally competent practice was the result of a growing awareness of diversity and contrasting health outcomes among immigrants and people from racial and ethnic minorities, as indicated by some studies in the USA and Canada, with these groups having a low likelihood of accessing or receiving culturally appropriate health and social care services (Hausmann *et al.*, 2011; Paradies, 2006; Ben-Moshe and Magaña, 2014; Bailey *et al.*, 2004). This concept, which originated as cultural responsiveness or cultural sensitivity, arose within literature in the USA in the 1980s, influenced by the 1960s and 1970s civil rights movements which demanded attention to racial and ethnic inequalities in society and respect for cultural diversity (Logan, 2012; Chiarenza, 2012). According to Chiarenza (2012), there are two basic assumptions within existing concepts of cultural competence: firstly, that it is an integral requirement for effective work with differences; and secondly, that it can be taught, learned, trained, and achieved, with the level of competence determined by the level of knowledge about another culture. In its first appearance in social work literature, the concept was referred to as 'ethnic competence' (Gallegos *et al.*, 2008).

Ireland is home to about 160 different nationalities due to inward migration. While enriching Irish society, this diversity has also posed challenges in relation to access and navigation of unfamiliar public services by service users and the delivery of services in an appropriate and culturally competent manner by service providers (HSE, 2019). In line with stipulations by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) Ireland has an obligation to provide children with disabilities and their family members (including migrants and people from ethnic minority groups) with the necessary protection and assistance to facilitate their full and equal enjoyment of the rights of persons with disabilities, including access to Early Intervention Services. This necessitates movement away from ethnocentric and uni-cultural approaches which prioritise the majority population and

marginalise other ethnic groups (Gerrish, 1997; Mitchell *et al*, 2002; Dalikeni, 2021) towards the development of necessary skills, knowledge and expertise within Irish health and social care services for culturally competent service provision, with a focus on meeting the individual needs of service users (Narayanasamy, 1999a; 1999b; Hilgenberg and Schlickau, 2002; Narayanasamy and White, 2005).

Although cultural competence was initially coined in relation to working with individuals and groups from non-white ethnic origins, it has evolved to include differences in religion, sexuality, ability and other identity markers (Abrams and Moio, 2009). However, cultural competence has been critiqued, amongst others, for focusing on knowledge and awareness of ‘others’ while failing to address structural factors that shape experiences and opportunities (Fisher-Borne *et al.*, 2015; Abrams and Moio, 2009). In addition, the dominant understanding of cultural competence tends to be very essentialist, by viewing culture as static and unchanging, linking culture with ethnicity and nationality, encouraging the view of Western cultures as superior to other cultures and not questioning Western social practices (Garrahan and Rozas, 2013). This has paved the way for intersectionality as an alternative way of engaging with difference. The concept of intersectionality, as discussed in the previous chapter, plays an important role in highlighting how different identities such as race, class and gender intersect to shape individual experiences (Hankivsky and Cormier, 2011; Mehrotra, 2010). Meanwhile, CRT, in which is found the origin of intersectionality, challenges the supremacy of white/Western culture.

In this chapter, I seek to explore how the concept of cultural competence is understood, its critiques and limitations, as well as its potential in addressing the challenges faced by African immigrant parents of children with disabilities. The chapter discusses how stereotypes can occur, leading to discrimination in interactions between parents and professionals and how these could be managed by both parents and professionals by learning about culturally relevant practices through the rethinking of often unquestioned norms and practices. I also seek to analyse the potential of the concept of intersectionality as a response to some of the critiques of cultural competence, and argue that exploring the intertwining of the two may offer ways of understanding parental experiences and professional responses within the Irish context (Lee and Zhu, 2020).

### 3.1 Understanding Cultural Competence

The idea of cultural competence has become increasingly popular in social work, counselling, nursing, medicine and other human service professions in countries like the UK, Australia, Canada and the USA, which are home to diverse ethnic groups (Harrison and Turner, 2011). Cultural competence has multiple definitions which have evolved over time, especially as different disciplines have developed their own understanding of the concept (Harrison and Turner, 2011). The most widely used definition of cultural competence sees the concept as “a set of congruent behaviours, attitudes and policies that come together in a system or agency or among professionals that enable effective interactions in a cross-cultural framework” (Cross *et al.*, 1989, p. iv in Harrison and Turner, 2011). This definition emphasises personal, organisational and systemic competencies. From a personal perspective, cross-cultural encounters can be seen in every human interaction, portraying cultural competence as the ability to appropriately relate to the specific social and cultural contexts of diverse individuals (Minervino and Martin, 2007).

The concept of cultural competence has been challenged in relation to the generalisation of specific cultural, social and religious groups in terms of interpreting their attitudes, behaviours and beliefs and boundary definition between stereotypes (Galanti, 1991). Useful generalisations may easily become stereotypes justifying prejudice especially when there are blurred boundaries between behaviours that are individual and those that are culturally determined. This has led to the birth of more specific cultural competence definitions. For example, the Seattle King County Department of Public Health (1994, in Minervino and Martin, 2007, p. 192) in the USA defines cultural competence as:

The ability of individuals and systems to respond respectfully and effectively to people of all cultures, classes, races, ethnic backgrounds and religions in a manner that recognizes, affirms, and values the cultural differences and similarities and the worth of individuals, families, and communities and protects and preserves the dignity of each.

This definition, rather than focusing only on the needs of vulnerable groups, indirectly refers to human rights and equality, with human dignity being portrayed as the main rationale underpinning cultural competence. Looking at this from an Irish perspective, health and social care settings have a legal obligation under the Employment Equality Acts (1998 and 2004) and

the Equal Status Acts (2000 and 2004) to prevent and redress discrimination on the grounds of gender, civil status, family status, sexual orientation, religion, age (does not apply to a person under 18), disability, race, membership of the Traveller community. Meanwhile, in the UK, it is against the law to discriminate against anyone because of age, gender reassignment, being married or in a civil partnership, being pregnant or on maternity leave, disability, race including colour, nationality, ethnic or national origin; religion or belief, sex and sexual orientation (<https://www.gov.uk/discrimination-your-rights>). While these lists seem comprehensive, there is no mention of class, which is one of the grounds on which immigrants may feel discriminated upon especially in relation to their socio-economic status (Coakley and Mac Einri, 2007; Devery, 2018). Health and social care professionals, thus, have a responsibility to accommodate diversity while promoting equal opportunities and positive action (The Irish Human Rights and Equality Commission Act, 2014). In light of this, cultural competence training will focus on explaining health service providers' obligations under the Equality Acts, defining the concepts of ethnicity, race, culture, equality and diversity and promoting greater awareness of issues of diversity affecting the delivery of services in intercultural workspaces (Minervino and Martin, 2007).

The Health Service Executive (HSE, 2008, p.126) in Ireland defines cultural competence from a policy perspective as the ability to obtain “the right policies, knowledge and skills to meet the needs and practices of people from different cultural backgrounds”, stressing the importance of gathering information on the way of life, diet, spiritual needs and language of service users. The use of the word ‘different’ in this definition sounds like ‘othering’ in relation to measuring service user interactions against the ‘norm’/dominant practices. This may lead to the exclusion of some groups and privileging of others (Minda, 1995). Also, the gathering of information on service users, if not handled with focus on the unique experiences of each individual service user, may lead to the development of stereotypes.

Other definitions of cultural competence are shaped by the need for collaboration with service users and reflexivity on the part of the professional as a means of developing a suitable intervention strategy (Williams, 2002; Pinderhughes, 1989; Miehl and Moffat, 2000). Most literature primarily focuses on cultural competence at an individual professional level rather than at an organisational level, thus failing to adequately address the interconnections between individual and organisational changes (Fisher-Borne *et al.*, 2015; Fitzgerald and Campinha-Bacote, 2019). Given that individuals and organisations are complexly interwoven, primary

focus on individual professionals impedes the provision of quality and equitable services to culturally diverse service users.

### ***3.1.1 Key Debates within Cultural Competence***

Despite an increase in literature on cultural competence in health and social care professions in the last two decades, UK social work scholars such as O'Hagan (2001), Laird (2008) and Parrott (2009), perceive professionals to be culturally insensitive. O'Hagan's (2001, p.97) book on cultural competence in caring professions claims that "there is no tradition of cultural sensitivity or cultural competence in health or social care professions, neither in their literature nor their practice". In the same light, Parrott's (2009) cultural competence in social work study highlights the highly critical stance of several studies in relation to the ability of current professional practice to meet the specific cultural needs of service users. Parrot (2009) also highlights a study whereby cultural identity is equated with a religion, region or country. Laird's (2008, p.39) book on anti-oppressive/culturally competent social work practice, encourages professionals to learn more about other cultures as a means of guarding against 'unintended racism'. The above authors acknowledge the ever-changing nature of culture and encourage professionals to guard against essentialist or one-dimensional views of culture (Harrison and Turner, 2011). However, a wide range of definitions and conceptualisations has led to a great deal of controversy around the concept, leading to the rise of questions in relation to its relevance or ability to solve structural problems like racism and poverty (Danso, 2016) which often affect immigrant families. Thus, cultural competence has been critiqued both in relation to its conceptualisation and application, especially in relation to its focus on knowledge acquisition on 'others', failure to address power relations, emphasis on formal training and flaws in the rating/evaluation of cultural competence.

In relation to conceptualisation, most literature on cultural competence places emphasis on professional acquisition of knowledge about the norms, values and personality traits of 'others' in order to fight against inequality, thus failing to acknowledge the role of structural forces like racism and poverty in creating health and social inequality (Dean, 2001). Focus on learning about 'other' ethnic and racial groups runs contrary to the practice of professionals learning from the service user. It may lead to the assumption that culture is static, create stereotypes about certain groups, and compromise the dignity and rights of those concerned, while leaving little room for focus on social justice (Johnson and Munch, 2009). Thus, Gross (2000) advises that it may not be possible for professionals to master minority cultural content, and a

perception of mastery may lead to a superficial understanding of service users. Based on the above argument, Fisher-Borne *et al.* (2015, p.171) state that “while cultural competence has provided a springboard for conversations around what it means to provide quality care, specifically to those from historically marginalized communities, it has not resulted in a transformative agenda to address inequalities”.

Definitions of cultural competence have also been critiqued for not taking into consideration power relations between parent, child and professionals, and the ‘othering’ of cultural groups (Condon *et al.*, 2020; Sakamoto, 2007). Perspectives of “the ‘other’” are often caught up in discourses that uphold whiteness as the default standard (Pon, 2009, p.61). The role played by whiteness in health and social care professions – that is, portraying whiteness as superior and as the norm or default standard by which ethnic minorities/ ‘other’ cultural groups are judged and evaluated - is seldom analysed by the concept of cultural competence. This portrays the assumption that workers are from a dominant culture (Harrison and Turner, 2011), subtly discriminating against other cultures. This is a new form of racism based on racial discrimination on the grounds of culture rather than biology (Goldberg, 1993). New racism<sup>8</sup> sees people from non-Western/non-white backgrounds as ‘others’, considering them to be archaic, backward, inferior and in need of assistance to be civilized. It is not easy to recognise new racism as racism because it is discussed in terms of cultural preservation, social justice, and nationalism, which marginalise people without referring to race (Pon, 2009). In this light, cultural competency is devoid of theorising power or critiquing oppressive systems like racism, ageism, sexism, ableism and heterosexism, and thus fails to interrogate how individuals come

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<sup>8</sup> The new racism concept originated in the 1980s in Great Britain in the wake of Margaret Thatcher’s Conservative government’s policies and practices which denounced immigration based on the argument that Britain would be ‘swamped’ by people from other cultures (Pon, 2009). In recent times, there has been increased movement towards right wing politics. Highly contested political debates have arisen in relation to migrant and refugee integration into their host countries. In 2009 in Ireland, Noel O’Flynn, a Fianna Fail TD, backed the proposal of Fine Gael’s Leo Varadkar to pay unemployed immigrants to leave the country (McInerney, 2009). In June 2016, the UK voted to leave the EU, with the rise in immigration as the key argument for this move, an argument that united Eurosceptics, anti-globalists and nationalists (McInerney, 2009). Meanwhile, the year 2017 saw integration issues dominating the headlines in relation to politicians’ views of immigrants during elections across Europe. For example, British tabloids expressed Britain’s experience of ‘crisis’ in relation to immigrant integration (Heffer, 2017); Marine Le Pen, the runner up in the French presidential race promised to take a tough stance against migrants who ‘refuse’ to integrate by choosing to continue living the way they used to live before coming to France rather than adopting the French way of life (Joseph, 2017); while Mark Rutte, Netherlands Prime Minister, in the face of electoral challenge from the anti-immigration party of Geert Wilders, was sympathetic towards public calls for the exit from the State of people who do not integrate, by saying that immigrants should “behave normally or go away” (The Associated Press, 2017).

to be ‘othered’ (Sakamoto, 2007). This calls for a refinement of the concept of cultural competence towards anti-discriminatory practice, focusing on analysing structural oppressions and power relations between service users and service providers, with an acknowledgement of the fact that there are different ways of knowing. Without this, cultural competence can “be reduced to the management of “diversity” within the current neo-liberal political climate, percolating through human service systems in the same way as "multiculturalism" and "empowerment" have done” (Sakamoto, 2007, p 109). This ‘whiteness’ in health and social care professions can be challenged through the recognition and integration of different indigenous knowledges and ways of knowing into the professional knowledge base. Looking at this critique, systemic change may seem unachievable. Williams (2003, p.274) counters this pessimism by envisioning cultural competence as “a body of knowledge that challenges and changes the systems and theories developed in dominant values and knowledge and responds to the needs of marginalized populations made invisible by the dominant powers that control the "recognition of voice, expertise and status"” (in Sakamoto, 2007, p. 110).

Although cultural competence is seen by some scholars as wanting in power analysis (Garrahan and Rozas, 2013; Ortega and Faller, 2011; Pon, 2009; Sakamoto, 2007), it is seen by others as encouraging professionals working in cross-cultural settings to critically reflect on how power and privilege due to a professional’s social status could be used exploitatively and how this could be averted (Hammell, 2013). Cultural competence has also been seen as a means of understanding the ‘person in the environment’, which is one of the basic social work values of working with the whole person in terms of their complex power relations and multiple identities; and a means of improving the population’s accessibility and utilisation of resources and reducing disparities (Dumas, 2012). Research by Mancoske *et al.* (2012) supports the above view by indicating that caregivers who view their children as being in receipt of linguistically and culturally competent care, have reported better clinical outcomes, including higher levels of access to services and active participation in service planning and overall greater satisfaction with services.

In relation to the application of cultural competence to professional practice, it has been critiqued on the grounds of emphasis on formal training and cultural competence ratings being flawed (Harrison and Turner, 2011; Kumaş-Tan *et al.*, 2007). Although some professionals believe that it is possible to learn about cultural competence through formal education (Robinson *et al.*, 2016), some have criticised formal training in cultural competency on the grounds that culture is not static, and training may cause professional blindness to individual

experiences (Harrison and Turner, 2011). These professionals hold that, “cultural competency is not simply a technical skill, a communication technique, nor something that can be learned overnight” (Fisher-Borne *et al.*, 2015, p.170). What cultural competence requires is an ongoing change in people’s thinking, understanding and interaction with those around them, without a specific endpoint (Dunn, 2002). There is currently little evidence to show that cultural competence training improves the quality of service delivery and health outcomes for ethnic minorities (Kleinman and Benson, 2006; Goode *et al.*, 2006; Bhui *et al.*, 2007; Horevitz *et al.*, 2013). In response to this criticism, Barn and Das (2016) and Lund and Lee (2015) are of the opinion that many critics mistakenly interpret the word ‘competence’ as referring to the achievement of a specific set of skills to enable mastery of other cultures by practitioners. ‘Competence’ indicates skills, abilities and knowledge (NASW, 2015) that can be improved or developed to effectively practice in a cross-cultural setting through acculturation (the mutually respectful adaptation of practitioner and service user to each other’s cultural beliefs, values and practices) and deculturation (mutual discarding of negative cultural aspects by both professionals and service users) (Danso, 2016).

Meanwhile, some commentators have suggested that cultural competence ratings are flawed, with one of the most used measures based on the presumption that culture is defined by race and ethnicity (Kumaş-Tan *et al.*, 2007). Other notions include presuming culture as belonging to “others” who are outside the “norm”, projecting cultural incompetence as being a result of personal biases and lack of knowledge and exposure to the “other” (Kumaş-Tan *et al.*, 2007, p. 548). Most ratings of cultural competence are based on self-reports by practitioners which cause them to be one-sided, given their evaluation of a practitioner’s level of competence from their own perspectives rather than seeking the perspective of the service user as well (Cartwright *et al.*, 2008; Mancoske *et al.*, 2012). Moreover, some scholars have identified the need to acknowledge structural and systemic inequalities in the definitions of culture and cultural competency and using specific rather than general behavioural indicators to assess cultural competence as a means of moving towards less biased cultural competency measures (Dumas, 2012; Kumaş-Tan *et al.*, 2007). In response to this criticism, a ‘Cultural Responsive Framework’ has been developed in Australia as a means of assessing the effectiveness of cultural competence in practice, by the use of accredited interpreters, encouraging service user participation, designating leadership responsible for the development of cultural responsiveness within organisations and involving carers and community service representatives in service plans (Department of Health Australia, 2009).

However, findings by Harrison and Turner (2011: 342) indicate that, “‘universal human values’ and ‘a person-centred perspective’ are more important than cultural competence”. These are based on treating people as individuals and respecting difference in relation to culture, social status and other attributes rather than focussing on cultural competence which represents the ethical position of practice. Britzman (2000) recommends that professionals should drop cultural competence, as it hinders self-reflexivity in practice and does not seek knowledge on social violence such as colonialism, slavery and racism, whose common aim is to suppress ethnic minorities/ ‘other’ cultural groups. This has led to the birth of cultural humility as an alternative professional approach with a focus on self-knowledge in relation to others, the acknowledgement of culture’s dynamic nature and the challenge of barriers impacting on individuals and institutions (Fisher-Borne *et al.*, 2015). This concept encourages the service provider to adopt a learning stance and engage in self-reflection about the cultural issues arising from both parties rather than focusing on mastering the understanding of ‘others’ (Fisher-Borne *et al.*, 2015).

Despite cultural humility being hailed as the best way of working in a culturally sensitive manner and being proposed as a replacement for cultural competence, based on critical analysis, it does not seem to add more value than cultural competence to professional practice. Cultural humility is not conceptually clear and coherent, lacks guidance in relation to cross-cultural practice, research and pedagogy, and has not been fully explored in social work and other health and social care professions (Fisher-Borne *et al.*, 2015). Ross (2010) sees cultural humility as based within cultural competence; Ortega and Faller (2011) see cultural competence and cultural humility as complementing each other; while the National Association of Social Work in the USA (NASW, 2015) sees cultural humility as a fundamental part of cultural competence. Thus, the NASW (2015) recently modified its cultural competence definition by drawing special attention to the important role of cultural humility in culturally competent practice. The problem, therefore, seems not to be the concept itself but the many ways in which it is (mis)understood, (mis)conceptualised and (mis)interpreted by professionals and researchers in different times and places. The concept of cultural competence has served in highlighting important issues of difference in professional practice for three decades (Garran and Rozas, 2013). It holds potential as an effective theoretical and practice approach, which can be adapted to move health and social care services to a new and enhanced level of working with diversity (Danso, 2016). Thus, it may not be necessary to disregard cultural competence

but rather to clearly define, expand and open it up to a greater focus on power relations and the different intersecting identities of service users.

### **3.2 Cultural Competence in Irish Policy and Service Provision**

The area of developmental health is an example of where dissimilarities or differences between the profiles of professionals and service users exist. For example, in the UK, 97% of Speech and Language Therapists are white, female, middle class and English-speaking while their service users are often racially, linguistically and culturally different from them (Norbury and Sparks, 2013). In Ireland, human resource data from three HSE administrative areas and St James Hospital Dublin indicates that only about 9% of health and social care professionals identify as being from minority ethnic communities (Spencer, 2014). Similarly, literature from a professional perspective often describes immigrant parents of children with ASD as different from professionals, hard to understand due to poor language mastery (Jegatheesan, 2010; Mandell & Novak, 2005), and often in denial about the child's diagnosis due to concerns in relation to labelling, based on cultural beliefs or social perceptions (Ponde and Rousseau, 2013). These studies are reflective of some of the realities of immigrant parents and of the power differentials between parents (service users) and professionals.

Service users' expectations of and engagement with health and social care services are affected by cultural perceptions. Given Ireland's increasing social and cultural diversity, health and social care services need to be equipped to offer equal access to, and use of services by, a variety of people. Equal access is not necessarily achieved by according the same treatment to all service users but by ensuring that all service users are offered equal opportunities to achieve the desired outcomes (Minervino and Martin, 2007).

Despite cultural diversity and discrimination being mentioned by many health and welfare services in Ireland, the knowledge, skills and attributes required for culturally competent practice are not clearly outlined in most policy documents and there is an absence of detailed discussion on the significance of and implications for practice of these factors (Christie, 2010). For example, cultural diversity and discrimination is mentioned by the Irish Association of Social Workers Code of Ethics (IASW, 2007), the Intercultural Health Strategy 2007-2012 (HSE, 2008) and CORU Code of Professional Conduct and Ethics for Social Work. CORU, which regulates Health and Social Care Professionals, regulates all professions represented in this research, apart from the Clinical Nurse Specialist. CORU encourages professionals to

“respect diversity, different cultures and values” (p.8) and include race, colour, nationality or ethnic or national origins as grounds for discrimination (CORU, 2011). Meanwhile, TUSLA’s Child Protection and Welfare Practice Handbook (HSE, 2011), stresses that ‘practitioners must be acutely aware of the culturally sensitive approaches required to work with children and families from different backgrounds’ (p.88). In addition, six annual policy reports on migration and asylum by the Economic and Social Research Institute and European Migration Network (Joyce, 2010) and the development of the Irish Human Rights Commission (IHREC, 2010), focused on addressing issues of racial discrimination concerning ethnic minority groups, asylum seekers and Travellers.

The Health Services Intercultural Guide (HSE, 2009) was the first to support the effective identification and addressing of the specific needs of service users with disabilities from diverse cultural and ethnic backgrounds, while planning for future care delivery. The Health Services Intercultural Guide (HSE 2009) was developed in response to the need expressed by healthcare staff for knowledge, awareness and skills in relation to providing services to people from different cultural backgrounds. It acknowledges the diverse cultural and ethnic backgrounds of healthcare staff while highlighting the needs of professionals from ethnic minority backgrounds (Spencer, 2014). This Guide, however, does not sufficiently recognise and emphasise cultural differences (McGregor *et al.*, 2019), given its lack of recognition of the different needs of individuals from specific minority groups in agency policies and procedures. This is evident in the limited success of operationalising cultural competence through the Intercultural Health Strategy (2007-2012) due to a lack of tools for translating concepts into practice situations, such as systematic skills training (Cairde, 2015).

Meanwhile, Irish policy documents, including the Diversity and Equality Charter (DCYA, 2016) focus on identity and belonging as a means of addressing diversity and inclusion, with State policy initiatives according more privilege to information gathering on different cultures, identities and languages. Despite two decades of policy attention, there has been a slow emergence of supportive actions in relation to professional development in the face of diversity (DCYA, 2016). This is evidenced in the Early Years sector, with a review by the Department of Education and Science (DES, 2016) indicating professional lack of confidence and expertise (47% of respondents) in working with families from minority ethnic groups. Thus, service engagement with families from diverse countries and cultures at both the micro and macro levels still demonstrates inadequacy and a dearth of confidence and competence. In addition,

there seems to be much reliance on individual professionals to cushion the impacts of structural inequality, racism and oppression created by the macro system for individuals from minority groups (McGregor *et al.*, 2019).

Despite the above policies and strategies, there is little or no data on the experiences or outcomes in relation to the practice of awareness-raising, or the nature of intercultural education within the Irish health and social care service (Spencer, 2014). Thus, advocacy for participation, empowerment, diversity and flexibility has not necessarily led to a change in organisational practices but has created discursive conflict situations whereby professionals find themselves within a variety of roles as outlined by policy (Rhodes and Scheeres, 2004). Rhodes and Scheeres (2004) advocate for ‘adaptation’ of policy application in working with diverse populations rather than blind ‘adoption’ of policy by health and social care professionals. This necessitates a reflexive practice approach based on a combination of knowledge, values and actions (Okitikpi and Aymer, 2010).

### **3.3 Cultural Competence and Intersectionality**

Cultural competence’s focus on developing a culturally competent workforce in healthcare, though well intended, has resulted in a number of limitations which include: unintentional over-emphasis on shared group characteristics, an essentialist/fixed view of culture, failure to address the power relations between the cultures and privilege and power positions between service providers and service users; and misusing culture as a substitute for racial/ethnic/minority group identity (Tervalon and Murray-Garcia, 1998; Fisher-Borne *et al.*, 2015; Prasad *et al.*, 2016). Despite the critiques of cultural competence, it has its strengths. First of all, it started conversations in relation to the provision of quality care, especially to people from historically marginalised communities (Sakamoto, 2007). Secondly, it relates to the social and cultural contexts of diverse individuals (Minervino and Martin, 2007). Thirdly, it encourages reflective practice in professionals in cross-cultural settings in relation to power and privilege (Hammell, 2013). Fourthly, it highlights skills, abilities and knowledge (NASW, 2015) necessary for cross-cultural service provision (Danso, 2016). With its focus on culture, cultural competence is important in this research when looking at the impact of parental cultural perceptions of disability on their construction of their child’s disability and engagement with Early Intervention Services. This leads to my suggestion of keeping cultural competence as a

concept in this research and complementing, rather than replacing, it with the concept of intersectionality.

The workings of racism can be better understood by exploring how race intersects with other dimensions of identity and social structure such as class, disability and gender to shape inequities (Gillborn, 2015). Although intersectionality originally limited its analysis to race, gender and class, it encourages a multidimensional view of individuals in relation to different intersecting identities. Applied to this research, it is not limited to race, gender and class but expands to incorporate all the other identities of African immigrant parents of children with disabilities which may affect their level of access and utilisation of Irish Early Intervention Services.

Intersectionality sees people as simultaneously occupying multiple positions within society (Hernandez and McDowell, 2010; Muntinga *et al.*, 2016; Ortega and Faller, 2011), while challenging the concept of culture as being static (Fisher-Borne *et al.*, 2015). This challenges the essentialist dimension of cultural competence. Positionality is connected to an individual's social location and worldview and influences their response to power dynamics in different contexts. This is important for health and social care professionals due to its impact on service provision, community participation and policy making (Klawetter, 2016). According to Ortega and Faller (2011), people's quality of life, expectations, life chances and capacities are influenced by intersecting group memberships. This perspective, while releasing the service provider from the expert role and placing them more in a learning mode, encourages the assessment of multiple identities of individuals by professionals and organisations and how people's worldviews are influenced by social experiences (Tervalon and Murray-Garcia, 1998; Dalikeni, 2021). This allows for the development of true partnership between professionals and service users, as health and social care professionals incorporate an intersectional analysis and understanding of the whole person with a focus on differentials in privilege and power within relationships (Pease, 2010). A good foundation for such an understanding is the willingness of professionals and service users to be open with each other and work together (Ortega and Faller, 2011).

Intersectionality incorporates power and privilege in work with service users from diverse backgrounds and encourages professionals to perceive service users as individuals with unique experiences rather than classifying them into racial groups (Robinson *et al.*, 2016). It also incorporates power and privilege in relation to interactions between people with disabilities

and people without disabilities. This goes beyond the perception of social categories as either inclusive or exclusive (Robinson *et al.*, 2016) and has led to calls for “the effects of power, privilege and ‘multiple positioning’ in the social arena” (Dhamoon, 2011, p. 230, in Robinson *et al.*, 2016, p. 509) to be included in cultural competence discourse, given that “the effects of societal mechanisms of power and privilege are generally not included when using the traditional cultural competence perspective” (Robinson *et al.*, 2016, p. 509). When an individual’s experience is viewed through the lens of intersectionality, there is less likelihood for professionals to generalise/aggregate social identities or make assumptions. Rather, there is more of an inclination to focus on the individual’s broader identity and unique life experiences (Hancock, 2007; Warner and Brown, 2011). This dismisses a one size fits all assessment and intervention approach within cultural competence and encourages professionals to adapt interventions to suit the needs of service users (Robinson *et al.*, 2016).

Meanwhile, the focus of intersectionality on social justice and respect of a person’s dignity and worth portrays cultural competence in a more comprehensive light by highlighting the importance of professionals having knowledge and understanding of the privilege and inequality of each aspect of social identity (Sensoy and DiAngelo, 2012). However, the use of an intersectional framework has been rarely incorporated into health and social care education even though it has the potential to enhance students’ future work with service users especially in relation to challenging diversity related issues like race, gender, ability and class (Luft and Ward, 2009).

The past two decades have seen scholarly debates in relation to the potential applications of intersectionality. Roberts and Jesudason (2013) acknowledge intersectionality’s application in relation to identity categories and systems of power within individual lives and recognition of differences between and within identity-based groups. They (Roberts and Jesudason, 2013) also see intersectionality as a powerful social change tool in terms of more effective alliance building between movements and highlight the potential of intersecting identities to create cohesion rather than division. Taking these perspectives into account, intersectionality has the potential to bridge the gap between separate attempts at cultural competence by health and social care professionals and organisations. Thus, I suggest that, an intersectional approach may be useful in fostering discussion and collaboration among health and social care professionals by illuminating their common values and similarities in their pursuit of cultural competence.

### 3.4 Conclusion

While terms such as cultural awareness, multi-cultural competence and multiculturalism have been applied by health and social care professions to recognise the importance of difference and acquire knowledge to improve service outcomes for service users, cultural competence is one of the latest efforts to explain professional commitment to enhance social justice in work with culturally diverse communities (Lum, 2011). In practice, cultural competence has focused on gathering information about culture (which includes behaviours, practices and norms) within certain groups, not limited to ethnicity but encompassing social groups such as people with disabilities and people with different economic backgrounds, with the aim of increasing the sensitivity of professionals towards service users.

Although cultural competence has been an ideal for health and social care professional education and practice, with varied approaches depending on discipline, worldviews and practice contexts, it has been challenged for its failure to address structural factors that shape the experiences and opportunities of individuals (Fisher-Borne *et al.*, 2015). Cultural competence has also been criticised for its tendency to equalise oppressions under an umbrella of multiculturalism, thus promoting, albeit unintentionally, a colour-blind mentality which undermines the seriousness of institutional racism (Abrams and Moio, 2009). Another critique of cultural competence is its focus on the knowledge and awareness of other cultures or experiences, leaving the practitioners unexamined and reinforcing the view of the dominant culture as the norm. This can lead to professional bias and stereotype. There are too many differences to master in order to achieve cultural competence. Professionals need to be aware of how their subjectivities influence their construction of and interaction with others, thereby focusing on understanding the process of constructing and contesting knowledge rather than on mastering cultural knowledge (Gross, 2000).

Meanwhile, emphasis has been placed on the need for cultural competence to consider the impact of privilege and power on the relationship between professionals and service users (Condon *et al.*, 2020; Sakamoto, 2007). I suggest the introduction of the concept of intersectionality into the discourse as a means of strengthening cultural competence by re-imagining how health and social care professionals engage with diversity in relation to power dynamics. This is based on intersectionality's definition as "the reality that we simultaneously occupy both oppressed and privileged positions and that these positions intersect in complex ways" (Sensoy and DiAngelo, 2012, p. 115, in Garran and Rozas, 2013, p. 99).

Despite the absence of a uniform definition of the concept of cultural competence, various critiques of the concept and barriers to its implementation, it is still widely accepted, especially in healthcare, as crucial to sound professional practice, research and policy and seen as the primary means of overcoming disparities in healthcare experiences for people from ethnic minorities (Office of Minority Health, 2001; Bean, 2006b; NHMRC, 2006; Danso, 2016). Historically, it is viewed as important in encouraging cross-cultural communication, improving access to better care, reducing health disparities and promoting health equity (Powell, 2016; Yancu and Farmer, 2017). The implementation by professionals of practice recommendations such as continuously reflecting on their own assumptions, biases and stereotypes, acknowledging the implications of their own ‘cultural lens’ (Allen, 2016), treating each family as unique, adopting a learning stance while working with families, using competent interpreters and involving parents in the care plan of their child, it has been argued, may go at least some way to improving the experiences of and outcomes for immigrant families of children with disabilities. Meanwhile, the above strengths of cultural competence, blended with intersectionality’s concern with power relations between professionals and service users, and between people with disabilities and people without disabilities, may greatly enhance the meaningfulness of service provision to immigrant families.

# **Chapter Four**

## **Methodology**

### **4.0 Introduction**

In this chapter, I describe and account for the research design and methods used in this thesis and the ensuing research process. The first section discusses theoretical underpinnings, unveiling the interpretivist perspective based on constructionism as the foundation of this qualitative research. This is followed by a description of the methodology and methods developed, including sample selection (purposive sampling) and data collection (semi-structured interviews), a discussion of the interview process and reflection on my insider/outsider positionality as a researcher. Meanwhile, ethical considerations regarding voluntary participation, confidentiality and anonymity are outlined. Finally, the chapter examines the data analysis based on a thematic approach.

### **4.1 Theoretical Underpinnings**

Interpretivism, which sees the world as a social construct with subjective meanings and interpretations, is the theoretical perspective that guided this research (Ritchie and Lewis, 2003). Interpretivism is located within a constructivist epistemology, which sees social phenomena as being in a constant state of change, given their dependence on social interactions as they occur (Neuman, 2006). Constructionism is guided by the idea that much of what people perceive as reality depends on shared assumptions and experiences (Sutton and Austin, 2015, p. 227). This coheres with this research in relation to its aim of gaining information on the unique experiences of African immigrant parents of children with disabilities.

The two main paradigms in social research traditions are the positivist and constructionist paradigms, with interpretivism being a particular approach that arises from constructionism (Grix, 2004). While positivism sees reality as concrete and measurable and is based on a deductive research strategy with defined rules and independent of the research setting, the interpretivist paradigm is premised on the existence of multiple realities (Crotty, 1998). Research based on interpretivism focuses more on multiple meanings rather than a single indisputable fact or logic (Gray, 2009). Interpretivism is underpinned by an understanding that

“subjective meanings play a central role in explaining social phenomena through understanding the ways in which individuals make sense of their social worlds” (Punch, 2005, p.32). I think this is important for this research as it creates room for the acknowledgement of the different perspectives and experiences of African immigrant parents of children with disabilities, while connecting the commonalities in those experiences. This reflects a valuing of multiple experiences rather than imposing a researcher’s frame of measuring experience.

Qualitative research is the mode by which the research was conducted. I chose qualitative research methods because they are helpful in attributing meaning to and developing explanations from participants’ descriptions of their experiences (Gray, 2004). Given that this research aimed to examine the access and utilisation experiences of African immigrant parents of children with disabilities in relation to Irish Early Intervention Services and professional experiences of working with immigrant families, the qualitative paradigm was relevant in providing an in-depth understanding of parent and professional experiences. Undertaking semi-structured interviews with participants provided a space for them to represent their experiences, unlike a structured approach which would have placed more control in my hands (as the researcher) to frame those experiences.

## **4.2 Methodology**

Qualitative research, as applied to this research, focuses on in-depth exploration of dimensions of issues that are not well understood. Qualitative research provides insights into people’s cultures, perceptions and experiences (Creswell, 2009). While qualitative research typically involves fewer participants than quantitative research, it encompasses detailed, rich and highly contextualised descriptions from each research participant. Thus, qualitative research involves intensive analyses, values open ended discovery and emphasises specific backgrounds to experiences while requiring the researcher to reflect on their influence on the research process (Levitt *et al.*, 2018). The qualitative approach advances the goal of this research to shed a light on the expectations, experiences, and service implications for African immigrant parents of children with disabilities availing of Early Intervention Services (Patton, 1990). Thus, based on the usefulness of qualitative studies in gaining understanding of people’s experiences while contributing to professional knowledge in the area of research, I saw qualitative research as a suitable choice of methodology to generate information on the lived experiences of research participants.

#### **4.2.1 Sample Selection**

Qualitative research often involves informal, small-scale data collection, with a purposive sampling selection method (Bryman, 2012; Ritchie *et al.*, 2003). Purposive sampling, also referred to as criterion sampling by LeCompte *et al.* (1993), is based on choosing participants because they possess certain characteristics that fit the criteria of the research objectives and enable detailed exploration and understanding of the central research themes. This is to ensure that all key themes relevant to the subject matter are covered, and to ensure the inclusion of some diversity within each key theme (Ritchie *et al.*, 2003). For example, while this research focused on the experiences of African immigrant parents of children with disabilities within Early Intervention Services, I also sought and included professional views to fully explore differences in perspectives between parents and professionals and the impact of this on service interaction. As discussed above, qualitative research aims at understanding phenomena, unpacking meanings and generating ideas, explanations, concepts and theories. This requires the sample selection capable of generating data about the relevant ideas, experiences and processes to clarify and inform an understanding of the subject matter (Ritchie *et al.*, 2003).

The sample included twenty participants, ten parents and ten professionals, from two Irish regions which serve large populations of diverse immigrant communities. Overall, there were seventeen female participants (nine parents and eight professionals) and three male participants (one parent and two professionals). While I aimed to include twenty participants in this research, the participant composition in relation to gender was not pre-determined. It was hoped that there would be an even distribution of male and female participants, but most people who agreed to participate in the research were female. I realised during data collection that it was predominantly mothers who brought their children to appointments and liaised with services, and the staff of Early Intervention Teams were also predominantly female. The overall sample size of twenty was not easy to attain especially in relation to parental recruitment and engagement, with many parents not wanting to partake in the research due to the sensitive nature of the topic. Thus, I did not restrict my sample size to a specific ratio of male/female participants.

Parent participants were first-generation immigrant families with a minimum of five and a maximum of fifteen consecutive years' residence in Ireland (see table 1 below), who had a child with a disability (0-6 years) and availed of Early Intervention Services. Parents interviewed (nine mothers and one father), were originally from Cameroon (4), Nigeria (5),

and South Africa (1). Children were described by their parents as having different health conditions including Autism, Tracheal Stenosis<sup>9</sup>, Down Syndrome, Intellectual Disability (ID), Stickler Syndrome, rare genetic disorder and no specific diagnosis. These children were at the time of interview aged between two and six years, with more boys than girls (eleven boys and two girls). It should be noted that some parent participants had more than one child with a disability. All parents interviewed had other children besides their child(ren) with a disability, with an average number of three children per family. All but one of the children whose parents took part in this research were born in Ireland. The mother of the one child with a disability who was born in her country of origin, moved to Ireland with her child when he was nearly four years of age. According to the child's mother, the child's physical disability (in relation to his mobility) started becoming evident to her not long before they moved to Ireland and was fully diagnosed about one year after their arrival in Ireland.

I recruited parent participants through Early Intervention Teams, recommendations by professional colleagues and personal contact with parents I knew to have a child with a disability, based on ethical guidelines. No parent of a child with a disability recommended another parent as they either claimed not to know of any or said they would prefer not to talk about the families they were aware of. Out of ten parents interviewed, only two parents expressed some knowledge of the Irish health care system based on their experiences of working within a disability setting. This knowledge, they said, helped them to navigate the system, but did not prepare them for the experience of being on the other side in relation to being a parent of a child with a disability and in receipt of services.

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<sup>9</sup> Tracheal stenosis is a very rare airway disease that can be life-threatening. Tracheal stenosis in children may be congenital or acquired, with congenital tracheal stenosis being more predominant in the paediatric population. Symptoms range from asymptomatic to biphasic stridor on exertion, desaturation or cardiac arrest. While acquired tracheal stenosis is often a result of surgical instrumentation or traumatic intubation, congenital tracheal stenosis often connects with other complications like pulmonary, cardiovascular and oesophageal abnormalities. A multidisciplinary team approach with huge family involvement is often required in the management of patients due to the requirement for multiple surgeries, procedures and admissions (Tan and Tan, 2018)

| <b>Parent Participants</b> |                                                        |                          |                                                           |
|----------------------------|--------------------------------------------------------|--------------------------|-----------------------------------------------------------|
| <b>No.</b>                 | <b>Pseudonym</b>                                       | <b>Child's Diagnosis</b> | <b>Length of Stay in Ireland at The Time of Interview</b> |
| 1                          | Linda                                                  | Autism                   | 6 years                                                   |
| 2                          | Alice                                                  | Autism                   | 14 years                                                  |
| 3                          | Brenda                                                 | Autism                   | 15 years                                                  |
| 4                          | Sandra                                                 | Autism and ID            | 7years                                                    |
| 5                          | Caroline                                               | Tracheal Stenosis        | 8 years                                                   |
| 6                          | Edwin (husband of Caroline and interviewed separately) | Tracheal Stenosis        | 11 years                                                  |
| 7                          | Yolanda                                                | Down Syndrome            | 15 years                                                  |
| 8                          | Susan                                                  | Stickler Syndrome        | 5years                                                    |
| 9                          | Mado                                                   | Rare genetic disorder    | 15 years                                                  |
| 10                         | Edith                                                  | No specific diagnosis    | 8years                                                    |

**Table 1: Sample of Parent Participants**

Table 1 outlines the number of parent participants, pseudonyms allocated to protect parent identities, child's diagnosis and the number of years of residence for each parent participant at the time of interview. Information on parents' country of origin, Early Intervention Team attended, age and gender of their child with a disability is deliberately omitted from the table and subsequent analyses due to the expressed fear by some parents of being identified.

One of my research aims was to capture the voices of African immigrant families who had unsuccessfully attempted to avail of disability services or had previously availed of and disengaged from Early Intervention Services. This proved unsuccessful after numerous attempts to reach out to this group by posting flyers of the research in some African churches, community halls and discussions with some Pastors and charitable organisations. Pastors and charitable organisations whom I contacted said although they were not aware of any families who had been denied services, they were aware of one or two parents who may have disengaged from Early Intervention Services, but these parents would not agree to partake in this research.

Professional participants comprised four Social Workers (SW) employed in Disability Services, two Speech and Language Therapists (SLT), one Occupational Therapist (OT), one Physiotherapist (Physio), one Psychologist, and one Clinical Nurse Specialist (CNS) with varying years of experience, in order to “ensure a variety of health service delivery perspectives” (Lindsay *et al.*, 2012, p. 3). These professionals (eight females and two males)

had at least six years' experience of working with immigrant families and at least nine years' experience of working with children with disabilities, aged between 0 to 6 years (see Table 2 below). Eight professional participants were originally from Ireland, one from Romania and one from India. I contacted them through their managers and subsequent snowballing. Professionals were recruited from four out of five statutory, non-statutory disability agencies and charitable organisations, following approval from the ethics boards of these organisations. I was unsuccessful in recruiting professional participants from one organisation following ethics approval.

| <b>Professional Participants</b> |                  |                                      |                                                                         |
|----------------------------------|------------------|--------------------------------------|-------------------------------------------------------------------------|
| <b>No.</b>                       | <b>Pseudonym</b> | <b>Job Title</b>                     | <b>Years of Working in Disability Services at The Time of Interview</b> |
| 1                                | Aoife            | Senior Speech and Language Therapist | 20 years                                                                |
| 2                                | Patrick          | Senior Speech and Language Therapist | 20 years                                                                |
| 3                                | Anna             | Principal Clinical Psychologist      | 20years                                                                 |
| 4                                | Abigail          | Physiotherapy Manager                | 12years                                                                 |
| 5                                | Róisín           | Social Worker                        | 9 years                                                                 |
| 6                                | Michael          | Principal Social Worker              | Over 15years                                                            |
| 7                                | Orla             | Senior Social Worker                 | 16years                                                                 |
| 8                                | Angela           | Senior Social Worker                 | 10years                                                                 |
| 9                                | Edel             | Senior Occupational Therapist        | 18 years                                                                |
| 10                               | Rita             | Clinical Nurse Specialist            | 28years                                                                 |

***Table 2: Sample of Professional Participants***

Table 2 outlines the number of professional participants, pseudonyms allocated to protect participant identities, job title and years of experience of working in disability services at the time of interview. Information on professionals' organizations is deliberately omitted to protect the identity of professionals and by extension, the identity of parents, as most parents were contacted via these organisations. Looking at the professional participant sample, none of the professionals were recently qualified. Newer recruits may be provided with more recent cultural competence training. In addition, the majority were female and white European. These may have had implications for the findings in relation to cultural competence training and practice as will be seen in the subsequent chapters.

When I made successful contact with interested participants, I sent an Information Sheet (Appendices 3 and 4) containing details of the research and a Consent Form (Appendix 5) to

them. This was followed by an agreement on a date, time and venue for the interview. Not all potential participants took part in the research. Four parents initially agreed to partake in the research but withdrew their consent just after their details had been shared with me by the organisation. Hence, I could not contact them further.

#### **4.2.2 Data Collection**

I conducted semi-structured audio-taped interviews with African immigrant parents of children with disabilities and healthcare professionals to obtain insight into their perceptions and experiences within Early Intervention Services. Review of available literature provided insight to existing knowledge about the research topic and highlighted research gaps. Previous research literature shaped the focus of fieldwork by guiding the choice and design of interview questions (King *et al.*, 2011; Honey-Arcement, 2016).

#### **4.2.3 Data Collection Method: Semi-Structured Interviews**

I utilised semi-structured interviews as a means of data collection, given the complexity of intersecting identities of African immigrant parents of children with disabilities and its impact on their interaction with services. My choice of qualitative semi-structured interviews was guided by the intention to gain diverse perspectives on research questions about the service interaction experiences of African immigrant parents of children with disabilities living in Ireland and availing of Early Intervention Services, and professionals' responses. It was also aimed at providing greater insight into the perceptions of barriers and facilitators by both healthcare professionals and African immigrant parents of children with disabilities. In the words of Braun and Clarke (2006, in Evans, 2018, p.2) "qualitative semi-structured interviews can be used as much to consider experience, meanings and the 'reality' of participants' experiences as they can be used to explore how these experiences, 'realities' and meanings might be informed by discourses, assumptions or ideas which exist in wider society". While semi-structured interviews are flexible in gaining in-depth knowledge of the experiences of participants by enabling them to reflect on and articulate their perceptions and experiences (Arksey and Knight, 1999), they also provide some structure to data collection in order to facilitate the collection of data relevant to the research objectives (Gray, 2009).

These interviews followed a semi-structured Interview Topic Guide (Appendix 6) that included open-ended questions. Areas discussed in the Interview Topic Guide included parental

perceptions of disability; parental experiences of Early Intervention Services; professional perceptions of culturally competent practice; professional evaluation of culturally competent practice; and parental and professional recommendations for service improvement. My use of an Interview Topic Guide during interviews facilitated coverage of the main topic, while giving participants a chance to discuss issues that were important to them (Choak, 2012). Based on the semi-structured nature of interviews, I did not strictly follow the questions order so as to encourage a natural conversation flow with participants. Sometimes I reframed or repeated questions to ensure clarity for participants. English was the first language of nine out of ten participants. One participant, whose first language was French, had a good command of the English language thus reducing any potential communication barriers.

### **4.3 The Interview Process**

Interview participants were not provided with the interview questions beforehand in order to guarantee spontaneity of responses. Participants commented on the interview questions being thought provoking and causing them to reflect on issues they had not previously thought deeply about. Parents said it provided them with an opportunity to talk about issues that they had not discussed with anyone before, while targeting their main points of concern and giving them an opportunity to voice their recommendations for service improvement, not only for their benefit but for the benefit of other parents going through similar experiences. Professionals said they found the questions to be a great reflective tool in relation to ideas, concepts, and beliefs that actually informed their practice and how service provision could be improved to accommodate the needs of immigrant families.

Interviews were conducted between September 2018 and January 2021. All professional interviews were conducted pre-Covid while three parent interviews were conducted during the Covid-19 pandemic. During the Covid-19 pandemic, I conducted interviews via video calls in line with public health guidelines at the time. Overall, interview venues and times were chosen by participants. All professional interviews took place in their work settings while seven parents were interviewed in their homes and three parents were interviewed via video call due the Covid-19 pandemic. The length of the interviews ranged from 40 to 80 minutes. I commenced interview transcription after the fifth interview and subsequently after each interview. This provided me with insights into which questions would benefit from more prompting and probing and dimensions from which certain questions could be asked.

I generally enjoyed the interview process and found it easy to build a rapport with both professionals and parents based on my position as both a social worker and an African immigrant parent. I felt humbled that parents openly spoke to me, while disclosing that they had not had an opportunity to express themselves in such ways before due to the lack of a neutral audience. However, the outpouring was sometimes overwhelming. I found it hard to hear parents express their raw feelings in relation to their child's disability, the stigma they experienced at the hands of those they expected to give them the most support and being left on their own to fend for themselves by close relatives and friends. The emotions/feelings of pain, anguish, longing, emptiness and loneliness which I picked up on in these parental voices tugged strongly at my heartstrings and caused me to sometimes struggle with maintaining a neutral presentation and maintaining a smooth flow of the interview.

#### **4.3.1 Insider-Outsider Positionality**

During interviews, I was conscious of how the interview process could be influenced by my simultaneous positioning as both an insider (member of a specified group or occupant of a specified social status) and an outsider (non-member) (Merton, 1972; Mohammad, 2001). My professional identity as a social worker could simultaneously qualify me as an 'insider' in relation to professionals and 'outsider' in relation to parents. Though not working on an Early Intervention Team, I represented one of the professions of the Early Intervention Team. This could position me as being more on the side of professionals than parents, especially as I went through organisations to get some parent participants. A few parents saw my professional identity as a gateway to channelling their grievances to the concerned agencies to effect meaningful change as soon as possible. This confirms the assertion by Carling *et al.* (2014, p. 41) that "when researchers are assumed to be connected with the authorities or other powerful institutions, potential (migrant) informants can see them as sources of either assistance or insecurity".

However, my status as a social worker caused some parents to be initially reluctant to fully engage with the topic out of fear that their responses would be directly fed back to their Early Intervention Team. This caused three parents to insist on their identity being kept as confidential as possible given that they were either the only family or one of a few from a particular nationality availing of Early Intervention Services in their area. These parents expressed concerns of easily being identified if their country of origin in addition to their child's diagnosis and/or area of residence were disclosed. In such cases, I revisited the

Information Sheet and Consent Form with participants, paying great attention to the aspect of confidentiality, the right to anonymity and the option of participants reading the findings and analysis chapters of the dissertation to ensure that their contribution to the research was accurately represented and analysed. Two parents said they would like to read the final draft of the findings and analysis chapters to see if they could be identified in any way and I agreed to share same with them. When the above chapters were ready, I went through them with each of the two parents and they both expressed satisfaction at identifying information not being included in the write up and gave consent for me to proceed without the need to change anything.

In addition, based on my professional identity, there was a propensity for some professionals to refer to ‘our professional values’ without naming them, assuming that I knew what these were. I had to request that they name these ‘values’ for the benefit of the interview as I was not there in my professional capacity but as a researcher. On a positive note, my insider status as a social worker may have made it easier to source and engage professional participants.

Meanwhile, my identity as an African immigrant parent (from Cameroon) positioned me as an insider in relation to parents. Even though I did not have a child with a disability, I could understand the perceptions of disability in parental countries of origin (as outlined by parents and based on my known perceptions of disability in Cameroon) and was considered as ‘one of us’ (Sanghera and Bjorkert, 2008) or as possessing insider knowledge and same understandings (Naaeke *et al.*, 2012) by parents. Some parents, for example, would say, “As an African, you surely know how disability is viewed in our countries of origin”. To avoid this getting in the way of the objectivity of this research, I adopted a learning stance by reminding parents that my views did not count in this research, while encouraging them to express their views as clearly as possible. This helped to refocus the interviews in the desired direction and my insider status as an African immigrant parent served as a good foundation for trust building with parent participants as it put them at ease and enabled them to discuss openly with me (Arfa *et al.*, 2020).

However, my insider status as an African immigrant parent also caused some parents to be initially reluctant to reveal certain sensitive information about their child’s condition out of fear of this information trickling into their community (Holmes, 2020). Most parents interviewed would not have openly spoken about their child’s condition to their African friends due to the

stigma attached to having a child with a disability in their countries of origin and some negative reactions to their child's disability from some members of the African community in Ireland. In such cases, confidentiality was revisited to reassure parents. In addition, because of my parent status, I could relate with some of the experiences of parents in relation to caring for and worrying about their child, which was significant in opening up interview discussions (Carling *et al.*, 2014).

#### **4.4 Ethical Considerations**

I sought and obtained ethical approval through UCC's (University College Cork) Social Research Ethics Committee (SREC) (Application Log 2018-058) prior to initiating contact with participants, participant organisations and commencement of interviews. This approval was granted on the condition that informed consent, data protection and security, privacy and anonymity would be ensured. Prior to the commencement of interviews, I also sought and obtained ethics approvals from participant organisations following the obtainment of approval from UCC's SREC. This was time consuming and was done concurrently with interviews. For example, while conducting interviews in an agency in which I had received ethics approval, I was applying for ethics approval in other agencies. It was very difficult for the agencies to ask parents to consent to participate in the research, given the sensitive nature of the topic. One ethical challenge for me was in relation to not being allowed to directly initiate contact with parents linked to participating organisations, as these organisations had to first of all obtain the consent of these parents prior to passing their contact details on to me. Many parents declined their contacts being shared with me, while some initially accepted for their contacts to be shared and later changed their minds before I could initiate contact with them (as mentioned above).

Research ethics guide a researcher's conduct in terms of principles on what is morally right or wrong (Barnes, 1979; Wellington, 2015). Ethical considerations impacted all stages of this research, including data collection, transcription, data analysis, drafting of findings and drawing of conclusions. These ethical considerations included voluntary participation, confidentiality and anonymity, and data management.

*Voluntary Participation:* It is a requirement to obtain people's consent before involving them in any form of primary research (Hickey, 2018). During this research, I obtained written consent from every participant and took steps to ensure this consent was informed. I distributed

posters (Appendix 1) and letters of invitation to participate in the research (Appendix 2), containing basic information on the research and the right to anonymity to participants and organisations. In addition, I sent an Information Sheet (Appendices 3 and 4) outlining details of the research and a Consent Form (Appendix 5) to those who expressed interest in participating in the research prior to the agreed interview date. This was to give them time within their own private space to read through the documents and decide whether they wanted to go ahead with the interview or not. Where participants agreed to go ahead with the interview, I went through the Information Sheet and Consent Form with them again, clarifying any issues and answering any questions they had to ensure they fully understood the options available to them and the implications of partaking in the research before signing the Consent Form. These options included the right not to answer certain questions if they so wished, to withdraw from the interview at any time or withdraw their consent to participate in the research up to two weeks after the interview. Research participation was voluntary with no monetary rewards.

*Confidentiality and Anonymity:* The probability of participants revealing sensitive information such as unconventional behaviour or racist comments, while answering questions, creates the need for their identities to be kept anonymous when writing results (Driscoll, 2011; Fisher and Anushko, 2008). Thus, a key consideration of this research was to protect the identity of participants by not including identifying information such as names, location, parental country of origin, area of residence, and name and location of disability service attending in the analysis. Pseudonyms were assigned to participants. Two parents who requested to see a draft of the findings were presented with same prior to my submission of the thesis, for consideration and feedback (as mentioned above). After reading the draft, these participants expressed that while they could identify their experiences, they were satisfied that all identifying information in relation to them had been anonymised. They also expressed appreciation at different parental voices being presented together, giving more credence to and acknowledgement of their experiences.

Given the sensitive nature of the topic and the potential for participants to experience some distress during and after the interview, I provided contact details of support persons in some participating organisations as provided to me by the organisations on request (for parents linked to these organisations) and other support persons and organisations to address the needs of upset parents following the interview. I also left my contact details for participants to contact me if they required further clarifications in relation to the research process. No contact was

received from participants post-interview in relation to the research. Some parents became upset during the interviews when talking about their child's disability and the treatment from close relatives and friends. In such cases, I would pause the interview for a few minutes and ask them if they wanted a break or would prefer to stop the interview. These parents said they preferred to keep going and completed the interviews. I conducted follow up phone calls with these participants, with their consent, a day after the interview to ensure the interviews had not caused them undue distress. They all said they were fine and appreciated the opportunity to talk about their feelings as it 'unburdened' them, given that they had not had an opportunity to express such before. They all agreed for their data to be included in this research.

#### *Data Management*

Data was kept confidential from third parties, including participant organisations. For the duration of the research, the data was only available to me and my research supervisors. It was securely stored in a locked cabinet, on password protected audio files and an encrypted laptop. Research participants were made aware of the above and advised that on completion of the research, data would be retained for a minimum of a further ten years, as per the UCC Code of Research Conduct, and then destroyed. Participants were given the opportunity to review a transcript of their audio taped interview, but none chose to avail themselves of it.

### **4.5 Data Analysis**

I analysed data thematically, as framed by the research questions. Thematic data analysis involved the identification of themes and patterns within the data, commencing at the stage of data collection, through to transcribing, reading, re-reading and analysing and interpreting data. Interviews were audiotaped and transcribed, with all identifying information removed from transcripts to ensure confidentiality. My choice of thematic data analysis was due to its propensity to "produce an insightful analysis that answers particular research questions" (Braun and Clarke, 2006, p.97). This approach was useful in inductive coding of the data and verifying the consistence of collected data with research questions. This inductive approach allowed "research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies" (Thomas, 2003, p.2). Themes constituted responses that captured key ideas within the research questions.

Using a thematic approach, I analysed data through three stages. First, I prepared data for analysis through transcription. Accurate transcription was ensured by listening to audio

recordings several times and writing down interviews verbatim, regardless of how intelligible the transcripts were when read back. This was done as soon as possible after the interview. Transcripts were anonymised to protect the identity of the participants by removing or changing names, places and significant events.

Secondly, I read and re-read transcripts several times to note emerging themes and patterns based on research questions, which I wrote down. I, then, organised data into themes, which involved combining codes from transcripts to present the findings of qualitative research coherently and meaningfully. Coding, which I undertook through NVivo12 Software, involved the “identification of topics, issues, similarities, and differences ... revealed through the participants’ narratives and interpreted by the researcher” (Sutton and Austin, 2015, p.228) and facilitated an understanding of the world from each participant’s perspective (Creswell, 2007; Miles and Huberman, 1984).

Thirdly, I interpreted and represented data by describing themes in detail, exemplifying them with extracts from interviews as a means of reflecting the epistemological and theoretical underpinnings of the research (Evans, 2018) and connecting findings to literature review concepts. Emergent themes are presented in chapters five, six and seven. As themes were also interpreted with regard to previous literature, findings confirmed, challenged or extended previous literature findings.

## **4.6 Conclusion**

This chapter has outlined how I utilised a qualitative approach based on a constructionist epistemology. The primary method I chose for this research was qualitative semi-structured interviews to facilitate the exploration of subjective viewpoints and the gathering of in-depth accounts of parental and professional experiences. Considerable attention was paid to the ethics of undertaking the research. The core themes that emerged from the data, as discussed in detail in the following chapters, include navigating and conceptualising disability, becoming a parent of a child with a disability, service access and utilisation experiences of African immigrant families, and understandings of cultural competence. I go on to discuss these themes in chapters five, six and seven.

## Chapter Five

### **Navigating and Conceptualising Disability: Becoming a Parent of a Child with a Disability**

#### **5.0 Introduction**

This chapter begins the exploration of findings from interviews with parents and healthcare professionals working in Early Intervention and children's disability services. It focuses specifically on how African immigrant parents of children with disabilities living in Ireland construct and understand their child's disability, based on their experiences both in their countries of origin and in Ireland. It also discusses the impact this has on them in relation to their support networks and engagement with Early Intervention Services. As will be seen in this chapter, making sense of impairment and disability in general, and their child's disability specifically, reflects the coming together of a diverse range of influences and perceptions which are often held in tension. Most notably, for example, parents express the challenges of navigating different understandings and constructions of disability between what they describe as their countries of origin, and Ireland as host country.

Before delving into the specifics of this chapter, it is important to note that an element of highly gendered care emerged from the findings both in relation to parent and professional participants. Most parent participants were mothers (nine mothers and one father), many of whom reported that the burden of care for their child with a disability fell more on their shoulders than on the child's father, in line with Blum (2015). For example, one mother said "I had to suspend my studies to stay home and care for her while her father worked to provide for the family" (Caroline, Child with Tracheal Stenosis). This reflects parental sacrifices for their child with a disability as laid down by Petriwskyj *et al.* (2017) and confirms findings by a study in Canada that mothers of children with disabilities provide about 96% of care for them (Yantzi and Rosenberg, 2008), while fathers often end up as bread winners in two parent households, (Hope and Oppenheimer, 1997), especially in immigrant settings (Skrinda, 2008). This is supported by findings in Ireland, which indicate a sharp rise in the percentage of female carers from 51.3% in 2011 (CSO, 2012) to 60.5% in 2016 (CSO, 2017). It is thus important to be aware of this gendered dynamic when exploring parental responses, given that much

literature uses gender-neutral language when discussing parents of children with disabilities, as highlighted by Reid (2004) and Scott (2010). The only male parent participant (Edwin) was the husband of one of the female participants but I conducted the two interviews separately to gain a father's perspective. In Edwin's responses, he identified himself as the breadwinner and his wife as the caregiver (confirmed by his wife in her own interview). In relation to professional participants, the gendered nature of service provision (female staff providing services to children and their mothers), as reflected in the sample (8 females and two males), is also worthy of note. In presenting findings, the child's diagnosis is placed next to the parent's pseudonym (e.g., Linda, Child with Autism) while the professional's job title is placed next to their pseudonym (e.g., Aoife, SLT).

This chapter is structured around two main sections. The first section explores parents' understandings and constructions of disability, as informed by constructions in their countries of origin, individual belief systems, and how they respond to understandings of disability in Ireland. The second section explores parent identities and learning how to be a parent of a child with a disability as migrant parents. This involves psycho-emotional dimensions of disability in relation to oppressive social structures, which shape understandings of disability and social reactions within families and communities, and their impact on parental sense of self, identity, and self-esteem.

## **5.1 Understandings and Constructions of Disability**

### **5.1.1 '*A child with a disability comes as bad luck*'**

Research findings concur with Ripat and Woodgate (2011), that perceptions of and attitudes towards disability vary from culture to culture and influence how parents give meaning to their child's disability. In some cultures, people with disabilities are subject to stigma and shame (Daudji *et al.*, 2011). Parents said children with disabilities in their countries of origin in Africa were mostly associated with bad luck, curses, evil, taboo and witchcraft, cohering with Onwuegbu (1977), Abang (1992) and Eskay (2009). This caused them to be rejected, dumped, hidden and sometimes killed (Groce, 2005). One parent said:

A child with a disability comes as bad luck ... Some families will even disown the child, give them to the orphanage or dump them with their grannies. If you are not lucky, they just dump them on the street ... They will be like

outcasts in their homes because of their disability (Yolanda, Child with Down Syndrome).

These perceptions and attitudes led to feelings of shame, rejection and inadequacy by parents, causing parents to feel powerless and vulnerable (Smith *et al.*, 2006), leading to the internalisation of certain societal expectations (Reeve, 2002). Some parents blamed the negative attitudes towards disability in their countries of origin (Nigeria, Cameroon and South Africa) on ignorance, while a few blamed it on limited resources such as inadequate maternity and medical services. In relation to ignorance, parents said many people in their countries of origin did not know much about disability. This caused them to avoid interaction with families of children with disabilities, as they neither knew how to react towards the children nor knew what to say to the parents. This lack of understanding, parents said, was more pronounced if the child's disability was not visible and led to different rights and statuses being attributed to children with different kinds of disability, in agreement with Groce (2005). In relation to visible disabilities, one parent said, "a child with Down Syndrome would be considered an outcast, while Cerebral Palsy would be classified as witchcraft" (Caroline, Child with Tracheal Stenosis). Thus, disabilities in parental countries of origin are viewed from a socio-cultural and spiritual dimension. In relation to invisible disabilities, one parent said the following:

I went home with my child and was trying to explain to my mom that he has a disability. My mom said "I don't know what you are talking about, he looks normal" ... My mom, aunts and uncles, my family generally are not accepting of the disability, and it has to do with the fact that he looks normal more than anything. ... Maybe it is in a way a taboo because in my language, there is no word for autism. There is a word for disability. It's a very negative word ... Autism is a new concept. They just don't get it and they don't tolerate it. My mom refuses to accept to this day that my child has a disability (Brenda, Child with Autism).

Looking at Brenda's quote, the lack of understanding and acceptance of her child's disability by her family seems to deny her identity as a parent to a child with a disability, thereby obscuring her needs which are then not visible to her family and community.

The above quotes from Caroline and Brenda attest to Blum's (2015) assertion that there are

often higher expectations for children with invisible disabilities (like autism) than for those with visible disabilities (like Down Syndrome, cerebral palsy, muscular dystrophy or blindness). The quotes also cohere with Kediye *et al.*'s (2009) conclusion that African communities attach more stigma to children with invisible disabilities. The attachment of greater stigma to children with invisible disabilities within African communities could be due to lack of understanding and cultural reference points in relation to invisible disabilities.

Meanwhile, two parents said they believe children with disabilities are regarded as outcasts in their countries of origin because of limited resources. Looking at Yolanda's quote above in relation to the child with a disability not being recognised, considered an outcast or defined as a burden/punishment - and Brenda's quote above in relation to ignorance and not recognising the child's disability - the denial of need becomes evident and can be linked to resources. Ignorance and denial may seem to be a necessary response, as it may be more manageable not to recognise needs that overwhelm us especially when we do not have the resources to respond to these needs:

I believe in my country, the reason kids with disabilities have been regarded as outcasts, is because of the limited resources we have. Going back since when our child was born premature [in Ireland] and with complications, she was in the incubator for about four months and that required 24hours care with electricity and everything. Going back to the country we come from, we don't have all those things because even the most expensive hospitals don't have electricity to sustain cases like that. So, putting all that together can make the parents [in country of origin] feel there is something wrong or the kids came into the world to put them through hard times (Edwin, Child with Tracheal Stenosis).

This view by Edwin contradicts Murphy's (1990) argument that the kind of services provided to people with disabilities are shaped only by cultural perspectives of disability. Rather, there can be an economic dimension underpinning responses to disability as mentioned by Edwin, who contextualises limited resources as causing negative perceptions of and attitudes towards childhood disability in their country of origin. Disability is hereby portrayed as an economic burden for the state, which needs resources to provide professional supports and Early Intervention Services in the form of specialised equipment, therapy, residential services and

much needed financial support to families of children with disabilities (Burton and Phipps, 2009). In the absence of a strong state-led health and welfare system, the burden of resourcing care falls on families, most of whom are already struggling financially. This layers disability upon pre-existing income inequalities. World Bank and UN (United Nations) statistics indicate Africa as having the highest level of inequality in the world in relation to income and resources (Beegle *et al.*, 2016).

The above parental responses are reflective of some principles of the social model of disability, in terms of a person's functional difficulties being related to disablist societies (Oliver, 2004). These are seen in terms of negative attitudes, limited access to resources and denial of rights and privileges to people with disabilities (Gilson and Depoy, 2000; Morris, 1991; Reeve, 2002). However, while all parents acknowledged the negative perceptions of and attitudes towards children with disabilities in their countries of origin, some parents highlighted that these perceptions are gradually changing, as "a lot of them now do understand. They take them home, give them love, and send them to good schools" (Alice, Child with Autism). This opens new opportunities for being a parent of a child with a disability in terms of recognition and respect. Parents praised this gradual positive perception and attitude change while acknowledging the need for a lot of work to be done in relation to awareness-raising.

### ***5.1.2 Professionals' Understandings of Parental Constructions of Disability***

Professionals had their own perceptions and understandings of how disability was understood within African families, based on their experiences of working with some African immigrant families. It is worth noting that all professionals, except for one, were white European/Irish, which would have had a bearing on their responses, and is also indicative of a lack of diversity more generally within Early Intervention Services staff. Some professionals highlighted parental feelings of shame around having a child with a disability and the stigma attached to having a child with a disability, as some of the factors affecting African immigrant parental access, utilisation and engagement with Early Intervention Services. One professional said, "I had one Nigerian family with two children with autism. The mother told me that she felt she could not tell her own mother that her children had autism because that would be a huge stigma for her" (Anna, Psychologist).

This sense of shame and stigma attached to having a child with a disability was attributed to parental reluctance towards recognising their child's behaviour as a disability. This is convergent with findings by Cho *et al.* (2003), that there is less likelihood for Asian/Pacific Islander families than for European families to agree that their child's behaviour is related to a disorder. For example, one professional said:

Many African families think it is just bad behaviour and if the child could be scolded, reprimanded or asked to sit still, they should be able to stop it. They do not understand that it is ... just the nature of the disability that the child is not able to sit focused (Patrick, SLT).

Concurring with Jarrett *et al.* (2014), professionals acknowledged that, while it is very challenging for any parent taking on such information, there was a whole other layer for migrant families around understanding the causes of disability or maybe attributing blame to themselves which undermined their identity and self-esteem. This made it very difficult for them to look for services or to accept for referrals to be made to services for their child by professionals. One professional outlined the potential effect on the child's identity formation and self-esteem of parental shame in relation to their child's disability in the following words:

Some of the feelings that parents have about trying to hide their child, you hope that people will learn that maybe that judgement isn't here because that's so important for the child's identity and their participation. It's all very well for a child coming in for physio and getting stretches but you might get a sense that there is a lesser or some kind of shame around them. That's massive around the child's self-esteem and the way they are going to be in the future (Abigail, Physiotherapist).

One theme that some professionals cited as coming across very strongly when they met African immigrant families, was parents not wanting anyone else, particularly within their own communities, to know about their child's disability. This relates to the view expressed by some parents that children with disabilities in their countries of origin were to be hidden and not seen in public. Professionals said the sense of shame around having a child with a disability made many parents reluctant to join support groups (especially groups specifically designed for African families) because they did not want other African families to know their 'business'. This was because it was a small community within which most people knew each other. These

support groups were seen by professionals as useful avenues for parents to meet and share their experiences with other parents of children with disabilities, learn from and support each other. However, parental feelings of shame socially excluded them and their children with disabilities (Reeve, 2002).

### ***5.1.3 Navigating Tension and Ambivalence in Disability Perceptions between Parents' Countries of origin and Ireland***

Building on Maloni *et al.* (2010) and Green (2003), parental perceptions of their child's disability were shaped by the way their families and communities behaved towards people with disabilities. In comparing perceptions of and attitudes towards children with disabilities in Ireland and in their countries of origin, all parents said their experiences of perceptions and attitudes towards children with disabilities in Ireland were far more positive than in their countries of origin. Parents said they found their countries of origin wanting in understanding and support, given the deplorable way in which children with disabilities were being treated. Parents said the negative reactions they received in relation to their child with a disability in Ireland mostly came from the African community rather than from the white Irish community. They cited a high level of understanding and compassion exhibited by Irish society in relation to children with disabilities. This societal acceptance, they said, which encouraged children with disabilities to participate in public spaces, caused children with disabilities to feel accepted and better integrated into society and parents to feel more relaxed and accepting of their identity as parents of a child with a disability. They did not have to conceal or keep their child's disability private, as could have been the case in their countries of origin. As highlighted by some parents, the key backdrop in their countries of origin was not just negative attitudes but also inequality and lack of resources:

In Ireland, the care and wellbeing of people with disabilities is priority. They have rights; they have choices, unlike where we are coming from. Where we come from, there is no support and no medical care. It's only done on individual basis depending on how wealthy you are (Mado, Child with rare genetic disorder).

To support Mado's statement, one professional said, "I have had children with Down Syndrome whose mothers mentioned that it's so great in this country that you can bring them out as she would be ashamed in her own country" (Anna, Psychologist).

Meanwhile, in relation to attitudes from the African community in Ireland, one parent said:

When my child is having a meltdown in the shop because of his autism it will be more the African community, particularly from my own country, that will come and pass remarks like: “discipline your child, ask your child to stop screaming” or “you know you are spoiling him, why is he acting up like this in a public space?” The Irish [white Irish] people will be more like “Are you ok? Do you need help?” (Brenda, Child with Autism).

Brenda’s quote portrays parenting in African communities as related to a popular African adage which says, “It takes a village to raise a child”. This means that anyone who interacts with a child, not just relatives and friends, has a responsibility to ensure the health and safety of that child. Thus, if someone sees a child misbehaving in a public space, they intervene without necessarily seeking permission from the child’s parent (Niala, 2011).

While many parents lauded the more positive attitude towards children with disabilities in Ireland, some pointed to the presence of negative attitudes and lack of awareness in some communities from those they deemed to be Irish. One parent said the attitude of members of the Irish public varied from community to community: “It depends on the area. In some areas where I shop, people say “come on, tell him to stop” (Linda, Child with Autism), regardless of their ethnicity or nationality. This shows that although Ireland has come a long way in terms of accepting and integrating people with disabilities (NDA, 2017), given their history of socially isolating and excluding people with disabilities (Dare and O’Donovan, 2002), “the feelings of shame and grief are still across the board in disability” (Róisín, SW).

One parent said she found some Irish people to be ignorant in relation to invisible disabilities, especially autism, despite the prevalence of autism in Ireland:

In Ireland, some people are ignorant. They don’t get it. They look at your child and think “he looks normal, what’s wrong with you woman, why are you letting your child to scream and to throw things and all of that?” In Ireland, I believe autism especially is so common. People shouldn’t be ignorant (Brenda, Child with Autism).

This view of societal ignorance of invisible disabilities in the Irish context is supported by

Kingston's (2007) view that a mother's parenting capacity is often judged negatively when a child with autism is having a meltdown in public. It also indicates how having a child with an invisible disability could deny a parent the right to be seen as the parent of a child with a disability, causing them to be judged without consideration to additional parenting needs. This could lead to the shaming of parents.

## **5.2 Parents' Experiences of Living with and Supporting a Child with a Disability**

### **5.2.1 Disability and Parenting Identity**

Parental beliefs about the origin of their child's disability were expressed in biomedical, religious and socio-cultural terms. While parents saw their child's condition as caused by genetic factors, medical conditions and environmental factors, they also attributed their child's disability to fate, religious and socio-cultural beliefs, in agreement with Danseco (1997). Many parents said they did not see their child's disability in the same negative light as people in their countries of origin. They attributed their different views to their educational backgrounds and work experiences or simply to the fact that it was now about their own child whom they had chosen to love and accept unconditionally. For example, one parent said, "I don't see it like that, maybe because of my science background" (Alice, Child with Autism). A second parent said, "They are my children. I have to love them. I have to accept it. They are part of me now. I have to give them that genuine love" (Sandra, Children with Autism and ID).

Sandra's statement in relation to 'I have to love' rather than 'I love' my children with disabilities portrays love and acceptance as a feeling or position that a parent adopts after struggling with this new identity and concluding that they have no other choice than to love their child the way they are, because it is their parental responsibility, in line with Young *et al.* (2020). Parental acceptance facilitated their ability to sensitively respond to their child's needs (Barnett *et al.*, 2003).

Parents acknowledged that it took them time to come to terms emotionally and cognitively with news of their child's disability. Parents outlined their initial reactions as disbelief, shock, anger, sadness, guilt feelings or self-blame for their child's disability; anxiety over the future of their child; fear and despair. Thus, before accepting their child's diagnosis, parents experienced profound grief and or distress. Doka and Martin (2020) refer to this as adaptive grief, reflecting grief as a unique process to everyone depending on personality and culture. For example, some parents said the following:

I remember the day I cried when they said she has a disability ... Now I love her just the way she is. I wouldn't change her for nothing in the world. She is perfect in my eyes as she is (Caroline, Child with Tracheal Stenosis).

I'm learning to accept that he has a disability but, in the beginning, I was upset... I was like "when I was pregnant, did I do something wrong?" (Brenda, Child with Autism).

Caroline and Brenda's initial reactions to their children's diagnoses gradually gave way to feelings of acceptance. This is in line with the position of Bruce and Schulz (2002) that families often go through an adjustment process to the news of their child's impairment, similar to a grieving process, because many parents neither expect nor desire to have a child with a disability.

Other parental reactions included:

At the beginning I was really shocked. I was angry ... but as time went on, I started making research about kids with autism, things to do with them, about their diet, their daily routine and everything (Alice, Child with Autism).

I do feel sorry for myself and asking, "why me?" I'm struggling with it but my thing is what can I do now to make my child's life better? (Linda, Child with Autism).

Alice and Linda's initial reactions of shock, anger and self-pity gave way to a focus on actions that could make life better for their children. Despite experiencing a myriad of negative feelings on the diagnosis of their child with a disability, parents stated that some of the negative feelings began to fade away with the passage of time, as they got to know their child. Parents said this caused them to discover their inner strengths and resilience, by giving them new insights to the meaning of life, love, commitment and hope (Scorgie *et al.*, 2004; Jennings *et al.*, 2014). Although the news of their child's disability initially disrupted existing parental beliefs and resulted in distress and grief, it effectively started the journey of meaning-making, leading to parental growth (Young *et al.*, 2020). For example, one parent said:

I just feel like having [a child with a disability] is a blessing in a whole, because that has changed me so much. It has brought out another aspect of me that I didn't know I had. I didn't know I had the amount of strength that I

can exhibit today in the world. It has made me stronger and it has made me to realise how lucky and how blessed we are to have a child like her. She is my number one motivation. She has touched me in the deepest part of my soul (Caroline, Child with Tracheal Stenosis).

Other parents said they were happy and thankful to God that their child did not have a more severe disability. Parents said they considered it a blessing that their child was born in this part of the world where disability was viewed more positively and services were available to support the child with a disability to achieve a better quality of life, than they would have had in their parents' country of origin. Thus, following a certain level of parental acceptance of their child's disability, parents seemed to positively reframe their perceptions of disability (Young *et al.*, 2020).

Meanwhile, some parents reported that they used to have negative perceptions of disability and would shun or tease people with disabilities, but lessons learned from having a child with a disability led to a positive change in their perceptions of and attitudes towards people with disabilities:

Before I came to Ireland, when I saw people running away from people with disabilities and saying they are evil, I'd be running away too. Having [my child] made me see things in another way (Edith, Child with no specific diagnosis).

Thus, interpersonal parental growth because of having a child with a disability, caused parents to become more compassionate and understanding and less judgemental towards other people with disabilities (Young *et al.*, 2020). This connects to the statement by Case (2000) that a child's diagnosis encourages parents to put themselves in the shoes of others in similar situations to understand how these people make meaning of their situations.

One theme that came across strongly from parental responses in relation to their perceptions of their child's disability was the belief that their child with a disability was given to them by God. Even though these parents were going through tough times in raising their child with a disability, they were still grateful to God for counting them worthy of such a 'special gift'. While this can be perceived as positive, it also constructs children with disabilities in a particular way – as 'special beings' (Danseco, 1997):

I used to think “oh my God I don’t know how parents with children with disabilities feel and how are they coping”. I just feel that if God doesn’t see that you will be able to take care of that child, especially in a way that I can’t really explain to anyone, it’s only another parent with a child with a disability that will understand my point of view; He wouldn’t give the child to you. They are the most amazing and the most special little people that you can find in the whole wide world (Caroline, Child with Tracheal Stenosis).

Gratitude and a sense that a child with a disability is given to strong and capable parents as indicated in the above quote by Caroline, could evoke a sense of parental pride. On the other hand, it could indicate that parents have less permission not to cope, which could add pressure on parents in relation to competently handling the extra needs of their child without much need for extra support.

### **5.2.2 *Psycho-Emotional Dimensions of Disability***

Parents of children with disabilities reported that they found lack of support, especially from family and friends, more stressful than their child’s disability, sometimes leading to social isolation, depression and burnout (Barlow *et al.*, 1998; Miodrag and Hodapp, 2010; Singer, 2006; Pelchat *et al.*, 2007; Hauskov-Graungaard *et al.*, 2011). Although parents identified social support from family members as being crucial, most of them reported the absence of their former social networks in their countries of origin (Jennings *et al.*, 2014). Some parents recounted the direct experience of negative attitudes by very close relatives and friends towards their child with a disability in their countries of origin, when they went with their child on a visit:

I remember when I went back home in 2017 with him. There were my mom’s friends who were saying that he is not a good child. They won’t say that to you. They will say it to others. They will be giving my child names ... and when you hear that in the end, it makes you feel bad (Edith, Child with no specific diagnosis).

These parents said they found the above experiences emotionally overwhelming, leaving them with feelings of shame, rejection and inadequacy. This lack of understanding and acceptance

of their child's disability by relatives and friends in their countries of origin created tension for parents between wanting to go back to their countries of origin but also feeling they would not be accepted. One parent said:

I don't go to [my country of origin] anymore because I'm ashamed. I don't want my friends to see my kid like that because when I told one of my friends back home that he's not talking, she said "does he not have a mouth?" (Sandra, Children with Autism and ID).

This reluctance to go back to their countries of origin because they did not want to expose their child to such a harsh environment, reportedly caused parents to feel excluded from a place they once called home and were eagerly looking forward to going back to. This caused parents to feel "stuck" in Ireland, supporting Constant and Zimmermann's (2016) view that on returning to their countries of origin after relocating and interacting with new socio-political realities, diasporas may face a clash of cultures, causing them to realise that they do not belong at home. This may lead them to search for new identities as they try to fit in and may cause them to revert to the host country. Thus, families of children with disabilities from minority ethnic groups have 'multiple identities', as they have different understandings of who they are, in relation to definitions of disability (Pierce, 2003; Liasidou, 2013; Jennings *et al.*, 2014). This places them at a higher risk of experiencing multiple levels of exclusion and discrimination, due to constant (re)negotiation of their identities between their home and host countries (Lee and Zhu, 2020). One professional summarised this experience in the following words:

A common expression for African families that I would have met is that they might have come to Ireland to make some money to have a better life but maybe with a plan to go home. With a child with special needs, they want to be back where their supports are, but they also know ... the stigma attached to having a child with a disability. So, they can feel like they are stuck here (Michael, SW).

This highlights the tensions felt by migrants about their country of origin versus host country and the challenges faced in relation to their ideas of 'belonging' and their own identity.

The above experiences in parents' countries of origin, in addition to negative attitudes from some members of the African community in Ireland due to the stigma attached to having a child with a disability, caused parents to feel rejected (Jewell and Blackmore, 2004). Thus,

parents were placed in a precarious situation as they could not seem to fully escape negative perceptions of disability. This indicates that ethnic minority people with disabilities can face discrimination both from within and without their communities (Pierce, 2003). In response to a lack of understanding and negative attitudes from family members and friends, parents said they withdrew from some of their relationships to avoid being hurt, hence becoming socially isolated:

Now I don't talk to my friends because I don't like how they talk about my kids. One of my friends described my son as "retarded". That very day I cut ties with her (Sandra, Children with Autism and ID).

As seen in the above quote, parents exercised agency to protect themselves and their children by making choices in relation to who they interacted with as a part of operationalising their parental identity. Some parents said they went as far as withdrawing from their faith communities, communities that once gave them a sense of belonging. As observed by one professional:

Parents' faith communities seem to play a big part as the general support system. It's really difficult when parents feel that that's not somewhere they can turn to or maybe they are being judged or their child, for whatever reason isn't as accepted (Orla, SW).

While parental grief and distress decreased over time with a certain degree of parental acceptance of their child's disability, parents continued to experience intermittent distress and grief. This is referred to as revision of identity by Petriwskyj *et al.* (2017) and described as an ongoing process with the child's growth and transition from one stage to another. Parents expressed the continued existence of their grief, though less pervasive, triggered by certain milestones or missed milestones in the life of their child, like birthdays (Young *et al.*, 2020). Some parents cited an awareness of missed milestones in the life of their child while socialising with friends as leading them to cut friendship ties to shield themselves from the pain this awareness came with: "I don't have friends anymore. I cut off all my friends because when you see other kids, it reminds you that this kid at this age should be like this" (Sandra, Children with Autism and ID). Thus, despite the presence of the child, parents grieved the loss of their 'hoped for' or 'normal' child, with parental grief aggravated by parents having to alter their beliefs and aspirations for their child in the face of inherent unpredictability in their condition (Barnett *et al.*, 2003).

Parents and professionals spoke of social isolation, lack of support and the challenges of belief systems around disability as some of the biggest issues faced by parents, with these impacting on parents' mental health:

One of the biggest difficulties for immigrant families is that they don't have their immediate families around them and I think that's very difficult when you have a new child. Most moms if they are living at home in their own country, they have their mother, they have their aunties and a range of different people to support them and that makes a huge difference for any new parent. But when you have a child with special needs it becomes much more difficult. There is the stigma attached to it, there is the child being more difficult to care for, all the extra appointments, there is huge pressure and families can feel very isolated here and it reminds them of the fact that they are immigrants because part of them wants to be back home with their families (Michael, SW).

The above statement by Michael (SW) highlights migration (Urquia *et al.*, 2010), becoming a mother (Leahy-Warren *et al.*, 2011) and the presence of a child with a disability (Home, 2002) as three significant intersecting life situations that may cause changes in social support for parents. Meanwhile, for parents who have understanding family members back home who could be of help to them here in Ireland, two parents said they invited their mothers to come and assist them, but they were denied visas. Michael (SW) corroborated this by saying that: "One of the barriers can be non-EU families accessing visas for families to visit. I think that is often a very big challenge. Even when people become Irish citizens, it can be difficult". This attests to the assertion by Jennings *et al.* (2014) that migration may cause families to lose social support especially in the absence of flexible immigration policies (Kediye *et al.*, 2009; Lonergan, 2009).

The social isolation experienced by parents significantly undermined their already limited support network, making the experience of raising their child with a disability more challenging. Many parents said they ended up having nobody to talk to, which could have been helpful in supporting them to navigate the changed vision of their child from the one they had anticipated prior to their child's diagnosis:

Some days I was stressed, no sleep. I was crying here in this house all day, no one to talk to, no family, no friends, and it's hard, it's very hard to cope with.

And you have other children that you have to mind (Edith, Child with no specific diagnosis).

This supports the view by Hauskov-Graungaard *et al.* (2011) and Miodrag and Hodapp (2010) that parents of children with disabilities, especially mothers, manage many different stressors and a high care burden but see their stress as being caused by lack of support rather than their child's disability (Hanvey, 2002). Raising a child with a disability is a very challenging experience requiring social, emotional and economic sacrifices on the part of the caregiver, thus necessitating a good support network to act as a buffer against the resultant stress. This highlights the sense of giving oneself up to the care of the child as a dimension of the identity parents grappled with (Petriwskyj *et al.*, 2017).

### **5.3 Conclusion**

From the above analysis, it can be observed that there is a complex intersection between culture, disability, social networks and economic positions, with socially and individually defined values shaping perceptions of culture and disability (Ripat and Woodgate, 2011). It is evident from parental and professional responses that the culture of blame and shame is still prevalent in parents' countries of origin and within a portion of the African community in Ireland. This negatively impacts on identity formation and sense of belonging by causing parents of children with disabilities to experience feelings of being 'in-between' spaces; for example, not feeling able to gain support from the African community either in countries of origin or in Ireland. Although an element of personal growth was reportedly experienced by parents through parental meaning-making and positive reconstruction of their child's disability, this was undermined by the significantly high level of social isolation experienced by these parents.

The key conceptual debates emerging from this chapter relate to the identity of being an immigrant parent of a child with a disability. This encompasses negotiating the parenting role in the face of different constructions and understandings of disability and challenges from both within and beyond their communities. Psycho-emotional disablism is a significant emergent theme that leaves an indelible effect on parents. These factors hold certain implications for parental engagement with community and healthcare services in terms of tensions and power relations between parent and professional (lay/expert) knowledges about disability and what it means to engage 'appropriately' with a service. The next chapter discusses these implications.

## Chapter Six

### Service Experiences of African Immigrant Families

#### 6.0 Introduction

As shown in the previous chapter, African parents of children with disabilities construct and give meaning to disability in different ways, based on different cultural understandings. In some cases, these can differ markedly from understandings of disability embodied in professional discourses, which in turn, may have implications for parents' access to and utilisation of Early Intervention Services. A range of international literature demonstrates that migrants and people from minority ethnic groups can experience significant barriers in accessing health and social care services and supports (Simon, 2001; Lindsay *et al.*, 2014). In an Irish context, specifically, very little is known about the experiences of African immigrant parents of children with disabilities in relation to accessing and utilising Early Intervention Services for their children (Devery, 2018; Pierce, 2003).

This chapter connects parents' constructions and understandings of disability and parenting identities, to their service access and utilisation experiences within Irish Early Intervention Services. While parents express gratitude for services in the context of limited expectations, some parents report feeling discriminated against in their interactions with services. Research in relation to immigrant parents raising children with disabilities shows that these parents often feel they are discriminated against by service providers, face oppression and experience asymmetric power relationships (Lee and Zhu, 2020; Kediye *et al.*, 2009). Parental experience of discrimination, both direct and indirect, is one of the main themes that cuts across the narrative in this chapter. Direct discrimination refers to being openly treated differently in an unfair manner from other parents, while indirect discrimination refers to specific cultural needs not adequately catered for by service providers (Thompson, 2021). As noted by Pierce (2003), research in other countries indicates the experience of double discrimination by people with disabilities from minority ethnic groups. Meanwhile, a survey conducted by the Migrant Rights Centre Ireland (2010) indicated that almost 80 percent of people from black communities or ethnic minority groups in Ireland had experienced some form of discrimination or racism on a day-to-day basis in different settings. These included health and social care settings, with black people at a greater disadvantage (Watt, 2008). Thus, the context of service engagement could be connected to wider experiences of both overt and indirect discrimination.

In this chapter, I draw on my analysis of interviews with parents and professionals to explore the facilitators and challenges for parental access and utilisation of Early Intervention Services, and implications for parental engagement. The concept of intersectionality is reflected in how a combination of social and cultural factors impact on the experience of marginalisation, oppression and discrimination by parents and highlights social hierarchies and unequal power relations (Liasidou, 2013; Kediye *et al.*, 2009; Lee and Zhu, 2020). Firstly, parental unfamiliarity with the system, including lack of information is discussed. This is followed by an exploration of contrasting perceptions about the role of professionals as experts and service expectations. The third section focuses on language and communication barriers in engaging with the Early Intervention process and professionals. The final section discusses the structural barriers related to the configuration of health services in a context of scarce resources.

## **6.1 Accessing and Experiencing Early Intervention Services**

In this, the main section of the chapter, I explore parents' experiences of accessing and using Early Intervention Services. Experiences were expressed as mixed. While some parents reported positive experiences, particularly of engaging with professionals, they more commonly expressed challenges that could hinder access, or limit their experience of services. On a positive note, parents described Early Intervention Services as:

An awesome approach to assisting families and children with disabilities, especially if gotten as early as possible. This is because in my child's case, physiotherapy really helped strengthen her muscles and speech and language therapy helped improve her pronunciation (Mado, Child with rare genetic disorder).

Some parents said that, based on their negative experiences of disability in their countries of origin, they were not expecting any form of support and were overwhelmed with gratitude by the help and support their child got, even without them asking for it. Some expressed satisfaction at the professional and courteous way professionals operated, while others said they found the service flexible and accommodating in terms of rescheduling appointments and home visits. For example, "the Physio, Speech and Language Therapist and Social Worker came to the house when I could not meet them at another place" (Yolanda, Child with Down Syndrome).

In general, parents exhibited a culture of gratitude and appreciation when comparing Irish disability services to those in their countries of origin, even if these services did not fully meet their expectations. Parents acknowledged that their child would not have had the same opportunities in their countries of origin in relation to follow up services and participation in different activities like other children. This appreciation caused some parents to be initially hesitant to talk about their struggles in navigating the healthcare system (Sandhu *et al.*, 2017).

In terms of challenges, the issues highlighted by parents can best be categorised in terms of four key barriers: unfamiliarity with the system, and how to negotiate it; contrasting perceptions of professionals as experts; language and communication barriers; and structural barriers related to the configuration of health care services. While some of these barriers have been acknowledged as applying to a range of groups, and not just immigrant parents, other experiences appear distinctive for African immigrant families. This is especially so in relation to parental identity, with parents expressing consciousness of not being originally from Ireland as giving them no sense of entitlement to services, causing them to approach with gratitude whatever was provided to them. This affected how parents related to services, with some parents feeling uncomfortable in having to fight for services in the same way as other parents and being reluctant to adopt an advocacy role for their child with a disability. Building on Sandhu *et al.* (2017), parental interpretation of health and social care support as privileges rather than rights could explain why parents responded to presenting challenges with more stoicism than non-immigrant families. Overall, parents were very aware of, and reflected on their identity as migrants in Ireland as they negotiated access to services on behalf of their children.

#### **6.1.1 Unfamiliarity with the system**

Unfamiliarity with the system, poor access to information and language and communication barriers are some of the challenges experienced by some African immigrant parents in relation to accessing health and disability services (Jennings *et al.*, 2014; Kediye *et al.*, 2009; Lee and Zhu, 2020). This left parents with little or no knowledge of where and how to get information on disability services, their rights and entitlements (Lindsay *et al.*, 2014). It is worth noting that out of ten parents interviewed, only two parents expressed some knowledge of the Irish health care system based on their experiences of working within a disability setting (as mentioned in

Chapter 4). Even with their work experience, these parents said they did not fully appreciate the complexities of navigating the healthcare system until they started seeking services for their own child, and wondered what the experience would be like for parents who had no knowledge of the system. Other parents said they knew nothing about the system. Parents who had some knowledge of the system highlighted the huge advantage in knowing the system, stating that the quality of services they received seemed to depend on their knowledge of services:

If they (professionals) know you know how the system works, they'll go with the rules but if they know you are naïve, they will try to make things difficult for you ... I was actually pointing out some stuff to them and they knew I knew what I was saying. This changed their attitude towards me and they began to treat me with respect (Yolanda, Child with Down Syndrome).

My child got Speech and Language Therapy immediately after he was diagnosed because I asked for that and then I got into Parents Plus program because I knew it was gonna benefit him. He is still getting Speech and Language Therapy from the HSE. I'm not paying. I asked for it and was given. But what about another parent who doesn't know the system? (Brenda, Child with Autism).

Meanwhile, one parent with more than one child with a disability explained that the experience they had with their first child with a disability helped them in navigating the system and getting services earlier for their other children with disabilities:

They had speech issues too. Same problem as their older brother. So, I quickly ran to get them private assessment, while on the HSE waiting list, due to previous experience with long HSE waiting lists. Following the assessment, they are now in a special needs pre-school and doing very well. If I didn't have that experience with [my first child], I wouldn't know what to do with them (Sandra, Children with Autism and ID).

Professionals, on their part, acknowledged the lack of parental understanding of the system while highlighting their own challenges in navigating and keeping up to date with some aspects of the Early Intervention service system. One professional noted that, "for anybody moving

into new systems, like the disability services and the Assessment of Need process, it is very difficult” (Róisín, SW), while another professional concluded that this could cause many children with disabilities to “end up being hidden at home or not going to school or left to their own devices in their neighbourhoods” (Michael, SW). Professionals highlighted that while many white Irish families had a good idea of how the system worked due to informal information channels and extended support networks, African families struggled to grasp the basics due to their limited support network.

Navigating through the system is much more difficult for African families and I’m not sure if the level of support is adequate to support them in navigating through it initially... It can be difficult across the board, but I think if you come to this country, and are not aware of how the systems work, it could be much more difficult and harder for you to navigate ... They definitely need additional assistance (Anna, Psychologist).

Anna’s mention of African families and other people who come to live in Ireland, makes it clear that the system is different for them and much more difficult to navigate especially if there is lack of knowledge of the system and not enough supports available. One key point emerging from Anna’s quote is that professionals perceived African immigrant families as needing extra support to navigate the system due to the intersection of immigrant parenting experiences, in agreement with Jennings *et al.* (2014).

One professional highlighted that parental knowledge of the system, to an extent, depended on how long they had lived in Ireland. This was contradicted by another professional, who said he had come across parents who had lived in Ireland for a long time but still did not know how to navigate the system. This suggests that professionals sometimes took it for granted that parents understood the healthcare system. A few studies in Ireland have indicated that service provider assumptions about service user knowledge and understanding of the workings and organisation of services, in addition to language, culture and finance are barriers limiting migrant access to healthcare in Ireland (Ralaheen Ltd.,1999; Royal College of Physicians of Ireland, 2016).

Looking at this parental dilemma of unfamiliarity with the system from another perspective, one professional cited a lack of confidence on the part of parents as a hindering factor in their pursuit of knowledge and understanding of the system:

A lot of African families would rely on me, maybe because I'm white, because I'm Irish, maybe because I'm a man ... that they don't have confidence sometimes in contacting State services like housing and they may want me to do it, maybe because I know the system or they feel their English isn't good enough, their literacy isn't good enough and they would rely on someone like me more to make those phone calls for them ... I'd say they don't always have the confidence to do it themselves. That is a bit of a barrier (Michael, SW).

Michael's identification of himself as white, Irish and male, highlights an awareness of some of his intersecting identities that may impact on his professional practice. As indicated by Michael, unfamiliarity with the healthcare system, in addition to communication barriers, seemingly caused some parents to lose confidence in their ability to seek support and thus depend on white Irish professionals to source these supports. Could this also be a result of African parental perception of professionals as the 'experts'? It is important for immigrant families to gain the necessary knowledge and skills to navigate the host country's health system to avail of the best possible care. However, a good professional understanding of the diversity in values and beliefs among families across cultures and the ability to reflect on assumptions in relation to immigrant families is imperative to optimal service provision to these families (Welterlin and LaRue, 2007; Minervino and Martin, 2007; Harrison and Turner, 2011).

### **6.1.2 Lack of Information**

In the words of Jennings *et al.* (2014, p. 1652), lack of informational support may cause parents to be 'functionally illiterate' in relation to not being able to navigate the social and health care system, thus engendering distress in parents. Ciribuco *et al.* (2017, p.99) concur with this by saying that 'functional illiteracy' is even experienced by some people from minority ethnic backgrounds within their own language. 'Functional illiteracy' in this context refers to a lack or insufficiency of information on the part of parents in relation to available services and supports necessary for managing their child's disability and lack of knowledge on how to seek healthcare. This was one of the challenges faced by parents, as outlined by both parents and professionals. For example, one parent said: "As African parents, we have little knowledge of what is happening out there. They [Irish parents] have all the knowledge, they know who to call, what to do" (Caroline, Child with Tracheal Stenosis). This view was supported by a professional in the following words: "I think for some of our Irish families, they might have a

better idea of how the system works and know the services that are available, but migrants may not” (Anna, Psychologist).

Thus, some parents complained that lack of timely information led to delays in assessment and intervention for their child with a disability. This was in line with Hibel and Jasper’s (2012) finding that immigrant children with disabilities experience more delay in initially accessing services than the host population. In the words of a parent:

I remember a [Medical] Doctor mentioning that I should go and register with an Early Intervention Team but didn’t give me any further information on what I was supposed to do. I didn’t pursue the suggestion (Mado, Child with rare genetic disorder).

In relation to financial support, one parent said she was neither made aware of the existence of the Domiciliary Care Allowance nor of the fact that she was eligible for it until some years after her child had been diagnosed with a disability; and when she applied, she was told that payments were not backdated. This delay in the provision of information on existing supports is seen by Skindra (2008, in Jennings *et al.*, 2014, p. 1652) as reflective of cultural incompetence within the system. One way of overcoming this barrier could be for professionals to work closely with communities in promoting intercultural awareness (Ciribuco *et al.*, 2017), awareness of structural barriers and professional responsibility to address these.

### **6.1.3 Who Is the Expert?**

In some cultures, especially within childcare services, professionals such as doctors, social workers and therapists are often perceived to have all the answers and not to be questioned. This is due to their specialised skills and knowledge gained through training, which gives them responsibility for the welfare of the child, in contrast to parents and guardians who are seen as “unqualified lay persons” (Case, 2000, p. 275; Hodge and Runswick-Cole, 2008). Immigrant families often look to healthcare professionals as people in authority and experts and are not comfortable with family-centred care practice within Early Intervention Services that involves parents and service providers in collaborative decision making (Honey-Arcement, 2016). Concurring with Honey-Arcement (2016), parents said they saw professionals as the experts and expected them to work with their child but felt challenged when required by professionals

to do most of the work with their child:

A parent could be saying yes to everything you say because you are in authority. Generally, African communities respect authority and they think everything you say is correct and should be followed through ... When you give them things to do at home, it's confusing that you the professional, are supposed to do things with my child, not me at home (Brenda, Child with Autism).

The challenge is to work with the child alone because most of the time when you go to see them [professionals], they will say you have to do this, this, this with the child. So, the big work is you the parent (Edith, Child with no specific diagnosis).

Brenda's quote indicates that an African parent may say 'yes' not necessarily because they agree with what professionals are saying but simply because professionals represent authority, thus highlighting a cultural difference in relation to authority. Edith's quote highlights parental struggles in relation to being saddled with the responsibility of doing most of the work with their child. These could be related to parents' backgrounds of coming from countries where the relationship between doctors and patients was based on doctors exerting professional authority through medical expertise, thus excluding patients from decision making and follow up processes (Arfa *et al.*, 2020). This is reflective of an unequal power balance (Hodge, 2006; Runswick-Cole, 2007; Hodge and Runswick-Cole, 2008)

Some professionals highlighted that African immigrant parental constructions and understandings of disability, based on their culture of origin and their cultural view of authority, influenced their perceptions of Early Intervention Services. This was evident in their expectation that professionals should do all the work for their child, the service curing their child rather than providing ongoing support as is currently the case, and professionals being seen as the experts in the field. These views by professionals lend credence to Schuman's (2000) statement that parental attitudes towards their child's disability are often shaped by their cultural orientation, especially in terms of their expectations of services, the role of the family and hopes for their child with a disability:

It's very much like "I give my child to the professional and the professional fixes my child. The responsibility of me doing something is quite less". So, if they come in a session, they might just sit in a chair while I work with the child, whereas if I'm working with an Irish family, they will get involved, they will sit on the floor, they will read out, they will ask you more questions, so they are more involved in what you do. That's the right way to do because the child is with me only for a short period of time, whereas most of the time is being spent at home (Patrick, SLT).

In such cases, Patrick said he explained to parents that they were the real experts, as he only saw the child briefly, from time to time. This made it more of a facilitating role in terms of showing parents what to do and supporting them, rather than doing everything for the child. In the words of another professional, "we have to help the parents see that they are still the specialists" (Aoife, SLT). Although it is not always visible, professionals may sometimes devalue immigrant families' perspectives, unintentionally, in their portrayal of the 'Western way' as the 'best and only way' (Welterlin and LaRue, 2007, p. 757). While some professionals said they viewed parents as the real experts, some professionals' accounts contradicted this and were suggestive of value judgements. For example, the line in Patrick's quote above in relation to "the right way", portrayed African parents as not doing things in the correct manner because they were doing it differently from white Irish parents. This perception is ethnocentric and does not constitute a culturally appropriate assessment (Dalikeni, 2021). Sometimes, for people to be treated equally there needs to be an understanding of difference or extra supports put in place to create a more level playing field.

The expectation by professionals for parents to do most of the work with their child portrays Irish Early Intervention Services as built on Eurocentric views (Dalikeni, 2022), dominated by white middle class values involving autonomy and independence, which can be understood differently by some cultural groups (Iwama, 2007). For example, as seen in the quotes of Brenda and Edith above, parental expectation for professionals to do most of the work with their child caused them to struggle with professional expectation of parents to exercise autonomy and independence in working with their child. Schultz (2004) sees the dominance of Eurocentrism as leading to a failure of services meeting the specific cultural needs of service users, thus creating barriers to access and utilisation of resources by minority cultural groups.

#### **6.1.4 Language and Communication Barriers**

Meaningful service provision to people from ethnic minority groups involves the provision of information in a manner that relates to their needs (Arfa *et al.*, 2020). The Office of the High Commissioner for Human Rights upholds the right of every individual to have access to information, in an accessible language and format specific to them, in relation to making decisions affecting their lives and wellbeing. This necessitates the consultation and inclusion of migrants in relevant public policy development (OHCHR, 1996-2023). Some of the communication challenges experienced by immigrant families included professional lack of intercultural communication skills, the use of medical terminology and lack of training in relation to working with families from different ethnic origins (Khanlou *et al.*, 2015). Thus, it is important for professionals to invest in learning the cultural context and communication style of families they work with (Welterlin and LaRue, 2007) by listening to and respecting them, being aware of their own knowledge and biases, and discussing their beliefs with the family (Magnusson and Mistry, 2017; Lindsay *et al.*, 2014b). Based on an awareness of language constituting one of the most pertinent barriers to migrants' access to healthcare, the Intercultural Health Strategy 2007-2012, launched by the Health Service Executive (HSE) contains many references to language, highlighting the provision of information to service users in an accessible format as a key priority in need of urgent attention. Meanwhile, the 2016 Census indicated that 612,018 people spoke a foreign language at home in Ireland while 8,669 people or 0.2% of the overall population were 'not at all' able to speak English (Ciribuco *et al.*, 2017). King *et al.* (2013) identifies language and communication barriers as one of the biggest barriers to service access and utilisation by immigrant families, which can lead to challenges for parents in understanding their child's diagnosis and reducing their likelihood of following through with recommendations for managing their child's condition. Language barriers may also lead to a lack of parental awareness of available services for their child, including community supports and resources, thus impeding the care parents receive for their child.

All the parents who took part in this research had a good command of the English language. However, some parents and professionals expressed that they had experienced communication issues which affected service provision in relation to access, utilisation and engagement. From the perspective of understanding and constructing their child's disability, some parents expressed that there was no word for certain disabilities (like autism) in their dialects which made it difficult for them and especially their family members (in their countries of origin) to

understand and accept their child's disability. Meanwhile, professionals expressed language and communication difficulties in the form of spoken language (where parents were not fluent in English) or body language and certain accents and nuances (where parents were fluent in English). One professional stated that "a lot of West Africans, Nigerians, speak good English and their communication isn't much of an issue ... but people from Cameroon and Congo, French speaking, that can be more of a challenge" (Orla, SW), with French speaking parents requiring the services of interpreters. Another professional said:

I've never had to use an interpreter with most African families I've met but I do think there is an issue around English being a second language for some families ... I think one of the main difficulties probably would be not so much people's understanding of English but my understanding maybe not of their English which would be very good, but their diction and accent is very strong and sometimes that can be quite difficult to understand especially over the phone when they are emotionally distressed (Michael, SW).

This professional went on to say language was never a barrier in their work with African parents, as they found that African families generally picked up the language with ease - "in general with African families, I find that people pick up the language" (Michael, SW).

A crucial element of communication is comprehension, which is often the casualty wherever there is a communication barrier. The transmission of information in a message is only seen as successful communication when the person in receipt of the information understands it as intended. This is something professionals need to pay special attention to when working with people from ethnic minority communities with little or no knowledge of the workings and organisation of services (Pierce, 2003), as is evidenced in the following professional's words:

I worked with a family and they thought that when somebody said the school was closed on Friday the 10th of September and Monday the 30th of October, they actually thought the school was closed for a whole number of weeks, not just those two days ... Little nuances like that are huge in terms of language (Edel, OT).

Language and communication difficulties may inhibit the development of a rapport between the service provider and service user (King *et al.*, 2013; Jennings *et al.*, 2014). This is not desirable, given that a good relationship between the service provider and service user is crucial to the delivery of optimal and effective services and may lead to positive intervention outcomes in terms of empowering the service user and enhancing their hope: “I try my best to give them what they can read and sometimes we also set up groups of parents who have similar cultures and we hope talking and interacting with each other can help them” (Patrick, SLT). This was in a bid to overcome language and communication barriers.

Meanwhile, the use of complicated medical vocabulary when working with people who have little or no understanding of fundamental health concepts can act as a barrier to their access of care, especially when professionals do not acknowledge this and take time to explain the illnesses or disability to those concerned. There is, thus, a need for communication to be clear and tailored to the needs of service users (O’Donnell *et al.*, 2016). In relation to situations where children were being given a diagnosis, parents expressed that they faced the diagnostic procedure with mixed emotions. They feared hearing the worst, while expecting answers to their questions in relation to their child’s development and hoping for a treatment of any diagnosed problem. Some parents complained about the ‘big words’ that were used during their child’s diagnosis such as “assessment” and “developmental delay”. They said these words were unfamiliar to them and when professionals were asked to explain their meanings, they seemed disinterested and were not clear enough in their explanations. This connects to parental experiences of the professional as the ‘expert’ and confirms professional use of language and diagnostics to sustain the exclusion of lay knowledge (Hodge, 2006; Runswick-Cole, 2007; Hodge and Runswick-Cole, 2008):

You become so aware of the big words. I remember they said, “he’s got developmental delay features”. What is that? ... What do you mean by that? Is it gonna go away? What help are we gonna get? (Edith, Child with no specific diagnosis).

Some parents said they found the assessment process and relay of their child’s diagnosis by professionals very cold and insensitive, which took them aback:

The way of telling people is so insensitive. The Psychologist after the whole assessment said “yes there’s something and it could be autism” but she didn’t want to elaborate on what autism is (Brenda, Child with autism).

Parents said they considered their child’s disability diagnosis as ‘bad news’. They commented that this blunt relay of their child’s diagnosis was unlike how it would have been communicated in their countries of origin, whereby the delivery of bad news was approached with a lot of sensitivity and caution. One parent highlighted the cultural differences between the African and Western approaches to delivering bad news in the following terms:

Where I come from ..., if someone dies, they send elderly people to go and tell the person that their relation has died. When they walk in, they don’t say “sit down” and “oh your son has died”. That’s regarded as being insensitive. They walk in and then ask “how are you? I have some news” and then they don’t say it straight away. They’ll chit chat a little bit and then kind of assess the moment to say it. You’ll never be on your own when you deliver bad news and the person will sense something is not right and then they’ll kind of be prepared and then you will tell them. In Western culture, you are supposed to say things as they are. You don’t put your words into things. If its autism, you say autism. If you are saying disability, you say disability. That then influences sensitivity if you are dealing with an African family because they will feel “oh my God, you are so cold” (Brenda, Child with Autism).

The way a child’s diagnosis is relayed to parents seems to be a broader issue within the Irish healthcare system as well as how professionals communicate with parents of children with disabilities, and the power embodied in the professional/parent relationship. The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (2007) in Ireland corroborates this statement by indicating the lack of sensitivity in the relay of a child’s diagnosis by professionals. This document also highlights the inappropriateness of some environments in which such information is passed on, causing additional stress to families at an already difficult time. In the cited study, while parents lamented the insensitive relay of their child’s diagnosis, professionals blamed the lack of clear guidance and training

for professionals in relation to relaying such information to families (Garcia and Magnuson, 2000).

The above parental challenges indicate that when service providers working with immigrant families from different cultural backgrounds are not aware of the understanding and management of disability across different immigrant groups, it creates a barrier for immigrant families who access and utilise these services (Fellin *et al.*, 2013). As one parent put it, “you would be lost, thinking “what is this disability they are talking about?” (Mado, Child with rare genetic disorder). Parental responses imply that family-centred care that is culturally sensitive and linguistically appropriate, as opposed to applying one method to all families, is an essential requirement for Early Intervention Services – that is, if the needs of African immigrant families of children with disabilities living in Ireland are to be adequately met (King *et al.*, 2013).

#### **6.1.5 Structural Barriers**

Research has shown that there are many structural barriers to the access and utilisation of Early Intervention Services, especially in relation to delays in assessment and inadequate intervention, causing some parents to resort to paying privately for assessment and intervention (Lindsay *et al.*, 2012; Barnados, 2017; Devery, 2018). These are common points throughout this chapter. Whilst structural issues within the health system are reportedly problematic for many families, these challenges are reportedly amplified for immigrant families (including some parents who took part in this research) due to limited knowledge of available services and resources, language acquisition, acculturation issues and poverty (Simon, 2001). Long waiting times, limited resources and the fight for services, discrimination and racism are discussed in this section.

##### **i) Long Waiting Times**

The earlier a child’s developmental delay is identified, the earlier the parents will know if the child has a disability and requires intervention, and the earlier supports will be put in place to encourage appropriate development for the child (UNICEF, 2012). Thus, long waiting times constitute a structural barrier to service access and contravene the fundamental rights of the child with a disability (UNCRC, 2006). The Disability Act (2005) in Ireland entitles all children to an Assessment of Need which involves an assessment of their health and

educational needs and drawing up of a care plan and a report produced within six months of receiving an application. A report published by Barnados (2017) indicates the Irish government as failing to have met the above requirements, with 96% of children in need of assessment waiting for over a year or two for assessment and a further twelve to eighteen months for recommended follow-on intervention services (Duncan, 2014; O'Brien, 2014; Deegan, 2011; Hough, 2010). Parents said once referred to the Early Intervention Teams, they had to wait for a very long time (many months and even years) for their child to be assessed and for intervention to commence: "It took a very long time, over months and even a year before she started getting services by the Early Intervention" (Mado, Child with rare genetic disorder).

Although parents acknowledged that long waiting times were being experienced by other parents, regardless of their country of origin, they said it impacted more on immigrant families as they had different understandings of disability and were unaware of available services and the functioning of the healthcare system, thus leading to significant delays in some of them seeking help: "Parents could be sitting at home with a child with Autism and thinking "no he'll be fine, he will outgrow". That then means that the child misses out on getting proper appropriate service" (Brenda, Child with Autism).

Brenda noted that immigrant parents who came into the country when their child had passed the age of being seen by the Public Health Nurse (PHN) were more vulnerable, as the PHN was usually the first person to pick up if a child needed to be assessed and advice parents on what to do: "Parents rely on the Public Health Nurse to detect that something is wrong with their child, especially culturally because autism is not a common thing in my country" (Brenda, Child with Autism). Another parent said they became aware of where they could go for help when their child was already much older and there was little hope of improving their quality of life.

The delay in parents seeking assessment for their child either due to a lack of understanding of their child's condition, a lack of awareness of where to seek help, or due to cross-cultural misunderstandings, placed immigrant families at a significant disadvantage in relation to timely access to crucial services. One parent evidenced discrimination in relation to service access on the grounds of culture by summarising, in the following words, their experience of how cross-cultural misunderstanding led to an unfair delay in service access for their child, compounded by the long waiting list:

I had been like shouting to the PHN when he was two to put his name on the waiting list to be assessed. We were very unlucky because the PHN said we are bilingual, because we speak two languages at home, that is why he is not picking up on language, that we should try and speak one language to him. So, she didn't put his name on the waiting list and when I later heard that there is a two-years waiting list, I started crying (Sandra, Children with Autism and ID).

Research highlights the first three years of a child's life as crucial, given that it is a period of rapid development which lays the foundation "for their physical and mental health, emotional security, cultural and personal identity, and developing competencies" (Ombudsman for Children's Office, 2020, p.17). Timely intervention, in the form of early and comprehensive information, services and support provision to children with disabilities and their families, enhances the child with a disability's chances of survival and flourishing in society (UNCRPD, 2006; UNICEF, 2012). This highlights early childhood as a critical period for the realisation of children's rights (Ombudsman for Children's Office, 2020).

The long waiting times may mean that children may not get a diagnosis until after the age of three, which reduces their chances of improvement. Many parents said they found the long waiting time frustrating as they not only had to wait but had no idea when their child's turn would come, echoing the experiences of parents in some international studies (Khanlou *et al.*, 2017; Marshall *et al.*, 2017; Hendrikson *et al.*, 2000). Some parents said this caused them to seek private diagnoses while waiting for the HSE diagnosis: "We went ahead to get a private diagnosis when my son was four" (Sandra, Children with Autism and ID).

Meanwhile, parents said they found the long waiting times "profoundly disempowering" (Devery, 2018, p.32), with many parents complaining of being unable to afford private services for their child with a disability. This left them with no other option than to wait on the HSE and accept what was offered, even though they felt it was inadequate. Parents who managed to pay for private services said they found it very costly and a heavy financial burden, with no government support in terms of tax relief: "I work full time. Sometimes we have to look for a private nurse funded by us... The government won't look at that even in terms of tax. It's quite challenging" (Edwin, Child with Tracheal Stenosis).

Thus, immigrant families can find themselves at a disadvantage in terms of socio-economic status and ability to pay for services, which is a feature of the Irish health care system (Coakley and Mac Einri, 2007; Devery, 2018). This is evidence of social hierarchies leading to the privileging of some groups and the marginalisation of others as laid out by the concept of intersectionality (Liasidou, 2013). However, some parents stated that they did not blame professionals for the long waiting times, as professionals only worked with what they were given. Parental blame was directed at the State for not putting in enough resources to ensure professional adherence to shorter waiting times:

The professionals in these services are brilliant but it's getting into services  
(Brenda, Child with Autism).

Sometimes, the delay is not from the workers. They are just workers. They work with what they see. Sometimes they may not be available, or the ratio is small and the kids are more ... So, it causes delay for some kids (Yolanda, Child with Down Syndrome).

One professional supported these parental views in the following words:

I don't think the State does enough for people with disabilities. I think it is very limited. We do not have enough resources (Edel, OT).

Thus, long waiting times were seen by both parents and professionals as resulting from limited resources.

## ***ii) Limited Resources***

Limited availability of services for children with disabilities was another structural challenge cited by parents, with parents attributing this to a loss of parental voice in the choice of services for their child. In addition to long waiting times, all parents complained of insufficient therapy being provided to their child: "He only got six sessions of Speech and Language Therapy and that was it, over two months" (Sandra, Children with Autism and ID). Parents commented that this experience was shared by other parents, irrespective of their nationality/ethnicity but was more pronounced for immigrant parents as they had reduced social capital, concurring with Home (2002), and did not know how to fight for services like Irish parents, who knew whom to contact or what to do:

I took him to private OT [Occupational Therapy], €80 per hour. I took him to private SLT [Speech and Language Therapy] too, €100 per hour. First when a child comes there, they assess him. The assessment for OT is €400. After the assessment, they will know what to do with him. With the SLT, it is €350 for assessment before they can take him at all. So, it's just crazy. At the end of the day, he's my son, not the government's son, so I started doing everything I can do to help him in terms of speech...I could not afford private therapy for long due to lack of money to sustain the high cost (Sandra, Children with Autism and ID).

Meanwhile, some parents complained of limited resources leading to their child being placed within the same settings as children with more profound disabilities, thus limiting the ability of their child to make significant progress:

The special needs playschool she is currently attending is completely different from her needs. There are 5 of them in the class. 4 of the kids are really disabled. ... She can walk, she can talk, she can eat, she can do other things but most of the other kids can't talk and can't walk. I'm happy with the fact that she is going there to play twice a week, but I don't think it is helping her. I feel it will bring her down (Edwin, Child with Tracheal Stenosis).

Edwin said before getting this pre-school for their child, they had applied to several organisations but had not received any favourable response. This was the only organisation that responded favourably to them which made them accept whatever was offered due to lack of alternative options. Edwin said, after accepting the pre-school offer, he constantly voiced his reservations to the administration but was always advised that limited resources were to blame.

In addition, some parents cited limited resources as leading to a lack of parental choice of schools for their child due to an insufficient number of schools for special needs children. Parents stated that they had to put their child's name down in many special schools, most of which were far from where they lived, and accept any that was offered to them. This was unlike the case with children with no disabilities who had a wide range of school options to choose from, especially within their locality. According to one parent:

My child is now on the waiting list with fifteen schools and these are not local schools. With normal, so to speak, children, you decide my child is going to this local school, but when looking for a preschool for my child with special needs it depends on what is available and that saddens me. Most of the services are full (Brenda, Child with Autism).

Recently, there have been plenty of media debates about the lack of school places for children with disabilities. A recent *Irish Times* article, for example, cited that “Up to 80 children with special needs in Dublin [were] without school places” (O’Brien, May 2022), with another describing special needs children being “bussed out of their communities due to shortage of school places” (O’Brien, October 2022). Meanwhile, RTE referred to the lack of school places for children with special needs “as an annual crisis” (Lehane, June 2022; Halpin, August 2022).

Some parents said they thought the Irish government was not allocating resources within Early Intervention Services in a manner that enabled children to get the maximum benefit in terms of therapy:

One professional told me that I’m qualified for somebody to come to my house about 3 hours a day for two days a week to help me because I have three children with disabilities and that will cost the government €18000 a year. I’m not contented with that because if I’m qualified for that and they say they will be paying that person €18000 per year, why not give me that €18000 and let me get therapy for these kids? ... So I said, “I don’t need them. If you can give me this money let me pay someone to come and help them let them improve, that will benefit them more” (Sandra, Children with Autism and ID).

This highlights a lack of parental voice in relation to resource allocation within disability services, with parents complaining of the service giving them what they thought was good for them rather than seeking their opinion on what they would prefer. One parent suggested that “it’s better to talk to parents and see what they want and see if they can offer that, not for them to impose” (Edwin, Child with Tracheal Stenosis). Looking at Sandra and Edwin’s accounts and reflecting on earlier quotes in the chapter – where parents saw professionals as in authority and just said ‘yes’ to whatever was offered - there seemed to be a change in parental attitudes during their interaction with services. Looking at Runswick-Cole (2007), parental involvement in the ongoing management of their child’s condition could have made some parents look

differently at available services and given them the courage to fully adopt an advocacy role for their child.

In addition to the experience of limited resources and contrary to the view held by many professionals that African immigrant families were not being marginalised, some immigrant parents experienced blatant marginalisation when it came to eligibility for certain support services, based on their residency status. This was especially true for parents within the direct provision system:

Families in direct provision are entitled to the services but not the benefits like the Domiciliary Allowance and the Carers Allowance and other benefits. They are not entitled to these until their legal status is established (Angela, SW).

Non provision of above can further limit the social and economic capital of families already struggling with the challenges of living and raising a child with a disability in a different socio-cultural setting (Green *et al.*, 2005). States and UN agencies are called upon by the Commissioner for Refugees (UNHCR, 2010) to protect refugees with disabilities against all forms of discrimination (including on the grounds of migration or residence status), assist and support them with their needs in a sustainable and appropriate manner (OHCHR, 1996-2023).

### ***iii) The Fight for Services, Discrimination and Racism***

One of characteristics of Early Intervention service provision, as highlighted by parents, was the fight to gain access to services for their child, convergent with findings by Devery (2018; see also Moloney *et al.*, 2021). As Linda (child with Autism) said: “From the first contact, you just have to be fighting and fighting”. Many parents acknowledged that it was the fighting that worked in Early Intervention Services in terms of knowing what they wanted and making persistent contact with the services to demand what their child needed (Hodge and Runswick-Cole, 2008). Parents observed that this fighting was not limited to accessing Early Intervention Services but was also characteristic of the child’s transition from one phase to another within the disability system, for example from pre-school to primary school, to secondary school and beyond. While some parents said they chose to fight for services, others said they chose not to, because they did not want to be seen as being ‘fussy’. This reflects findings by Lindsay *et al.*,

(2012) that immigrant clients often feel it is inappropriate for them to ask about other services or resources that may be of help to them:

Some Irish parents told me they had to fight to get those services. They told me that we can call this Taoiseach or this Councillor, the HSE, but I'm not Irish and I don't want to be that kind of person that has just come into a country and I'm trying to be fussy. So, we let things go sometimes, not wanting to put pressure. ... We are from a community that will look at you as if you are doing something bizarre if you start fighting (Caroline, Child with Tracheal Stenosis).

This corroborates findings by Lindsay *et al.*, (2014, p.e14) that immigrant families often hold back from advocating for their child because they do not see it as culturally appropriate.

In general, parents said the idea of fighting for services upset and emotionally drained them, especially as they were still trying to make sense of their child's disability. The need to fight for services, according to parents, caused some parents to take a step back and decide to keep their child at home until they were of school going age before re-embarking on seeking assessment for their child. One parent who worked in disability services highlighted how this made them understand why some parents did not engage with or withdrew from services:

I usually fight for families and now I have to fight for my own child. It's so frustrating and causes a lot of upset and I understand why some parents would give up and go "no, my child will stay at home without going to a crèche. I'll wait until he is five and I'll try to see if there's a school or whatever" and then that's when they start the process of assessment (Brenda, Child with Autism).

Parents said while the fight for services was not limited to immigrant families but also applied to white Irish families, they as African parents had to fight more than Irish parents to get services due to discriminatory practices in relation to being treated differently from white Irish parents. Two parents highlighted a feeling of being treated differently because of their skin colour and ethnic background. This view was contrary to the view held by most professionals that service provision was the same for every family regardless of their ethnic origin:

When you look at the [white] Irish parents and the immigrant parents, there are two different ways [the service] treats them. Our child was in the hospital for two years. There were times we felt like she was being treated differently... They would take her from the ward and put her in the sluice room when an Irish kid was brought in. It was just like a big playroom with no heating and she caught bronchitis several times. Irish parents would object to their child being moved to that room and the hospital would listen to them ... We tried it sometimes and they would behave as if they were listening and still put her in there ... Other parents would come once a week but when we didn't go for a few hours, they would start calling. At one point we told them that ... it is the responsibility of the hospital to provide a nurse for her. We had an argument ... and in the end they provided a nurse for her ... that's the fight (Edwin, Child with Tracheal Stenosis).

Edwin said the rationale given to them by hospital staff for moving their child was that she was doing better than others in the same ward and by virtue of being African, was 'strong'. This suggests overt racism/discrimination on the grounds of ethnicity, supporting findings by Arfa *et al.* (2020) that skin colour influences the services people receive and how they are treated. It also connects with findings of a survey at a Danish hospital in relation to negative perceptions of and attitudes towards immigrant patients (Michaelsen *et al.*, 2004). These stereotypical attitudes and experiences of being treated differently than the majority may be seen by parents as offensive and cause them emotional distress. This sense of discrimination, in addition to other barriers related to being immigrants, may negatively impact on parental engagement with services. It is thus important for healthcare professionals to be aware of, reflect on and amend their attitudes while interacting with immigrants as a step towards providing available and appropriate services to all service users. However, parents said they endured such discriminatory practices by telling themselves that their child's condition would have been worse if they were in their countries of origin and adopting an attitude of gratitude. This connects to findings by Lindsay *et al.* (2012), that immigrant clients are often grateful for received services.

While some parents reported being discriminated against, some parents believed service provision was impartial and inclusive, stating that everyone was treated the same regardless of

their nationality and ethnicity. This was in line with Larkin and Moore's (2005) belief that service provision is universally impartial:

When it comes to babies, there is no segregation. They are all inclusive. I work with them. I see how it's being done ... I don't think there is something a child will need and will not be given, whether black or white, except they know your child doesn't need it but you think your child needs it (Yolanda, Child with Down Syndrome).

They look at any child based on the needs. With my child, they never asked me where I came from or anything. They told me the services that they could offer and we have been availing of a few of the services since we joined them (Mado, Child with rare genetic disorder).

One professional confirmed these by saying that:

When a child is referred to us, it depends on whether or not the child meets the criteria. It's the same for African parents as it would be for all other parents (Abigail, Physiotherapist).

Impartiality in this context meant the application of a 'one size fits all' approach by professionals, an approach critiqued by Robinson *et al.* (2016) as not encouraging professionals to adapt interventions to suit the needs of service users. Although this approach did not consider the specific cultural needs of families attending the services, some parents saw it from a positive light due to an initial lack of expectation of support for their child.

## **6.2 Conclusion**

From the above analysis, it can be observed that African immigrant parents of children with disabilities who took part in this research experienced significant challenges in accessing and utilising available services, though cushioned by a few positive experiences. Parents appreciated the opportunities their child with a disability had in Ireland, unlike what would have been the case in their countries of origin but saw their culture of origin as a barrier to them accessing available services and being provided with services in a culturally appropriate manner. Cross-cultural misunderstandings acted as a barrier to professional collaboration with immigrant clients (Harry, 2008). These challenges, embedded in cultural differences, structural barriers and the way services are configured (which contribute to undermine the rights of the

child with a disability), are reflective of the concept of social identity, which focuses on how “we see ourselves in relation to others, as well as the very ways that we position, align, differentiate, and categorize ourselves” (Garrahan and Rozas, 2013, p. 99). Some of the challenges (e.g. long waiting times) experienced by parents in navigating the complexities of the Irish health system and its shortcomings were shared by most parents availing of Early Intervention Services but were more enhanced for immigrant families, leading some parents to feel like they were being discriminated against by services. In relation to children waiting a long time for assessment, I strongly advocate for the HSE and the Department of Health to urgently address the issue of long waiting lists by ensuring the provision of adequate resources (human, financial and technical) to Early Intervention Teams to facilitate the recruitment of more therapists for timely management of Assessment of Needs (Ombudsman for Children’s Office, 2020). This will go a long way to ensure that the basic human rights of children with disabilities are met, especially in relation to their health and wellbeing.

Looking at the above challenges experienced by African immigrant parents of children with disabilities in Ireland, the concept of “double stigma” as put forward by Albright (1997), becomes evident. This concept is reflected in parental shame due to the stigma attached to having a child with a disability in their cultures of origin (as seen in the previous chapter) and the challenges of raising their child in a different country with unfamiliar systems. These placed parents at a disadvantage, both socially and economically, and limited their opportunities for a better quality of life. Findings by Jennings *et al.* (2014, p. 1647) support this view by revealing that immigrant mothers of children with disabilities are “doubly marginalized”. Despite the above challenges faced by African immigrant parents of children with disabilities in relation to access and utilisation of Early Intervention Services, their high level of engagement with Early Intervention Services, as reported by professionals, attested to their resilience and determination to ensure the best outcome for their child with a disability.

While some authors focus on the assumption that service provision quality is usually the same for all families (Larkin and Moore, 2005), other authors argue that ethnic minority families require a certain level of targeted support to benefit from equal access (Slade, 2014; Welterlin and LaRue, 2007; Birkin *et al.*, 2008; Khanlou *et al.*, 2015 and Khanlou *et al.*, 2017). Meanwhile, Danseco (1997) sees an investigation of the interface of parental beliefs, professional beliefs, culture and childhood disability, as the route towards effective intervention with people from different cultural groups. This requires acknowledging and combatting existing systems of power, without which many opportunities will be missed for

both professionals and service users, especially immigrant service users (Garraan and Rozas, 2013). Following this chapter's discussion of the service access and utilisation experiences of African immigrant parents of children with disabilities, the next chapter will explore the different understandings of cultural competence and its usefulness in addressing some of the challenges faced by these parents.

# **Chapter Seven**

## **Exploring Understandings of Cultural Competence**

### **7.0 Introduction**

Chapters five and six explored some of the barriers/challenges faced by African immigrant parents of children with disabilities in accessing and utilising Irish Early Intervention Services. These were discussed within the contexts of diverse parental identities, roles, social isolation and experienced discrimination in relation to services received. This chapter explores the concept of cultural competence as a potential guide for professionals in responding to and addressing the issues raised in chapters five and six. The issues illuminated in chapter six raise particular challenges in terms of whether cultural competence can adequately address the barriers and inequities faced by immigrant families. As the previous chapter indicates, the structure and configuration of services, and inadequate resourcing, remain clear barriers circumscribing migrant families' access to Early Intervention supports and services.

In Ireland, the HSE aims to deliver culturally competent, respectful and responsive services to people from diverse cultures. There is a focus on intercultural training to support the integration of cultural competence by HSE staff into the workplace. A second focus is to engage with professional bodies and colleges, to ensure the incorporation of intercultural awareness into the training of health and social care professionals. In addition, consideration is being given to the development and implementation of strategies to encourage the recruitment, development, promotion and retention of staff from different backgrounds. All of these are aimed at providing care of the highest quality to all service users regardless of cultural background, ethnicity, literacy or English proficiency (Intercultural Health Strategy, 2018-2023). However, as will be seen in this chapter, professional approaches seem to be more in line with knowledge gathering in relation to the preferences and practices of immigrant families and comparing these against the Irish norm, with the 'Irish way' being portrayed as the 'correct way' and immigrant families being encouraged to adopt the 'Irish way' of life (Christie, 2010).

This chapter presents findings on professional knowledge, understanding and practice of cultural competence in Early Intervention Services, and implications for African immigrant parental responses to services in relation to their child with a disability. Section one discusses the transition of Ireland from a white, Catholic and insular State, characterised by emigration

to a global society (Inglis, 1998; Inglis, 2008) and implications for professional practice within Early Intervention Services. The next section frames cultural competence at an interpersonal level by discussing professionals' understanding of cultural competence based on their education and training, while highlighting the need for a concerted approach (at an organisational level) towards cultural competence. This is followed by an examination of the role of professionals as 'cultural brokers' in working with immigrant families in the face of challenges in relation to trust and rapport building, time constraints, and service interaction with gender and ethnicity. The final section investigates professional self-evaluation in relation to culturally competent practice.

### **7.1 Professional Perceptions and Experiences of Cultural Diversity**

Considering the increasing diversity of Irish society, with immigrants from different parts of the world, including Africa, one professional recalled growing up in a predominantly white (Curry *et al.*, 2010; Gilligan and Curry, 2010) and Catholic (Inglis, 1998) Ireland in the following words:

Ireland when I was growing up was white with freckles ... It really was a different kind of society then. It's so different now ... When I was a child, there were no African people in Ireland except seminarians ... In my whole education in Ireland, there were no African children. Actually, there was nobody that wasn't Irish at all in my school. So, it was a big change in Ireland to have so many different nationalities, not just from Africa (Aoife, SLT).

Aoife went on to share her experience of working at a time when there was a lot of inward migration from different parts of the world:

When we started getting a lot of families coming into Ireland from abroad, there was a thing of like "you have to do everything". It was nearly like "the Irish way is the bad way". The approach would have been "Yes let me know your way and I will do it your way" ... There was a stage I nearly felt that I disagreed with what I felt people wanted me to do, that they wanted me to be ... because that is not the right approach either and I think there is a sense of if people are coming into a country, that's what they are coming into. If I'm going to France, I'm obviously going to eat French food. I'm not going to

expect the French to eat Irish food. So, I think there has to be a balance (Aoife, SLT).

Aoife presents the ‘Irish way’ and the ‘immigrant way’ as in opposition to each other, while seeking a balance between the two. The desire for a more balanced approach could be reflective of the fear of immigrant cultures overriding the host culture (Pon, 2009) and necessitating a complete overhaul of professional approaches to service delivery, given that it was not just one but several different cultures. It could also be about holding on to professional expertise (Urban *et al.*, 2017, p.6). However, the French food analogy is reflective of the French assimilationist model (Betts, 2005) which postulates the adoption of a French way of life as a prerequisite to immigrant integration into French society. Setting up services based on such a dichotomy may encourage the amplification of differences, which could negatively affect the engagement of services with African parents, with service provision more focused on imposing the dominant norms.

When asked about their thoughts in relation to practice in the current culturally diverse Ireland, Aoife said, “I think it’s a little bit more balanced now”. This status quo, according to Aoife, was professional adherence to Irish policies while accommodating the extra needs of immigrant families. Balance here seems to be more in line with cultural assimilation. This is reflected in the observation of one parent in relation to Early Intervention Services not being flexible enough to accommodate African practices in order to make services more culturally appropriate for African families:

They don’t really research what is good for black children especially in terms of nutrition recommended by Speech and Language Therapists. They think food is food, what the whites take will be good for the blacks as well. The blacks might want something different, but they have no choice but to go with what is available ... They must try and inculcate or incorporate African diets for these children ... They should check what a lot of healthy black children eat. We have lots of vegetables in Europe but there are some key healthy African vegetables for speech (Yolanda, Child with Down Syndrome).

Yolanda’s statement highlights the expectation by professionals for immigrant families to conform to the Irish way of life rather than making efforts to understand the values, beliefs and practices of these families and adapting services to better meet their needs (Condon *et al.*,

2020). This portrays the Irish way as superior and as the norm or default standard by which ethnic minorities/ 'other' cultural groups are judged and evaluated (Pon, 2009; Garran and Rozas, 2013). Yolanda's statement coheres with Aoife's initial point in relation to migrants being expected to adopt the Irish way of life, an approach that inadvertently discriminates against other cultures (Harrison and Turner, 2011), fails to acknowledge the different intersecting identities of migrants and clearly highlights the power imbalance within this relationship. This validates intersectionality's advocacy for the challenge of unequal power relations and social hierarchies (Liasidou, 2013).

## **7.2 Professionals' Framing of Cultural Competence**

This section focuses on professionals' understanding of the concept of cultural competence based on their education, training and practice experiences. Cultural competence requires professionals to be aware of their own cultural values, biases and attitudes and the potential effects of these on their work with service users. It also requires sensitivity to service users' beliefs, values and attitudes, an openness and curiosity in relation to learning about other cultures (Beagan, 2015), and flexibility in professional thinking and practice (Pinderhughes, 1989). In the current atmosphere of globalisation, migration and cultural diversity, respect for diversity, which is at the core of social work values is imperative in working with people from diverse ethnic and cultural groups (IFSW, 2014). In the words of one professional:

As a Physio, SLT, OT, it's part of your professional code of conduct that you treat everybody with respect regardless of their race, culture, age, ethnicity (Abigail, Physiotherapist).

The concept of cultural competence seemed to be relatively known to professionals who participated in this research, but more commonly as something they became aware of in practice rather than in their professional training (Lindsay *et al.*, 2012). Given that none of the professionals interviewed were recently qualified, this raises the question as to whether qualifying training might have improved in the interim. Most professionals said they came to know about cultural competence through discussions at team meetings, presentations, trainings, their professional codes of conduct, working in different countries and working with families from diverse cultures:

It's something that I would have sought out myself or we would have sought out as a team because we had a period there, probably about ten years ago, when we had very large numbers of families coming particularly from African countries. As a team, we would have sought to get ourselves trained to make sure we are providing the best service to everybody we are working with (Anna, Psychologist).

I didn't learn in a school setting how to work with other cultures ... a lot of my learning came from discussing and interacting with parents. In giving emotional support to these families, you start learning bits from them.... This involves the discussion of "what is it like for you? When you were growing up, what was?" (Aoife, SLT)

Aoife's quote indicates some interest in the lives of these families and seems to be at odds with her earlier quote in relation to immigrants not to expect to be treated differently. Aoife credits this to 'intimate interactions' with families:

Your relationships get very intimate with families in that you are working with one family for quite a while. If you talk about your child's feeding as a baby, that's really intimate (Aoife, SLT).

Meanwhile, two professionals said cultural competence was part of their professional training, one of whom did not complete their training in the Republic of Ireland:

I learned about cultural competence through formal education. It was incorporated in your training as a social worker ... I did not complete my training in Ireland (Angela, SW).

Cultural competence education and training is crucial in preparing professionals for the reality of culture tensions and clashes (Sousa and Almeida, 2016; Robinson *et al.*, 2016). However, professional education, like social work education, has been criticised by some authors as being poor in nurturing student cultural competence (Pacheco *et al.*, 2003; Furness, 2005; Barn, 2007; Laird, 2008; Harrison and Turner, 2011). In recent times, some colleges of Social Work, Medicine, Nursing, Education, Law and Engineering in the USA, for example, are working on developing the cultural competence of their future professionals through role playing, media use and clinical experiences (Puckett, 2020). The US context is reflected in the Irish context in

the form of CORU (Health and Social Care Professionals Council), a professional regulatory authority for most of the disciplines involved in this research (Social Work, Physiotherapy, Speech and Language Therapy and Occupational Therapy). CORU is tasked with protecting the public through the promotion of high standards of professional education, training, conduct and competence, with respect for diversity, different cultures and values of all service users (Coru.ie). However, Fisher-Borne *et al.* (2015) cautions against seeing cultural competency as a technical skill or communication technique that can be acquired at short notice, but rather as a foundation for the establishment and pursuit of a social justice agenda that is transformative in tackling and opposing social inequalities. This approach should view difference as a contributory resource (Williams and Graham, 2010) and practical steps taken to amend service provision to cater for the needs of disadvantaged groups.

When professionals were asked to define cultural competence in their own words, some of the key points that stood out were knowledge and awareness of the experiences of others, respect, honesty, dignity and reflective practice:

I think cultural competence means that you know what the experiences of coming from a particular place are and what the important things are to the people who would live in that place and then as a result of that, what are the things that matter to those people (Aoife, SLT).

For me, culturally competent practice is about taking time to reflect and to try to understand what the experience is for every person. To try and understand what it means for that person to be in a disability service, what it means for them emotionally. It's really about time and space in relationship building. It's trying not to make assumptions about anybody and trying to be aware of your own assumptions that you might be making because everybody is very different as in Irish families are different, so every African family is very different, with different ideas and thoughts (Orla, SW).

Aoife's quote portrays cultural competence as information gathering in relation to the values, experiences and needs of families. Meanwhile, Orla focuses on reflective practice in the sense of putting oneself in the shoes of others to be able to understand their experiences as a prerequisite for rapport building. Orla also highlights being aware of professionals' own biases while asking service users about their understanding of disability and available support

systems, given that different families have different ideas and thoughts in relation to disability, influenced by social experiences (Tervalon and Murray-Garcia, 1998). This is more in line with the constructivist paradigm, which sees cultural competence as geared towards critical, reflective practice as a means of assisting healthcare professionals in reducing health inequalities (Garneau and Pepin, 2015). One parent supported Orla's view by saying that, "people will engage with you more if you can identify with how they interpret things or how they see things" (Brenda, Child with Autism).

Some other professionals relate cultural competence to being aware of the challenges facing immigrant families and working honestly with them, while ensuring the same treatment for all service users regardless of culture of origin/ethnicity (Anna, Psychologist); and reading up about the culture of service users. The above professional responses are reflective of respect for the intrinsic dignity and worth of a person and recognition of human relationships as important (IFSW, 2014). However, the focus seems to be more on interpersonal communication, relationships between individual professionals and families and acquiring knowledge on the beliefs and experiences of families rather than on practically amending service provision to accommodate the needs of individual families.

Parents, while appreciating the support received from services, given negative experiences in their countries of origin, decried the 'one size fits all' approach being used by professionals when it came to the question of cultural competence: "I think there is that lack of cultural competence in terms of professionals providing services to ethnic minorities" (Brenda, Child with Autism). Parents cited their experienced challenges and barriers in accessing and utilising Early Intervention Services, as outlined in the previous chapter, as evidence of culturally inappropriate service provision.

In a study carried out by Harrison and Turner (2011), healthcare workers believed that the promotion of culturally competent practice for the benefit of disadvantaged groups requires organisational commitment in relation to time and resources. This opinion was reflected in professional responses to whether culturally competent practice was being applied in all Early Intervention Teams across Ireland. While some professionals expressed the opinion that culturally competent practice was being applied in all Early Intervention Teams, some disagreed, and others said they did not know. Overall, professionals stated their desire and willingness to be supported in the provision of culturally competent services (HSE, 2005),

while highlighting the lack of adequate training, huge caseloads, and time constraints, as some of the barriers experienced:

Yes, I think that most people want to. That doesn't mean most people are culturally competent. I think there is probably a greater need for more training (Michael, SW).

No, because families still have difficulties accessing services and I know our own families have difficulties, but they know the system. But for immigrant families, language is a massive barrier, not knowing how our system works, even having someone explain the system is different from the system they've come from, so it's very problematic even from day one and I don't know, we don't give it the time that it needs to make it run smoothly as possible, particularly if there is a language barrier. We are probably better than we were, but we have a long way to go (Rita, CNS).

The above professional responses seem to reflect culturally competent practice as a highly individualised venture, with cultural competence being evaluated based on individual professional performances without paying attention to whether the organisation is culturally competent and supports the worker to be so. This highlights the burden on individual professionals to manage fallouts of structural inequality and other ills of the macro system impacting on minority populations (McGregor *et al.*, 2019).

### **7.3 Health Care Professionals' Experiences of Working with Immigrant Families**

In their experience of working with African families, professionals said they came across many cultural differences in relation to issues such as feeding, play, the use of the right hand, paternal involvement in the care of their child with a disability and the intersection of gender and ethnicity (in relation to some fathers preferring that male professionals engage with fathers rather than mothers). Professionals said this knowledge caused them to reflect on their practice and rethink how service provision could be made more flexible to accommodate some of these cultural differences for a more culturally appropriate service provision for African families. This again raises issues around expert/lay knowledges, which are mediated by different cultural understandings.

In relation to feeding, one professional said they learned about a new way of feeding with the use of fingers from an African parent, something they were previously unaware of both personally and professionally:

In Ireland, if you are talking to parents about feeding, it's a lot in the beginning about bottle, the spoon, whereas none of that here. She fed with her fingers. That was my first experience. All my activities for helping the lips move were built around a spoon. So, I thought "I have to totally rethink all this" because she is doing it with her hands and the child is really enjoying it and she has this great sense of it. There were big changes. I would never have thought that you could use your fingers to feed a child because all Irish people feed with the spoon, now I know they [some Africans] don't and using the spoon is not important to them (Aoife, SLT).

In relation to play, some professionals observed that many African families they worked with did not play with their children but rather expected their children to play with each other, unlike white Irish families:

We do an awful lot of work through play. Not every culture plays and that will be another thing that I will find with quite a few African families ... They expect the children to kind of amuse themselves. Where we will expect the children to learn about size and colour and all these through play, their concept is "they will figure it out" and so they don't place the same importance having some skilful play activities or some pretend play (Aoife, SLT).

There seems to be an underlying assumption in Aoife's statement that all white Irish families play with their children while not all African families do, thus causing the statement to come across as potentially essentialist about what 'African families' are like.

Meanwhile, the invisibility of the father of the child with a disability during appointments was highlighted by many professionals as something that was prevalent in African communities unlike in white Irish communities. Professionals said African children with disabilities were mostly brought to appointments by their mothers, unlike Irish families where the child's father and siblings would sometimes accompany them to their appointments:

Mostly what I find is some mothers bring the child and the dad or any other siblings don't really accompany her. Irish families that I work with, both of them will come. Sometimes the dad will come, the siblings are also involved. So, everybody in the family is kind of in tune with the things (Patrick, SLT).

Patrick's quote above raises, for me, the question in relation to whether white Irish fathers have always been involved in the care of their child with a disability, given Ireland's history of socially isolating and excluding people with disabilities (Dare and O'Donovan, 2002). Patrick's statement portrays cultural practices as fixed, which is something to guard against because cultural practices do change and are fluid.

Professionals said that while they made efforts to respect and accommodate the cultural values of African families, they sometimes came across challenges. One example was in relation to the "male head of household model" when it came to obtaining information from the child's mother, who was often the primary caregiver. One professional said the following:

One of the things I will be very conscious of as a man, for some cultures, it might not be appropriate or there might be a certain level of discomfort with, for example, a woman being on her own with a male professional like me. And in some cases, it may be more appropriate for the husband to be in a discussion with another male. That can be a challenge at times but in general that has been more of a feature of Muslim families than African families in general (Michael, SW).

Michael's (SW) observation in relation to Muslim families confirms the assertion by Treas *et al.*, (2014, p.6) that marriage in Islam is highly regulated by holy law, which while advocating a principle of male superiority, like the 'Pauline Tradition' (St. Paul's view of Christianity) also lays down concrete rules in relation to male guardianship and protection of women. Although most professionals said they generally did not experience gender barriers in relation to working with African immigrant families, a few professionals said they struggled where the cultural values of the family they worked with would have encouraged a male-to-male interaction and frowned on a male to female interaction (Lindsay *et al.*, 2014). It should be noted that this challenge was exclusively cited by male professionals. These professionals said they were sometimes blocked by the child's father from speaking to the mother of the child

with a disability, who happened to be the main carer, knew more about the child's condition and was in a better place to implement recommendations. One professional said:

I have struggled at times, because I'm a male social worker, that the father of the child with special needs might have wanted to be present and sometimes would not have had his wife present in the discussion and I would have felt that in practice the mother would have had the greatest knowledge and would have been providing most of the day-to-day care (Michael, SW).

This highlights issues about sexism and women's rights that may need to be considered, as well as individual men's interpretation of cultural values. It also highlights the complexity of intersectional identities.

In relation to applying cultural competence to their day-to-day work with African immigrant families, professionals cited differences in views and understandings of a child's disability between parents and professionals as challenging them in their role of supporting these families, given that most professionals were raised and trained from a Western perspective (Welterlin and LaRue, 2007; Pon, 2009):

I have seen that a couple of times we are on different paths maybe in our understanding of disability and it's about meeting families where they are at and trying to bring them to where we all have the one goal of intervention and support of the child and the child's needs. I would have struggled initially to understand the different viewpoints that we would have had (Róisín, SW).

Looking at the 'cultural tension' between parents and professionals, the concept of 'cultural brokerage'<sup>10</sup> as put forward by Lo (2010) and Lo and Stacey (2008) could be helpful in

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<sup>10</sup> Cultural brokerage is defined as the "act of bridging, linking or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change" (Jezewski, 1995, p. 20, in Pang *et al.*, 2020, p. 372). This portrays cultural brokers, who may be either family members, members of the community, teachers or other professionals (Cooper, 2014; Lazarevic, 2017; Weiss, 1994), as problem solvers who pay attention to intersecting components like the socio-economic context, age, type of disability and cultural background while applying networking, advocacy and mediation strategies. This model was adapted from the healthcare industry to the disability field by Jezewski and Sotnik (2001). It is still an emerging field in relation to immigrant families of children with disabilities (Lindsay *et al.*, 2014a) despite growing evidence of positive outcomes in working with culturally diverse populations in special education, therapy and rehabilitation (National Center for Cultural Competence, 2011; Wenger, 1995).

explaining the role played by health care professionals in navigating tensions between the different understandings of disability between parents and professionals and enabling families to receive care and resources that are meaningful to them. To bridge this gap, professionals had to strategize on how to adequately meet the needs of service users from different backgrounds with limited knowledge of the Irish healthcare system, cohering with Lindsay *et al.* (2014). Professionals said they had to ‘culturally translate’ (Lo, 2010, p. 487) the two orientations by first investing time and resources in building rapport and trust with the parents; not imposing a particular way of doing things; finding out what was relevant and meaningful to them; understanding where they were in relation to their culture and how it affected their engagement with services; and providing additional support for them. Some professionals said: “What we do is we invest a lot from the beginning in building up relationships and trust” (Angela, SW); and “I suppose it’s about always asking the family what they want and what is important to them” (Michael, SW). In terms of providing additional support to families, one professional said the following:

I understand that where other people can seek informal support, maybe they don’t have that luxury and so additional support is required. So, I suppose it’s just being mindful of the skill set that I bring and tailoring it to where the parents are at and their needs. It’s more enhanced for immigrant families for a little while until they get an understanding of what’s going on (Róisín, SW).

While parents said it would be helpful to them if professionals were culturally competent by being aware of their culture and working with them along those lines, some parents said they preferred for professionals to treat them the same way they treated Irish parents, regardless of their culture of origin. This is because they did not want to feel let down, as they did not think culturally competent practice could be satisfactorily implemented. This supports findings by Barn and Das (2016) that some parents prefer not to be ethnically matched or think the best way to navigate the system and avoid being hurt is to look at things from the dominant cultural perspective rather than from their own cultural lens, thus preferring to be culturally assimilated:

Being in Ireland for ten years, I have learned to forget about the cultural differences because that’s when we get things wrong, in my opinion. I look at things the way the people look at it. When you bring in cultures, things can change either in a negative or positive way. When my child was born, they tried to bring up the cultural thing at the hospital that because she was from

Africa, she was strong. I didn't look at it that way. I just looked at her for who she is, and I think it works that way for us. Sometimes we tend to make mistakes when we look at culture because we might end up feeling like we are not being treated right (Edwin, Child with Tracheal Stenosis).

The Public Health Nurse mentioned something about culture and I didn't want to talk about it because I don't want to feel let down. I don't want to feel like I'm being treated different (Edwin, Child with Tracheal Stenosis).

Edwin's quotes above reflect a view of culturally nuanced professional practice as an indication of being treated differently. This evokes parental fears of expecting too much from service provision in relation to compatibility with parental cultures, as a deficit in such could leave parents feeling disappointed. Edwin's choice to turn a blind eye to cultural differences reflects his experience of his child being discriminated upon while in hospital due to her ethnicity, as discussed in the previous chapter. The discrimination of their child, preceded by references to her ethnicity, could have caused Edwin to see a focus on cultural differences as a means to justify discriminatory practices. Beagan and Chacala (2012) observe that most literature on cultural diversity often exclusively attributes 'difference' to the service user. Thus, some professionals commented that a few parents were more focused on adopting the Irish way of life rather than reflecting on their experiences in their countries of origin, which caused professionals to learn little or nothing from them in relation to their culture: "I didn't learn that much from her because she was really keen to know that "I'm in Ireland, I'm going to become Irish"" (Aoife, SLT).

What stands out in this, and some preceding sections, is the greater focus of professionals on the behaviour of service users and less focus on the biases of service providers (Garrahan and Rozas, 2013). Learning was more about what African families did differently from white Irish families without questioning Irish practices. This approach reflects a "deficit-oriented view" (Abrams and Moio, 2009, p. 246) of African families with the potential of 'othering' non-white Irish families who will never measure up to what is seen as the norm.

### **7.3.1 Trust and Rapport Building**

When professionals acknowledge their own biases and assumptions and learn about the perspectives of the families they work with and what is important for them, it goes a long way

to make rapport building and advocacy more engaging and more relevant for immigrant families of children with disabilities (Lindsay *et al.*, 2014b). While many professionals said they would treat all families fairly and give some extra attention to families with extra needs, they acknowledged the difficulty in gaining the trust of and building rapport with some African families (Lindsay *et al.*, 2012):

I feel some immigrant families, particularly in the Early Intervention service might be a little bit suspicious of us coming, afraid to open up and give us information. I suppose it's working with the families and trying to gain their confidence and their trust, depending on where people are coming from (Anna, Psychologist).

Some parents admitted to not fully trusting the intention of professionals given past negative experiences in some healthcare settings. They said they were not comfortable with the treatment received from services, as they believed there was a clear difference in the treatment of African and non-African children within health care services by either not giving them enough attention or giving them too much attention. One parent made the following comment:

I always feel like the way we are being treated sometimes, either they overdo it to please us, that may end up making you to feel uncomfortable ... With my child, the pre-school always try to make me feel like they are doing something extra ... because my child is the only African child in that place ... Sometimes I don't understand if what they are doing is real, based on negative experiences we've had in the last 3years with some health services (Edwin, Child with Tracheal Stenosis).

Thus, some negative parental experiences in the past may impact on future parental rapport with professionals. Parents may become doubtful and suspicious of certain professional efforts at rapport building and amendment of practices to meet the specific needs of children from these families. Trust and rapport building in such cases may require an increased and collective effort on the part of professionals across all health care settings rather than professionals within a specific service.

When there is an absence or a breakdown of relationship between a professional and service user, there is less likelihood for the service user to engage with the service, thus negatively

affecting outcomes for the child with a disability (Lindsay *et al.*, 2012). It is important for professionals to be aware of the personal experiences of service users that they work with and be flexible in service provision to accommodate the beliefs and values of these families (Rhodes and Scheeres, 2004). One professional observed how knowledge about specific cultural practices and seeing things from the family's perspective rather than making assumptions enabled them to understand and better meet the needs of a family:

I remember an African family ... they could only use their right hand. They weren't allowed to use their left hand. So, everything had to be done with one hand. I needed to know that, or I might have thought the child had weakness on their left side and jumped into conclusions that would be inaccurate (Edel, OT).

According to Edel, she attributed the above practice to one specific family's way of doing things based on their specific cultural and religious background. In this case, Edel was using it as an example to indicate the importance of a person-centred approach towards working with service users in order to better understand them and provide meaningful service to them.

Meanwhile another professional recounted their experience of a relationship breakdown with a parent as a result of acting without having background knowledge of the family:

I got a very difficult situation with one family, huge attachment issues ... and we had to make a referral into Tusla, not realising there was already history there. And it was very difficult to try and pull back, to work through the process with mom, a very angry mom. She was distressed and angry and I just found the experience so traumatic. I just wonder if I had a little more experience of working with her, I wonder if it would have made it a bit easier. I don't know but I did think that "I could have handled that better" (Rita, CNS).

Some parents said they felt the individual needs of their child with a disability were not taken into consideration when allocating services to them. One parent explained how a service that could have been of benefit to their child turned out to be an unpleasant experience for the child because the service could not be adapted to accommodate the dietary preferences of the child. This discriminatory practice led the parent to decline the service in the best interest of her child:

I had to reject one offer from the school. They said every Friday, one woman will take them from school to go and play with them when they close at 1pm and bring them home later ... they went twice and I said no ... One of my children doesn't like to eat outside and they don't want us to give any food that they can microwave. So, that's why I'm not comfortable with it. Anything they give him to eat there, he won't eat it. He will cry cry cry, his eyes will be red. Before he comes back, he will be hungry. So, I said let them come home to eat (Sandra, Children with Autism and ID).

Thus, for trust and rapport building to be effective, professionals need to identify and pay attention to the past experiences and specific cultural needs of immigrant families (Parrott, 2009). This encourages the assessment of multiple identities of individuals by professionals and organisations (Tervalon and Murray-Garcia, 1998) to ensure meaningful service provision.

### **7.3.2 Time Constraints**

Culturally competent practice requires professional investment in time to get to know service users and their families in order to gain knowledge and understanding of what they consider important, and how their ability to engage with services may be influenced by their cultural beliefs (Lindsay *et al.*, 2014). However, findings by Harrison and Turner (2011) indicate that healthcare professionals are not often allowed adequate time to build and nurture relationships with service users, which is an important component of good practice with service users from diverse backgrounds (Harrison and Turner, 2011; Devery, 2018). Professionals involved in this research supported this view by highlighting time constraints as one of their main barriers to culturally competent practice. This could be seen in previous chapters whereby time constraints was cited by parents as a barrier to successful intervention in terms of therapy and can be seen in subsequent paragraphs, with some professionals citing it as a barrier to them availing of cultural competence training. One professional explained the impact of time constraints on rapport building with African immigrant families in the following words:

We are under huge time constraints. Ideally for Early Intervention, I should be going out to every family at least once, know where they live. I would say the relationship you have with the family is very different when you go out to their home as to when they come to you in the service because first of all you see where they live and are in their world. When they come in, they have to

come in, queue if they are in on time or shown into a meeting room. Sometimes I have to have an initial session with them in the clinic, the child is restless and am not getting a full picture of the child. There's one family I worked with for the last two or three years I will say and it was only this summer I went out to do a piece of work at home with regards to their equipment and because I wasn't rushing, I sat down and I learned so much about that family ... That was so relevant to my work with them. I have a more trusting relationship with them and am more understanding (Edel, OT).

While Edel's views above could serve as an example of good practice with any service user, it is a positive step towards ensuring culturally competent practice with immigrant service users. This is especially important for African immigrant families due to their perceptions of authority, the stigma attached to having a child with a disability in their cultures of origin and previous experiences with the system, as discussed in the preceding sections.

One parent corroborated the above professional observation in relation to understanding parents more during home visits than in clinical settings in the following words:

Culturally, in terms of engaging with me, in terms of inviting me to the office and then sitting like this with me, it doesn't take on board my culture because this could be intimidating ... you are not gonna get much from me (Brenda, Child with Autism).

The intimidating aspect for Brenda seems to be that of sitting at a table, in a formal and unfamiliar setting, with a professional whom she considers to be an expert in their domain and considering herself as a lay person with nothing to offer, which may cause her to accept without question whatever is being said. This is unlike in her home, where she would have the comfort of familiar surroundings, a more settled child, and some control over aspects of the meeting like sitting arrangements, which may make her more relaxed and more likely to engage in a meaningful conversation with the professional. Thus, the organisational setting can sometimes act as an impediment to professionals' attempts to appropriately respond to the needs of service users from diverse backgrounds through deadlines and time constraints (Harrison and Turner, 2011).

Despite many professionals saying that they were making efforts to improve their levels of cultural competence, a few professionals said they were making no major improvement efforts at culturally competent practice due to time constraints:

I'm just going day to day ... To say I haven't got time shouldn't be an excuse but that's the only one I can give, that it's not really a priority as it should be (Rita, CNS).

Rita went on to say that they were often told "there may be a lecture coming up. It might be good for you to go to". They were not given time off to attend training but were rather expected to squeeze time into their busy schedules, which was often impossible due to caseload demands. This, according to Rita, did not portray cultural competence training as an organisational priority, despite individual professional interests in availing of same.

One part-time professional, who had signed up for cultural competence trainings but was unable to attend during her working hours due to busy schedules, said she chose to attend these training events outside her working hours:

I go to courses in my own time ... rather than say that I want to do my hair, I want to do my nails (Edel, OT).

From the above professional accounts, it seems individual professionals were being saddled with the responsibility of providing culturally competent services rather than organisations, thus individualising the responsibility, in agreement with McGregor *et al.* (2019).

#### **7.4 Professional Self-Evaluation**

Health care professionals have often been accused of being culturally insensitive by scholars including O'Hagan (2001), Laird (2008) and Parrott (2009). This has contributed to the development of discussions on professional self-reflection as assisting professionals in broadening their perspectives on how service users may perceive themselves or like to be perceived and critically evaluating their practice (Lay and McGuire, 2010). Professionals said they practiced self-evaluation in relation to culturally competent practice by looking at the level of engagement of the family they worked with, asking for feedback from parents and engaging in reflective practice:

I assess myself based on how open and how engaged a family are with me (Rita, CNS).

I suppose that if people are happy to meet with me again and they don't cancel appointments on me, that means they are comfortable with what I have to offer (Michael, SW).

Thus, professionals evaluated themselves based on how receptive families were, how open families were about their perceptions and experiences, and how easily families approached professionals for help and engaged with provided services. In terms of overall parental engagement, most professionals said they found a very high level of engagement with services despite the request for more informal supports by African families:

African families feel we could do more around creating informal supports for them but for engagement there have been no problems ... once you do the introduction, the family engagement for African families is very good in that they seek out the support needed (Michael, SW).

While most professionals said it was rare for an African family to disengage from the service, one professional said parental engagement varied, depending on the service offered:

A couple of years ago, we ran a group for African mothers, struck by the fact that many children were from African background and some of the mothers could be on their own. There were fathers there as well. There was no particular structure to it. Parents could come along and talk about particular issues that they wanted. The uptake varied; it was on a monthly basis. Maybe they weren't ready to engage. We haven't done it since then (Anna, Psychologist).

Meanwhile, some professionals said it was hard to determine the level of parental engagement given that they relied on parental feedback in relation to doing recommended exercises at home with their child:

If the person is not engaging in terms of following recommendations, that's a harder one to prove ... but as long as they keep coming in, they want something from you and you'll eventually find some level of commitment to something (Aoife, SLT).

Thus, in a bid to encourage parental engagement, Aoife suggested “getting back to that meeting of minds and trying to find out something that means something to the parents”. This highlights the need for adequate training and partnership work with parents on support skills for their child’s ongoing development (IASLT, 2017).

When rating themselves on how culturally competent they thought they were, some professionals said:

I will not describe myself as culturally competent (Aoife, SLT).

I have moved different countries, then I’ve travelled different parts of Ireland, but I still don’t understand every culture (Patrick, SLT).

I suppose I will be 7 or 8 on a scale of 10. I think generally I have a good awareness and openness to people’s experiences and allow people to talk through their experience and things that are difficult, very emotional and very personal for people ... I don’t think one can even get to the point where you are culturally competent because it’s an ongoing process of being open to learning and how you respond to people (Orla, SW).

When professionals reflect on the effects of their own cultural background on professional-service user interactions, this provides a chance for the consequences of power to be addressed by cultural competence, with power being referred to by Pinderhughes (1989) as an important but often unaddressed aspect in cross-cultural encounters (in Garran and Rozas, 2013). Although this awareness of power differential is essential in cross-cultural-work, there needs to be an awareness of how an individual’s positionality can be impacted by macro-level socio-political forces and interpersonal dynamics, thus necessitating the inclusion of power and privilege in discourses on culture, social identity and cultural competence (Abrams and Moio, 2009). Considering this, one professional said:

I’m always thinking about my own practice. Am I doing enough to ensure people are included or have an understanding of what we work? It will be interesting to hear what families have to say. We think we are doing okay but really are we missing a whole lot? Because there is a power differential between the professionals and people who need to get the service from us (Orla, SW).

This power differential is evident in the above responses to professional self-evaluation, with professionals evaluating themselves based on how comfortable service users are with them. Power differences are acknowledged while identifying that these could be overcome by professionals reaching out to service users in a manner compatible with service users' understanding and experience. Looking at previous chapters and previous sections of this chapter, power differentials are also evident in aspects such as the relay of a child's diagnosis, meeting settings, professional expectations for parents to do most of the work with their child, parental opinions not adequately valued and services not taking into consideration the limited support networks of families. These power differentials have the potential to reinforce the privileging of some groups and the discrimination of others, in line with Robinson *et al.* (2016).

Williams (2002) sees cultural competence as thoughtful decision-making and practice improvement through "reflection and evaluation" (in Williams, 2006, p. 218). Following self-evaluation in relation to culturally competent practice, many professionals said they tried to improve their level of cultural competence by gaining knowledge of the cultures of families they worked with through personal research, training, speaking to families they had previously worked with, supervision (both formal and peer supervision) and reflective practice, amongst others:

I've gone to training on cultural diversity and assessing children from different cultural backgrounds ... I try to talk to some families that I had previously in order to better understand what the current families could be going through and how best to approach them (Anna, Psychologist).

I would do supervision with my line manager and go through any issues or areas of weaknesses I think I might have or that I can improve on (Abigail, Physiotherapist).

Anna's statement relates to going back to African families they had previously worked with to gain an understanding of what their current families could be experiencing and how best to approach them. This is contrary to seeking this information directly from the families concerned, whose situation may be completely different. Fredor (2014) refers to such practice as cognitive short-cuts which may lead to difficulties in relation to generalising or stereotyping, or ignoring alternative explanations and may cause certain things to be missed by professionals.

Meanwhile, some professionals said they sought advice from their African colleagues when working with African families, especially where the presenting circumstances were challenging, to ensure that they were providing services in a culturally appropriate manner to these families: “I have an African colleague here who keeps me on track on a regular basis. So, that helps” (Michael, SW). This corroborates the findings of Heer *et al.* (2016) that working in teams that have professionals from diverse ethnic groups, representative of the community being served, is helpful in the delivery of culturally competent service, especially in terms of identifying specific needs. This recognition and integration of different indigenous knowledges and ways of knowing into the professional knowledge base challenges whiteness in healthcare settings (Dei, 2000). It should be noted that nine out of ten professionals interviewed were white Europeans. Given the current multicultural landscape, healthcare settings need to reflect the service user base to adequately meet the needs of each service user, as highlighted by one parent:

Allocate somebody as an advocate that would better understand and fight for immigrant families .... For example, if an African or Asian parent has a child with a disability, the government can allocate one person to fight for the needs of those immigrants from the same area of origin (Caroline, child with Tracheal Stenosis).

Caroline’s statement evidences the need for professionals from service users’ cultures of origin as they would better understand and advocate for the needs of these families.

## **7.5 Conclusion**

The increased diversity of the Irish population has caused the Irish health care system, including Early Intervention Services, to experience an enrichment of its knowledge base but also challenges in relation to providing culturally appropriate services to families from diverse backgrounds, including African immigrant families. Faced with the challenge of mediating tensions in relation to different perceptions of disability between parents and professionals, professionals were seen to adopt the role of ‘cultural brokers’ in their work with African immigrant families, while focusing on mutually shared goals for the development of the child with disabilities. While professionals thought they were doing their best to provide services in a culturally competent manner, parental responses indicated the contrary, to the effect that they

felt service provision in Early Intervention Services was not culturally appropriate and more inclined towards getting immigrant families to adapt to the Irish norm.

Professional focus seemed to be more on gaining knowledge on specific practices, norms and behaviours within certain cultural groups and comparing them against the Irish norm rather than paying attention to structural barriers and wider social inequalities impinging on the rights of these groups. This was based on the assumption that when a professional recognises culturally specific practices in relation to a service user, their sensitivity towards that service user would increase (Garrahan and Rozas, 2013). There also seemed to be more focus on interpersonal relationships between parents and professionals rather than on the adoption of targeted approaches to meet the specific needs of immigrant families. Professionals seemed more inclined to treat all service users the same, regardless of their ethnicity or nationality and less inclined to identify and examine their own personal biases and implications for service delivery. This provokes an assimilationist discourse and a discourse of power and privilege in relation to culture, social identity and cultural competence (Abrams and Moio, 2009). Focus on an individuals' broader identity and unique life experiences, as proposed by the concept of intersectionality, will pave the way to addressing social hierarchies and power inequalities that could reinforce the privileging of some groups and the discrimination, exclusion and marginalisation of others (Hancock, 2007; Warner and Brown, 2011; Robinson *et al.*, 2016). This discourages a one size fits all assessment and intervention approach within Early Intervention Services and encourages professionals to adapt interventions to suit the needs of service users (Robinson *et al.*, 2016).

Although professionals acknowledged the availability of cultural diversity/cultural competence training, they highlighted the barrier of time constraints not only in relation to availing of this training but also in relation to rapport building with African families. Looking at the above analysis, the onus of ensuring cultural competence in practice seemed to fall more on individual professionals rather than on the organisation and broader systems, despite an integrated systemic approach to cultural competence being widely theoretically advocated (Harrison and Turner, 2011). This portrays plans in relation to promoting cultural competence practice within the Irish healthcare sector (Intercultural Health Strategy, 2018-2023) as mere theory that needs more action to make it a reality. If healthcare providers, systems and organisations do not work hand in hand to provide culturally competent care that encompasses the intersecting identities

of service users, it leaves service users at a higher risk of experiencing negative health outcomes due to poor quality of care (HSE, 2019).

## **Chapter Eight**

### **Re-imagining Cultural Competence and Recommendations**

#### **8.0 Introduction**

Cultural diversity has created a need for cultural sensitivity in service provision to people from ethnic minorities within Irish Early Intervention Services, with emphasis on seeking to ensure equality and diversity in service provision. Cultural competence has been seen by some disciplines such as social work, as a dominant approach to addressing cultural diversity in healthcare services (Beagan, 2015). Although there are various definitions of cultural competence, there are important consistencies among these definitions which cannot be ignored. These include the focus on professional knowledge, skills, and awareness development in relation to recognising, respecting differences in values and beliefs; and adjusting practice to accommodate and provide effective interventions for people from different cultural groups (Balcazar *et al.*, 2009; Black and Wells, 2007; Haltiwanger, 2010; Lindsay *et al.*, 2014; Quereshi, 2004; Suarez-Balcazar and Rodakowski, 2007; WFOT, 2010).

However, despite the contribution of cultural competence towards highlighting differences in professional practice in the past three decades (Garran and Rozas, 2013), it has been criticised on several fronts. Critiques include its failure to address the impact of power relations between professionals and service users; the dominance of an essentialist view of culture; lack of uniformity in its application across services due to different understandings of the concept; and applying general attributes to specific groups without consideration of individual intersecting identities and experiences. From this perspective, I suggest introducing the concept of intersectionality to complement cultural competence discourse and practice (intersectional cultural competence). Intersectionality may be helpful in relation to recognising, acknowledging, and addressing power imbalances in the relationship between professionals and service users. It enhances awareness of the complex interaction of diverse identities of individuals, and how these influence their perceptions of, approach to and engagement with services. Intersectionality, I suggest, has the potential to strengthen the social justice underpinning of cultural competence, as will be discussed in this chapter.

This chapter summarises the overall findings of this research, in line with debates in the literature, while highlighting some salient points that emerged, including meaning reconstruction and the implications of diverse intersecting parental identities on their interaction with Early Intervention Services. Embedded in all sections of this chapter are the contribution of this research to theoretical knowledge and implications for policy and practice. Section one discusses the parent transformation process in response to having a child with a disability and its impact on parent identity formation. This is followed by an examination of the impact of cultural perceptions on parental interaction with services, the usefulness of cultural competence in addressing the experiences of African immigrant parents of children with disabilities and an introduction to the concept of ‘intersectional cultural competence’. In addition, recommendations from both parents and professionals for the improvement of service provision quality, research strengths and further research suggestions are discussed.

## **8.1 Conceptualising Parent Identities**

In many cultures, including some African cultures, as indicated by the findings of this research, stigma and societal oppression is attached to disability. The resultant internal (feelings of worthlessness, being misunderstood and less valued) and external (missed opportunities) psycho-emotional consequences lead to a loss of opportunities and experiences for parents of children with disabilities, as outlined by Reeve (2002) and Thomas (2004). These negative societal reactions come from within families, communities, education settings, health settings and other services, thus portraying a power imbalance, whereby people without disabilities have the power to exclude people with disabilities (Thomas, 2004). This stigma is not only attached to the child with a disability but also to their family members, causing psychological stress for parents, undermining their self-esteem and identity, thus supporting findings by Reeve (2002). Parents who took part in this research found it hard to accept the inferiority status allocated to their child and family, and social interaction inequalities (Jarrett *et al.*, 2014). These experiences diminished African immigrant parents’ ability to adequately advocate for their child with a disability and negatively affected parental interactions with Early Intervention Services.

Some researchers are of the opinion that in the aftermath of adversity, recovery depends on a person’s ability to let go of former, inadequate perceptions and create new and hopeful perceptions that include new realities and identities (Aldwin, 1994; Meichenbaum and

Fitzpatrick, 1993). Connecting these to this research, despite the many and profound challenges experienced by parents, resilience, built on hope, shone through the shadow of negative feelings, as parents got to know their child. As parents tried to come to terms with how to live with their child's diagnosis and the choices available to them, the processes of meaning making, image-making and choice making were activated (Wilgosh and Scorgie, 2006). Some parents coped by replacing the prior hopes and expectations they had for their child with the reality of their child's condition. This motivated some parents who previously held negative views in relation to people with disabilities to abandon such views and become more tolerant and accepting of people with disabilities. It also provided parents with a strong sense of meaning, and more patience and openness to learning new skills in the course of caring for their child with a disability (Jennings *et al.*, 2014).

However, even after coming to terms with their child's diagnosis, parents experienced emotional setbacks from time to time in relation to anger and frustration due to inappropriate remarks about their child, reminders of missed milestones in their child's life, unrealistic expectations of professionals and social rejection. In agreement with Wilgosh and Scorgie (2006) and Wade (1998), I think professional awareness of this back-and-forth movement of parental image making and meaning making of their child's diagnosis may make professionals less likely to judge parents and more likely to adequately support parents through these disorganisation and reorganisation processes. Thus, it may be helpful for professionals to have an awareness of the personal, social, and cultural factors that might impact on parental perceptions and family outcomes following their child's diagnosis. This may improve parent-professional relationships, assist professionals in supporting parents in the re-examination of their misconceptions in relation to disability, and improve parental interactions with services for the ultimate benefit of their child with a disability.

## **8.2 Parental Interaction with Services**

Culture of origin played a key role in determining the Early Intervention Service access and utilisation experiences of African immigrant parents of children with disabilities who took part in this research. This emphasises the prominence of cultural awareness and sensitivity within disability services in tailoring interventions to individual family characteristics, as suggested by Wilgosh and Scorgie (2006), as a foundation for respectful and meaningful parent-professional relationships.

On a positive note, when parents reflected on what their experiences would have been like if they were living in their countries of origin, they were very grateful for the services received, as it was not something most of them had anticipated. Parents acknowledged that their child was better off in Ireland where they were in receipt of services that they would normally not be able to avail of in their countries of origin. Parents also appreciated the impartiality of service provision based on services of the same standard being provided to all children regardless of their cultural or ethnic background.

On the other hand, parents experienced many challenges in terms of accessing and utilising Early Intervention Services, which diminished their service interaction experiences. These challenges included structural challenges such as long waiting times, inadequate services, fight for services, racism and discrimination; and other challenges such as parental lack of knowledge of disability-related services, unfamiliarity with the system, language and communication issues, different perceptions of the roles of service providers and families, resulting in inadvertent discrimination against these families. Cultural barriers were at the core of these challenges, as these parents were neither born nor raised in Ireland and had to learn from scratch about how to go about seeking services for their child with a disability. In addition, it confused some parents when they were given exercises to do at home with their child rather than professionals delivering the intervention with the child. This was contrary to their view of professionals as the experts and as those with the knowledge and skills to do such and destabilised expectations of the parent-professional relationship. Thus, family-centred practice, which forms the basis of Irish Early Intervention Services, challenged parental cultural views of authority as something to be held in awe, and those in authority not to be questioned under any circumstances.

Meanwhile, the findings of this research confirm findings by Hodge and Runswick-Cole (2008) in relation to parental expertise not always being sought, with professionals preferring to stay within the security of their expert positions (Hodge, 2006; Runswick-Cole, 2007), thus leaving parents feeling disempowered and vulnerable. This was especially so when parents' intimate knowledge of their child was not considered by professionals, with many professionals seen as focusing more on the child's disability rather than getting to know the child. This unequal balance of power caused some parents to acquiesce with professionals' decisions even though they may not have been happy with them and caused others to resist outright certain interventions for their child. However, some parents reported positive parent-professional

partnership experiences in relation to professionals being helpful. This highlights the importance of a respectful and open-minded partnership between parents and professionals, with professionals not always focusing on what they know, but adapting what they know to accommodate the specific needs of service users to ensure a higher level of service user engagement and satisfaction. It builds on findings by Lindsay *et al.* (2014b) that service interaction has more meaningful outcomes in relation to trust, rapport building and parental advocacy for immigrant families when their perspectives and experiences are sought, understood and taken into account by professionals. This is in addition to professionals acknowledging and questioning their own biases and assumptions.

Another barrier to parental interaction with Early Intervention Services was the construction and understanding of disability in parental cultures of origin, which encouraged negative attitudes towards children with disabilities from some members of the African community in Ireland. Given the small sizes of these communities, where most people knew each other, and to protect their children from these negative interactions, some parents chose not to engage in group work within services out of fear of news of their child's disability leaking to their community through another African family that might have attended the group. Meanwhile, due to the stigma attached to having a child with a disability in their countries of origin, some parents would have initially resisted engagement with Early Intervention Services, especially in relation to accepting the child's diagnosis.

Intersecting social and structural issues caused parents to feel 'stuck' in Ireland. Parents were faced with different choices, all of which had their shortcomings. One choice was to go back to their country of origin with their child, to live in a culture they understood and where they would have a wider support network. This choice was blighted by the stigma attached to having a child with a disability, limited and expensive resources to cater for children with disabilities in parental countries of origin. This led parents to abandon this option in favour of staying in Ireland with their child with a disability, given the more positive perceptions and attitudes towards children with disabilities and the availability of resources to cater for these children. However, on closer observation, parents realised complications arising from their choice to stay in Ireland with their child with a disability, as they found that despite the overall positive attitudes towards children with disabilities and the provision of support to all children and their families regardless of their countries/cultures of origin, parents had many hurdles to overcome.

One of these hurdles was the negative perceptions of and attitudes towards their child's disability from some members of the African community in Ireland, who happened to be their friends and part of their social support network. Where this arose, parents broke up friendships and their engagement with their support networks like their faith communities, leading to social isolation. A second hurdle was the challenges of raising their child in an unfamiliar environment with lack of traditional support networks due to restrictive immigration policies as experienced by Somalian immigrant mothers of children with ASD living in Canada (Kediye *et al.*, 2009). A third hurdle parents experienced was their lack of knowledge and understanding of the Irish healthcare system, which made it difficult for them to navigate the services and optimally advocate for better care for their child with a disability, especially given the inadequacy of resources and the culture of parents having to fight for services and service provision not reflective of the cultures of parents. As one parent put it, "It is Western culture and things are done in a Western way, but we come from a different culture" (Brenda, Child with Autism). In addition, conversant with findings by Lee and Zhu (2020) in relation to Asian immigrant mothers of children with ASD living in Canada, parents felt pressured to adapt to the 'Irish way' of doing things with little or no consideration to their different cultural origins and experiences and a lack of understanding of their perceptions and understandings of disability. This left parents at crossroads, unsure of which direction to take, as all the roads held significant challenges for their families due to the intersecting complexities both at an individual and socio-structural level. Reflecting on experiences in their countries of origin in relation to children with disabilities, parents decided to stay with the Irish system. They approached it with a manner of gratitude, as it seemed a far better option than going back to their countries of origin.

As indicated in the previous chapters, parents experienced many challenges when it came to accessing and utilising Early Intervention Services. However, professionals were not immune to such challenges. While parents struggled to know and understand the healthcare system, professionals struggled with providing services to families who had different constructions and understandings of disability from them and different expectations of services than they were trained to offer. Despite professional willingness to provide culturally appropriate services, they were greatly constrained by limited resources, which was seen by both parents and professionals as the main challenge and barrier to developing accessible and responsive Early Intervention Services to African immigrant families of children with disabilities. These limited resources were in the form of inadequate time, lack of cultural competence training, inadequate

staffing and caseload demands. This highlights professionals as working at an individual level with families without the necessary organisational investment in vital resources to encourage and ensure continuity of in-depth interactions with immigrant families of children with disabilities, as suggested by Harrison and Turner (2011) and Lo (2010). This has significant implications in relation to the translation of policy to practice. With increasing global attention to issues of intersectionality, the connection between disability and migration needs more in-depth consideration in state policies and service practices, especially from a human rights perspective, with a view to protect migrants affected by disability from all forms of discrimination (UNHCR, 2010).

### **8.3 Re-imagining Cultural Competence as Intersectional Cultural Competence**

While the HSE advocates for respect for diversity within Irish health and social care services, findings from this research indicate that this is not reflected in practice due to insufficient clarity as to practical implementation of culturally sensitive practice and lack of organisational commitment to facilitate professional practice in a culturally competent manner, both of which are compounded by limited resources. The concept of cultural competence has, in this research, served as a guide to understanding how Early Intervention Services respond to the needs of African immigrant families. However, the concept has been criticised for not taking into account the impact of privilege and power relationships between professionals and service users; and for generalising specific groups in relation to behaviours, attitudes and beliefs, without taking into full consideration the unique intersecting identities and experiences of individual service users (Sakamoto, 2007; Galanti, 1991). These critiques portray cultural competence in its current format as unhelpful. Despite these criticisms, concurring with Danso (2016), I suggest that cultural competence has the potential to be theoretically and practically adapted to enhance the ability of health and social care services to work with diversity. This has led to my suggestion of introducing the concept of intersectionality into the discourse and practice of cultural competence in relation to the incorporation of power and privilege into health and social care professionals' work with people from diverse backgrounds.

With its roots in critical race theory and black feminism, intersectionality, as postulated by Kimberle Crenshaw (1991), highlights the importance of being aware of the role of unequal

power relations and social hierarchies in privileging some groups and excluding other groups based on dominant social, cultural, economic and political arrangements (Lee and Zhu, 2020; Liasidou, 2013; Green *et al.*, 2005). This is evident in the findings of this research, with professional expectation of African immigrant parents to do things the ‘Irish way’ rather than adapting service provision to meet the individual needs of these families, thus undermining their dignity and worth, leading to discrimination. The intersecting identities of African immigrant parents in relation to race, religion, socio-economic status, legal status, gender, cultural understandings of disability (stigma attached to disability), language abilities, national origins and lack of understanding of the health and social care services, which affect how parents perceive themselves and are perceived within society, do not seem to be adequately taken into consideration in relation to professional interactions with parents. There is more of an inclination towards exploring these different dimensions of identity in isolation rather than collectively. This fails to capture the complexities involved in the interaction of these identities and paves the way for social structures and relations that are oppressive and discriminative (Liasidou, 2013; Gillborn, 2015). This caused African immigrant parents of children with disabilities availing of Early Intervention Services to experience exclusions at different service levels based on the failure of the service to adequately address their intersecting identities, in line with Bešić (2020).

Intersectionality, while seeing people as in simultaneous occupation of different positions within society (Hernandez and McDowell, 2010; Muntinga *et al.*, 2016; Ortega and Faller, 2011), challenges the essentialist dimension of cultural competence which views culture as static (Fisher-Borne *et al.*, 2015). This encourages professionals to move away from the expert role and adopt a learning role, assess the multiple intersecting identities of individual service users and how these impact on their quality of life, expectations, life chances and capacities and worldviews, to effectively pave the way for the development of genuine professional partnership with service users (Ortega and Faller, 2011). This intersectional analysis of the whole person by professionals, if applied to Irish Early Intervention Services, will enable a facilitation of professional perceptions of individual service users as having unique life experiences and broader identities rather than classifying them into racial groups based on assumptions, or general experiences gained from working with other members from the same racial group. An intersectional analysis will also contribute towards dismissing cultural competence’s ‘one size fits all’ assessment and intervention approach, as applied by Early

Intervention Service professionals, and encourage the adaptation of interventions to adequately address the needs of individual service users (Robinson *et al.*, 2016).

Thus, intersectionality's focus on respect of the dignity and worth of a person, critiquing and challenging the structures of privilege and inequality, shines a more comprehensive light on cultural competence. This moves cultural competence towards professional awareness, understanding and acknowledgement of the inherent privilege and inequality in each social identity like race, class, ability and gender (Sensoy and DiAngelo, 2012; Luft and Ward, 2009) and also how these identity categories come together/intersect to create different experiences. This, I suggest, may help to bridge the gap between different understandings and applications of cultural competence; and foster discussions and collaboration by health and social care professionals through the illumination of commonalities of their values and rationale for pursuing cultural competence.

Based on the above analyses, my original theoretical contribution towards a more responsive Irish Early Intervention Service provision is an intersectional approach to cultural competence, which I hereby refer to as 'intersectional cultural competence'. This will be helpful in guiding professional work in relation to outreach, advocacy and prevention (Anderson *et al.*, 2009). It will also encourage health and social care professionals and organisations to effectively work collaboratively within the individual, family, community and cultural contexts of service users. In addition, intersectional cultural competence in Early Intervention Services has the potential to ensure meaningful service provision to African immigrant parents of children with disabilities and other service users from diverse backgrounds, by maintaining scepticism towards homogeneity of social identities, acknowledging intersecting identities and pursuing knowledge competency in the meaning of relevant social identities (Flynn, 2020).

In line with Campinha-Bacote (2018), I perceive intersectional cultural competence as the interconnected process whereby health and social care professionals and organisations strive to continually work effectively together within the service user's individual, family and community cultural context. Intersectional cultural competence encompasses more complex definitions of culture rather than simplified understandings of culture. A principal focus on culture (as with cultural competence) to understand and engage with service users from racial and ethnic minority groups may be counter-productive in relation to encouraging the development of stereotypes and ignoring other salient characteristics that influence the service

outcomes of people from racial and ethnic minority groups. By maintaining that multiple social statuses (social locations) are held by people from racial and ethnic minority groups and these statuses contribute in shaping their views, needs and experiences, an intersectional framework will enhance a person-centred focus for all service users, help to diminish disparities in service experiences, ensure a more equitable treatment for all service users and effective culturally inclusive service delivery (O'Reilly, 2020; Bell and Gregore, 2015). I think the application of an intersectional framework to self-awareness exercises, professional training and academic research may improve the ability of Health and Social Care Professionals to communicate with and meaningfully work with service users from diverse groups, including African immigrant parents of children with disabilities.

#### **8.4 Recommendations for Change in Early Intervention Services**

Early Intervention Services were perceived by parents in a variety of ways: as a service that identified children with disabilities or special needs, linked children with services, made sure services were appropriate, efficient and met the child's needs, and made sure that services were accessible to children as early as possible. However, many parents experienced Early Intervention Services as a service with long waiting lists leading to late diagnosis of and intervention for children, services not appropriately matched to the needs of the child, parental opinions not adequately respected and parental cultures not being considered.

Considering the above parental experiences, parents proposed recommendations for improving the working relationship between professionals and service users, enhancing the experiences of African immigrant parents of children with disabilities and consequently improving outcomes for the child with a disability. Professionals also proposed recommendations that they thought could improve their ability to provide services to African immigrant families in a culturally appropriate manner. Recommendations included valuing parental opinions more, accessible information/parent education, culturally appropriate services, allocating an advocate for immigrant communities, and the need for investment in more resources, better coordination of services and training.

#### **8.4.1 “My Opinion Should Be Valued More”**

Parental participation is very important in ensuring positive outcomes for the child with a disability (Baker-Ericzén *et al.*, 2013; Figueiredo and Gil, 2013; Günther and Hautvast, 2010; Hendriks *et al.*, 2001; Hock *et al.*, 2015). This participation includes opinion sharing with professionals, participation in therapeutic activities such as role plays and games and continuing intervention at home (Brassart *et al.*, 2017). However, the discrepancy between service organisations and African immigrant families’ needs, challenges these families’ use and navigation of Early Intervention Services. The mother is frequently the primary caregiver for children with disabilities in many African families and thus plays a crucial role in the access and utilisation of healthcare services. An awareness, understanding of and response to the perceptions of mothers in relation to their own needs, resources and challenges may go a long way to enhance interactions between professionals, children and their families and ensure the delivery of health care services in a culturally competent way (Daudji, 2011; Arfa *et al.*, 2020). In this light, parents suggested a more consultative rather than prescriptive approach by professionals when working with parents in relation to their child with a disability. A consultative approach should take into consideration the overall family and cultural dynamics, rather than focusing on what professionals think is best.

Involving parents by carefully listening to them and effectively communicating specialist information may to improve intervention outcomes for the child with a disability. This may help in building parental confidence and self-esteem, which has a positive effect on outcomes for the child with a disability, as indicated by Case (2001). Due to complaints by some parents of their opinions not being respected by professionals, I agree with Maatta’s (2017) suggestion for professionals to build an understanding of migrants through insights into their individual personal histories.

#### **8.4.2 Accessible Information/Parent Education**

The timely provision of information on available supports to African immigrant parents of children with disabilities is important. This is because these parents were not born and raised in Ireland but grew up in different countries and within different systems, which made it difficult for them to navigate the Irish system. In addition, Early Intervention Teams or services should improve accessibility through the raising of public awareness by advertising services in public places, including the internet. Information put on the internet should be up to date, straightforward, detailed and accessible to avoid parental frustration. It is also recommended

for culturally sensitive walk-in clinics to be established, in the form of open sessions within communities, to mitigate African immigrant family waiting times for services. This reflects Lindsay *et al.*'s, (2012) suggestion that immigrant parents be encouraged to advocate for themselves and their children by being made aware of available resources and how to avail of them.

#### **8.4.3 Culturally Appropriate Services**

Research findings suggest that Early Intervention Services see people with disabilities as a homogenous group and do not consider the fact that ethnicity is one way in which people with disabilities differ (Pierce, 2003). Parents were not in favour of this homogenous approach as reflected in the following words, “Ireland has people from other countries coming in who need to be provided with services and that should be reflected in services, through sensitive and correct approaches” (Sandra, Children with Autism and ID). Some parents felt that professionals did not consider their cultures when working with them and were not aware of how their culture constrained them from speaking up in relation to the care of their child. Some parents said they would have liked professionals to exhibit cultural sensitivity by taking time to know and understand what was important to them and the impact of their cultural beliefs on their motivation and ability to apply recommended interventions. Thus, an awareness of parental cultures could go a long way to improve the delivery of services in a culturally sensitive manner and encourage better engagement from parents, while discouraging the use of a ‘one size fits all’ approach. It is worthy of note that there are different cultures in Africa even within the same countries and communities. Thus, Nandan’s (2014) advocacy for the application of a constructivist theory to professional practice, given its assumption that identities are constructed socially within a context and continuously change due to internal and external circumstances, is worthy of attention. The child’s best interest should always be at the core of every intervention, thus necessitating an adjustment of policy and practice in disability services to accommodate the personal situation, context and needs of the child concerned (Ombudsman for Children’s Office, 2020).

Given the limited understanding of disability by some parents, “questions such as, “What do you know about Down Syndrome?” or “Have you ever had contact with a family who had a child with cerebral palsy?””, as outlined by Wilgosh and Scorgie (2006, p.217) may assist professionals in detecting the beliefs and assumptions shaping parental responses to the diagnosis of their child’s disability. Thus, building on Danesco (1997), I would suggest that

professionals ask parents on an individual basis about their cultural backgrounds, practices and beliefs, as a means of bridging differential values and practices. This approach would assist professionals in reaching out more successfully to African immigrant parents of children with disabilities. Considering this, professionals may benefit from reflective practice as a tool to ensure, maintain and improve culturally competent service provision by asking themselves questions such as “did I meet the needs of this family or am I relevant for this family?” (Angela, SW). In addition, professional development of an open and respectful attitude towards cultural experience, while adopting a ‘not knowing’ stance devoid of expectations and assumptions (Dyche and Zayas, 2001; Dean, 2001), may contribute towards diminishing power imbalances between the professional and the service user and focusing more on the ability of the service user to educate the professional.

Meanwhile, it may be helpful for professionals to draw on community capacity, for example African faith communities, to reduce the isolation experienced by African parents, by raising awareness in relation to disability and providing information on how families of children with disabilities could be supported. This is because professionals expressed that most African families they worked with, were Christian and their faith seemed very important to them in relation to processing emotional issues connected to having a child with a disability.

#### ***8.4.3.1 “Allocate Somebody as an Advocate That Would Better Understand and Fight for Immigrant Families”***

One crucial aspect in the delivery of culturally competent services involves professional teams being representative of the communities they serve and their ability to identify specific needs (Heer *et al.*, 2016). This may require the involvement of ethnic minority representatives in strategic planning and consultation forums to give a voice to these communities. To avoid dissatisfaction and the experience of ‘loss of control’ with services for African immigrant parents of children with disabilities and people from other ethnic minority groups, more needs to be done to encourage full participation of people from ethnic minorities in the design and delivery of services. To tackle barriers to parental engagement such as lack of trust and fear, some parents recommended the allocation of an advocate within disability services for immigrant families of children with disabilities, preferably from the same countries or regions of origin as parents availing of services, because this person would better understand their needs and know how to help them.

#### **8.4.4 More Resources and Better Coordination of Services**

The obligation of states, is to undertake all measures, including legislative and administrative, to the peak of their available resources to ensure respect of the economic, social and cultural rights of children (Ombudsman for Children's Office, 2020). In the face of limited resources, the state has an obligation to ensure the relevant rights are respected to their maximum extent under the prevailing circumstances. Thus, lack of adequate resources can hamper the realisation of the rights of children with disabilities (Ombudsman for Children's Office, 2020). Inadequate services do not affect only children with disabilities but also affect their families (Home, 2002).

While all parents experienced setbacks in relation to resource constraints, they did not blame professionals but blamed the healthcare system. Parents highlighted that in addition to Early Intervention Services being understaffed, professionals were not being adequately resourced to facilitate the efficient discharge of their duties despite the prevalence of disability in Ireland. This led parents to advocate for the employment of more workers, allocation of more time for therapy sessions, more local schools, social support, and professional training in Early Intervention Services to improve outcomes for children with disabilities. In the words of one parent, "My advice is that let them give the kids services. With the diagnosis, when there is no service, what is the purpose of diagnosis then?" (Sandra, Children with Autism and ID).

It is also recommended for professionals to be more aware of the different experiences of African immigrant families, spend more time with them to understand their cultural backgrounds, build rapport and trust with them. These would enable professionals to support parents in a more inclusive way. It is also important for more time to be allocated for therapy sessions to allow therapists enough time to assess the child's progress and effective follow up with parents to improve outcomes for the child. In addition, the introduction of more special schools, especially within local communities currently without such facilities, would greatly benefit African immigrant families of children with disabilities. This is because, unlike members of the host community, these families do not know whom to contact to advocate for their child to gain a place in the nearest available special school.

Furthermore, with parenting experiences of African immigrant parents intersecting with lack of support, systemic and other barriers, social support seems to be a protective factor in preventing parental depression and improving the quality of life for both parents and their child with a disability (Jennings *et al.*, 2014). In the face of social isolation due to the absence of

family and community support, some parents suggested the organisation of informal gatherings by Early Intervention Teams, for children with disabilities and their families, as a means of combatting the social isolation being experienced by most African parents of children with disabilities.

#### **8.4.5 Training**

The development and practice of cultural competence by service providers requires a continuous focus across all levels of disability services, including managerial, operational, and administrative levels on awareness, skills, knowledge and behaviour. Despite efforts by the HSE to facilitate the provision of culturally competent services, the findings of this research indicate a lack of culturally appropriate service provision to African immigrant families of children with disabilities availing of Early Intervention Services. As a result of this, it is recommended for professionals to be culturally aware by educating themselves on how to get African populations to engage with them. One parent said this education “could be as basic as how to engage with non-Irish or ethnic minorities or African communities” while suggesting that “the best way is meeting them halfway” (Brenda, Child with Autism).

Professionals recommended more cultural competence training to ensure that they were on the right track because “being informed is the best way to understand something” (Angela, SW). Despite professionals’ readiness to embark on cultural competence training and some cultural competence training being rolled out by the HSE, caseload demands and significant referrals on waiting lists seemed to hold them back. These contributed greatly to shifting the education side to the bottom of the list of priorities for professionals, even though training should reasonably be at the top of the list and offered on a regular basis to keep professionals upskilled, to enable them to offer the best services they can and be as respectful as they can. Professionals did not only want to work with African families, but wanted these families to engage with them, as family engagement would mean the “best use of our time and best use of their time and support for their child” (Rita, CNS).

Professional accounts of individually coping with the challenges of providing culturally competent services by using the internet to learn about parental cultures and learning from the experience of working with diverse families, indicates the need for cultural competence to be an integral part of practice by services. The achievement of this can be facilitated by the

incorporation of “cultural assessments” into care plans, with the aim of identifying cultural needs specific to individuals and families, as outlined by Heer *et al.* (2016, p. 114). This could be done through checklists on information like the family role in caregiving, cultural beliefs, religious values and acculturation levels; and a reflective approach to multidisciplinary team working to assist service providers in formulating and asking culture-related questions in teams. As reflected in the findings of this research, some Early Intervention Teams seem to be already engaging in reflective multidisciplinary team working. This regards solution-focused talk rather than problem-focused talk in relation to effectively working with immigrant families to overcome challenges through patience, trust and flexibility. However, more teams need to adopt and implement this approach through direct experience and reflection for the realisation of a more comprehensive application of culturally competent practice across Early Intervention Services. Meanwhile, the incorporation of cultural competence in the formal training of healthcare professionals may go a long way to improve future culturally competent service provision in Early Intervention Services.

Professionals need the support of their agencies to implement change. All the learning gained from working with African immigrant parents will better benefit parents if used to redesign service provision to accommodate the specific needs of African families availing of Early Intervention Services. There is currently a demand for additional measures to be put in place for equal opportunities and access for all groups of people requiring health care by the values and principles of the HSE, as put forward in the Second National Intercultural Health Strategy (2018-2023). The HSE plan, as laid out in the Second National Intercultural Health Strategy (2018-2023), was to develop an online intercultural health awareness training programme to support the integration of cultural competence by HSE staff into the workplace, and to engage with professional bodies and colleges to ensure the incorporation of intercultural awareness into the training of health and social care professionals. On this basis a new accredited Intercultural Awareness eLearning Programme was introduced in 2020 (HSE, 2020). Will this offset the deficit of culturally appropriate service provision to African immigrant families of children with disabilities availing of Irish Early Intervention Services? While training is important, a targeted approach will be more meaningful in relation to adapting service provision rather than just gathering knowledge on the values, practices and beliefs of families and measuring them against the norm to see if they fit or not. Given the highlighted challenges experienced by parents, it is hoped that the above recommendations will be taken on board by

Irish Early Intervention Services to ensure a much-desired redesign of service provision to accommodate the specific needs of African immigrant families of children with disabilities.

### **8.5 Strengths of the Research**

This is one of the first studies to include the voices of black African immigrant parents of children with disabilities living in Ireland in relation to facilitators and challenges in accessing and utilising Early Intervention Services. The overall sample size of twenty participants and participant engagement are positive factors, given the difficulties faced in recruiting parent participants. As discussed in Chapter four, many parents did not want to partake in the research due to the sensitive nature of the topic. Meanwhile, the resonance of key findings with previous literature is suggestive of authenticity.

### **8.6 Areas for Further Research**

My research findings suggest that there are a number of other areas which would merit investigation. Given the dominance of female participants which may be attributed to the caregiving role of mothers and female dominance in the caring professions, as discussed in the previous chapters, it may be worthwhile for future research to adopt research strategies that are more productive in gaining the perspectives of male participants. Meanwhile, it may be helpful to capture the experiences of immigrants from other African countries besides Nigeria, Cameroon and South Africa. In addition, comparative research in relation to service experiences of immigrant and non-immigrant families may shed more light on existing gaps for immigrant families.

### **8.7 Conclusion**

I conducted this research to generate knowledge about the level of accessibility to Irish Early Intervention Services from the viewpoint of black African immigrant parents of children with disabilities. Findings generated by the research questions highlight amongst others, tension and ambivalence in the relationship between parents and professionals, based on constructions and understandings of disability and service expectations; parental experience of discrimination; and the impact of intersecting identities on parental service experiences. This resonates with findings by Dalikeni (2021, 2022) in relation to constant tension and misunderstanding between African asylum-seeking families and social workers within the Irish social care and child

protection system in relation to acceptable child rearing practices. Research findings confirm literature in the USA and Canada (Lindsay *et al.*, 2012; Lindsay *et al.*, 2014) to the effect that service provision to immigrant families of children with disabilities is not culturally appropriate within Irish Early Intervention Services. This indicates a gap between the public ideal of equal health and social care service provision to all and the reality of African immigrant families of children with disabilities' experiences of discrimination and racism, thus challenging both disability and immigration policies, especially from a human rights perspective. This creates the need for individual and systemic mobilization to fill this gap by tailoring service provision to meet the specific needs of service users.

In this research, I use the concept of cultural competence to encourage professional awareness of cultural diversity (between parents and professionals and between different groups of parents), understanding of the 'person in the environment' and critical reflection on how power and privilege can be used exploitatively and how this could be averted (Hammell, 2013). This is because of the influence of African immigrant parental cultures on parents' understanding of disability, approach to and engagement with services. Meanwhile, I use the concept of intersectionality to highlight how different intersecting identities of African immigrant parents of children with disabilities cumulate to affect their experiences of services, challenge an essentialist view of culture, white supremacy, the Eurocentric nature of service provision, and demand equity in service provision and significant attention to power relations within Early Intervention Services. In this way, cultural competence and intersectionality serve to complement one another, to create a better understanding of the needs of African immigrant parents of children with disabilities who took part in this research and provide for more equitable Early Intervention Service delivery.

## References

- Abang, T. B. (1992) 'Special Education in Nigeria', *International Journal of Disability, Development and Education*, 39, 13-18.
- Abrams, L. S., and Moio, J. A. (2009) 'Critical race theory and the cultural competence dilemma in social work education', *Journal of Social Work Education*, 45(2), 245–261.
- Ahmed, S., Castaneda, C., Fortier, A., and Sheller, M. (2003) *Uprootings/regroundings: Questions of home and migration*, Cambridge, Cambridge University Press.
- Al-Ali, N., and Koser, K. (2002) *New approaches to migration: Transnational communities and the transformation of home*, London, Routledge.
- Albrecht, G. L., Devlieger, P. J., and Van Hove, G. (2009) 'Living on the Margin: Disabled Iranians in Belgian Society', *Disability & Society*, 24 (3), 259–271.
- Albright, A. L. (1997) *Immigrant families of disabled children: An exploratory study* (dissertation), University of Alberta, Calgary.
- Aldwin, C. M. (1994) *Stress, coping, and development: An integrative perspective*, New York, Guilford Press.
- Allen, K. M. (2016) 'Cultural Competence in Healthcare Social Work', In Allen, K.M., and Spitzer, W. J. (eds) *Social Work Practice in Healthcare: Advanced Approaches and Engaging Trends*, USA, Sage, pp. 413-438.
- Alston, R. J., and Mngadi, S. (1992) 'The interaction between disability status and the African-American experience: Implications for rehabilitation counselling', *Journal of Applied Rehabilitation Counselling*, 23, 12- 16.
- Amedeo, G. (2009). *The descriptive phenomenological method in psychology*, Pittsburg, PA, Duquesne University Press.

Anderson, M., Rodney, P., Reimer-Kirkham, S., Browne, A., Khan, K. and Lynam, J. (2009) 'Inequities in health and healthcare viewed through the ethical lens of critical social justice: Contextual knowledge for the global priorities ahead', *Advances in Nursing Science*, 32(4), 282-294, doi: 10.1097/ANS.0b013e3181bd6955.

Annamma, S.C., Connor, D. and Ferri, B. (2013) 'Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability', *Race Ethnicity and Education*, 16(1), 1-31, DOI: 10.1080/13613324.2012.730511.

Ansley, F. L. (1997) 'White supremacy (and what we should do about it)', In Delgado, R. and Stefancic, J. (Eds.), *Critical white studies: Looking behind the mirror*, Philadelphia, PA, Temple University Press, pp. 592-595.

Aquino, V., and Buczkowska, T. (2022) *Protocol to Support Victims of Racism and Discrimination: Working for Equality*, Immigrant Council of Ireland (ICI).

Arfa, S., Solvang, P. K., Berg, B., and Jahnsen, R. (2020) 'Disabled and immigrant, a double minority challenge: a qualitative study about the experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway', *BMC Health Services Research*, 20 (134), 1-16. Accessed at: <https://doi.org/10.1186/s12913-020-5004-2>, on 04/01/21.

Arksey, H., and Knight, P. (1999) *Interviewing for Social Scientists*, London, Sage.

Armstrong, D. (1995) *Power and Partnership in Education*, London, Routledge Falmer.

Baca Zinn, M., and Thornton Dill, B. (1996), 'Theorizing difference from multiracial feminisms', *Feminist Studies*, 22, 321–331, doi:10.2307/3178416.

Bailey, D., Scarborough, A., Hebbeler, K., Spiker, D., and Mallik, S. (2004) *National Early Intervention Longitudinal Study: Family Outcomes at The End of Early Intervention*, Menlo Park, CA, SRI International.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., and Charman, T. (2006) “Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: The Special Needs and Autism Project (SNAP)”, *The Lancet*, 368 (9531), 210–215.

Baker-Ericzén, M. J., Jenkins, M. M., and Haine-Schlagel, R. (2013) ‘Therapist, parent, and youth perspectives of treatment barriers to family-focused community outpatient mental health services’, *Journal of Child and Family Studies*, 22(6), 854–868.

Baker, C., and Imafidon, E. (2020) ‘Traditional beliefs inform attitudes to disability in Africa. Why it matters’, *The Conversation*, Accessed at: <https://theconversation.com/traditional-beliefs-inform-attitudes-to-disability-in-africa-why-it-matters-138558#:~:text=Traditional%20beliefs%20about%20the%20causes,that%20disability%20is%20God's%20will>, on 31/10/22.

Balcazar, F., Suarez-Balcazar, Y., and Taylor-Ritzler, T. (2009) ‘Cultural competence: Development of a conceptual framework’, *Disability and Rehabilitation*, 31, 1153–1160, doi:10.1080/09638 280902773752.

Banks, J., Grotti, R., Fahey, E., and Watson, D. (2018) *Disability and Discrimination in Ireland: Evidence from the QNHS Equality Modules 2004, 2010, 2014*, Copyright is held jointly by the Economic and Social Research Institute and the Irish Human Rights and Equality Commission.

Barlow, J., Harrison, K., and Shaw, K. (1998) “The Experience of Parenting in the Context of Juvenile Chronic Arthritis”, *Clinical Child Psychology and Psychiatry*, 3 (3), 445–463.

Barn, R., and Das, C. (2016) ‘Family group conferences and cultural competence in social work’, *British Journal of Social Work*, Advance online publication. doi:10.1093/bjsw/bcu105

Barn, R. (2007) ““Race”, ethnicity and child welfare: a fine balancing act’, *British Journal of Social Work*, 37 (8), 1425–1434.

Barnardos (2017) 'Waiting Lists Affect Child Development', available online at: <https://www.barnardos.ie/assets/files/pdf/2017-Barnardos-Waiting-Lists-Briefing-Paper.pdf>, Accessed on 10/4/18.

Barnes, J.A. (1979) "*Who should know what?*" *Social science, privacy and ethics*, Cambridge, Cambridge University Press.

Barnett, D., Clements, M., Kaplan-Estrin, M. G., and Fialka, J. (2003) 'Building New Dreams: Supporting Parents' Adaptation to Their Child with Special Needs', *Infants and young children*, 16(3), 184–200. DOI: 10.1097/00001163-200307000-00002.

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., and Brayne, C. (2009) "Prevalence of Autism-Spectrum Conditions: UK School-Based Population Study", *The British Journal of Psychiatry*, 194, 500–509. doi:10.1192/bjp.bp.108.059345.

Beagan, B. L. (2015) 'Approaches to culture and diversity: A critical synthesis of occupational therapy literature', *Canadian Journal of Occupational Therapy*, 82(5), 272-282, DOI: 10.1177/0008417414567530.

Beagan, B. L., and Chacala, A. (2012) 'Culture and diversity among occupational therapists in Ireland: When the occupational therapist is the "diverse" one', *British Journal of Occupational Therapy*, 75, 144–151, doi:10.4276/030802212X13311219571828.

Bean, R. (2006b) 'The Effectiveness of Cross-Cultural Training in the Australian Context, a report prepared for the Department of Immigration and Multicultural Affairs on behalf of the Joint Commonwealth, State and Territory Research Advisory Committee', Canberra, Commonwealth of Australia.

Beegle, K., Christiaensen, L., Dabalen, A., and Gaddis, I. (2016) 'Poverty in a rising Africa', International Bank for Reconstruction and Development / The World Bank, Washington DC, [www.worldbank.org](http://www.worldbank.org). <https://www.brookings.edu/blog/future-development/2019/03/28/poverty-in-africa-is-now-falling-but-not-fast-enough/>

Bell, K., and Gregore, D. (2015) 'Transforming and Implementing Intersectional Cultural Competency Curricular Changes to Improve Health Care Delivery for LGBTQ Patients', Accessed at: <https://aptaeducation.org/abstract-archive/view.cfm?id=2289514>, on 14/10/22.

- Ben-Moshe, L., and Magaña, S. (2014) 'An Introduction to Race, Gender, and Disability: Intersectionality, Disability Studies, and Families of Color', *Women, Gender, and Families of Color*, 2 (2), 105–114, doi:10.5406/womgenfamcol.2.2.0105.
- Beresford, B., Rabiee, P. and Sloper, P. (2007) 'Outcomes for Parents with Disabled Children', *Research Works*, 2007-03, Social Policy Research Unit, University of York.
- Berry, T. R. (2010) 'Engaged pedagogy and critical race feminism', *Educational Foundations*, 24, 19–26.
- Bešić, E. (2020) 'Intersectionality: A pathway towards inclusive education?', *Prospects*, 49, 111–122, <https://doi.org/10.1007/s11125-020-09461-6>.
- Betts, R. (2005) *Assimilation and Association in French Colonial Theory, 1890-1914*, 2<sup>nd</sup> ed., Lincoln and London, University of Nebraska Press.
- Bhui, K., Warfa, N., Edonya, P., McKenzie, K. and Bhugra, D. (2007) 'Cultural competence in mental health care: A review of model evaluations', *BMC Health Services Research*, 7(15), available online at [www.biomedcentral.com/content/pdf/1472-6963-7-15.pdf](http://www.biomedcentral.com/content/pdf/1472-6963-7-15.pdf), Accessed on 03/06/2017.
- Birenbaum, A. (1992) 'Courtesy Stigma Revisited', *Mental Retardation*, 30, 265–268.
- Birkin, C., Anderson, A., Seymour, F. and Moore, D. (2008) 'A parent-focused early intervention program for autism: Who gets access?', *Journal of Intellectual and Developmental Disability*, 33 (2), 108-116.
- Blacher, J., Neece, C. and Paczkowski, E. (2005) 'Families and Intellectual Disability', *Current Opinion in Psychiatry*, 18, 507–513, Doi:10.1097/01.yco.0000179488.92885.e8.
- Blacher, J. (1984) 'Sequential stages of parental adjustment to a birth of a child with handicaps: fact or artifact?', *Mental Retardation*, 22, 55–68.
- Black, R. M., and Wells, S. A. (2007) *Culture and Occupation: A Model of Empowerment in Occupational Therapy*, Bethesda MD, AOTA Press.

Blum, L. M. (2015) *Raising Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality*, USA, New York University Press.

Bourdieu, P. (1991) *Language and symbolic power*, Cambridge, Harvard University Press.

Bowleg, L. (2012) 'Once you've blended the cake, you can't take the parts back to the main ingredients: Black gay and bisexual men's descriptions and experiences of intersectionality', *Sex Roles*, this issue, doi:10.1007/s11199-012-0152-4.

Bradley, V. J. (1992) 'Overview of the family support movement', In Bradley, V. J., Knoll-J, and Agosta, J.M., *Emerging Issues in Family Support*, Washington, The American Association on Mental Retardation.

Brassart, E., Prévost, C., Bétrisey, C., Lemieux, M., and Desmarais, C. (2017) 'Strategies Developed by Service Providers to Enhance Treatment Engagement by Immigrant Parents Raising a Child with a Disability', *J Child Fam Stud*, 26, 1230–1244 DOI 10.1007/s10826-016-0646-8, p.1231.

Braun, V., Clarke V. (2006) 'Using Thematic Analysis in Psychology', *Qualitative Research in Psychology*, 3, 77-101, www.QualResearchPsych.com.

Brett, J. (2002) 'The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is it time for an alternative model of disability?', *Disability and Society*, 17(7), 825-843, DOI: 10.1080/0968759022000039109.

Bricher, G. (2000) 'Disabled people: health professionals and the social model of disability, can there be a research relationship?', *Disability and Society*, 15, 781–793.

Britzman, D. P. (2000) 'Teacher education in the confusion of our times', *Journal of Teacher Education*, 51(3), 200–205.

Bruce, E., and Schultz, C. (2002) 'Non-finite loss and challenges to communication between parents and professionals', *British Journal of Special Education*, 29(1), 9–13.

Bryman, A. (2012) *Social Research Methods*, 4th ed., Oxford, Oxford University Press.

Bryman, A. (2008) *Social Research Methods*, 3<sup>rd</sup> ed., Oxford, Oxford University Press.

Buckley, S. (2002) *Issues for Families with Children with Down Syndrome*, Hampshire, The Down Syndrome Educational Trust.

Burns, N. (2017) 'The human right to health: exploring disability, migration and health', *Disability & Society*, 32(10), 1463-1484, DOI: 10.1080/09687599.2017.1358604.

Burton, P., and Phipps, S. (2009) 'Economic Costs of Caring for Children with Disabilities in Canada', *Canadian Public Policy / Analyse de Politiques*, 35(3), 269-290.

Byrne, B., and De Tona, C. (2012) "'Trying to find the extra choices': migrant parents and secondary school choice in Greater Manchester", *British Journal of Sociology of Education*, 33(1), 21-39, DOI: 10.1080/01425692.2012.632865.

Cairde (2015) *Ethnic Minorities and Mental Health in Ireland: Barriers and Recommendations*, Cairde, Dublin.

Calavita, K. (2005) *Immigrants at the margins. Law, race and exclusion in Southern Europe*, Cambridge, Cambridge University Press.

Campinha-Bacote, J. (2018) 'Cultural competemility: A paradigm shift in the cultural competence versus cultural humility debate - Part I', *OJIN: The Online Journal of Issues in Nursing*, 24(1), doi: 10.3912/OJIN.Vol24No01PPT20.

Campinha-Bacote, J. (2013) *A biblically based model of cultural competence in the delivery of healthcare services: Seeing "Imago Dei"*, 2<sup>nd</sup> ed., Cincinnati, OH, Transcultural C.A.R.E. Associates.

Campinha-Bacote, J. (2011) 'Coming to know cultural competence: An evolutionary process', *International Journal for Human Caring*, 15(3), 42-48, doi: 10.20467/1091-5710.15.3.42.

Carey, M. (2009) *The Social Work Dissertation: Using Small-Scale Qualitative Methodology*, England, Open University Press.

Cargan, L. (2007) *Doing Social Research*, Maryland, Rowman and Littlefield.

Carling, J., Erdal, B. M., and Ezzati, R. (2014) 'Beyond the insider–outsider divide in migration research', *Migration Studies*, 2(1), 36-54.

Carroll, C., Murphy, G., Sixsmith, J. (2013) 'The Progression of Early Intervention Disability Services in Ireland', *Infants and Young Children*, 26, 17-27.

Cartwright, B. Y., Daniels, J., and Zhang, S. (2008) 'Assessing multicultural competence: Perceived versus demonstrated performance', *Journal of Counselling and Development*, 86, 318-322.

Case, S (2001) 'Learning to Partner, Disabling Conflict: Early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities', *Disability and Society*, 16(6), 837-854, DOI: 10.1080/09687590120083985.

Case, S. (2000) 'Refocusing on the Parent: What are the social issues of concern for parents of disabled children?', *Disability and Society*, 15 (2), 271-292.

Castles, Stephen (2010) "Understanding Global Migration: A Social Transformation Perspective", *Journal of Ethnic and Migration Studies*, 36(10), 1565–1586, doi:10.1080/1369183X.2010.489381.

Chambers, D. (2012) *A Sociology of Family Life: Change and Diversity in Intimate Relations*, Cambridge, Polity Press.

Chiarenza, A. (2012) "Developments in the concept of 'cultural competence'", In Ingleby, D., Chiarenza, A., Devillé, W., and Kotsioni, I. (Eds.), *Inequalities in health care for migrants and ethnic minorities*, Antwerp, Garant, pp. 66-81.

Child Development Institute (2007) *Achieving Cultural Competence: Children's Mental Health*, Toronto, Child Development Institute.

Cho, S., Singer, G. H. and Brenner, B. (2003) 'A comparison of adaptation to childhood disability in Korean immigrant and Korean mothers', *Focus on Autism and Other Developmental Disabilities*, 18(1), 9–19.

Choak, C. (2012) 'Asking Questions: Interviews and Evaluations', In Bradford, S. and Cullen, F. (eds) *Research and Research Methods for Youth Practitioners*, London, Routledge, pp. 90–112.

Choo, H. Y., and Ferree, M. M. (2010) 'Practicing intersectionality in sociological research: A critical analysis of inclusions, interactions, and institutions in the study of inequalities', *Sociological Theory*, 28, 129–149. doi:10.1111/j.1467-9558.2010.01370.x.

Christie, A. (2010) 'Whiteness and the politics of 'race' in child protection guidelines in Ireland', *European Journal of Social Work*, 13(2), 199-215, DOI: 10.1080/13691451003690858.

Ciribuco, A., Naughton, A., and O'Connor, A. (2017) 'Language and Migration in Ireland', Immigrant Council of Ireland (ICI), Dublin.

Coakley, L., and Mac Einri, P. M. (2007) 'The Integration Experiences of African Families in Ireland', Dublin, Integrating Ireland.

Collins, P. H. (1990) *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*, New York: Routledge.

Condon, L., McClean, S., McRae, L. (2020) "'Differences between the earth and the sky': migrant parents' experiences of child health services for pre-school children in the UK", *Primary Health Care Research and Development*, 21(e29), 1–8, Doi: 10.1017/S1463423620000213.

Condon, L., and Mytton, J. (2019) 'Travellers, migrants and refugee children', In Emond, A. (ed) (2019) *Health for all children*, 5th ed., Royal College of Paediatrics and Child Health, Oxford, OUP.

Constant, A. F., and Zimmermann, K. F. (2016) *Diaspora economics: New perspectives*, UNU-MERIT working paper series, Harvard University and UNU-MERIT.

Cooper, C. R. (2014) "Cultural Brokers: How Immigrant Youth in Multicultural Societies Navigate and Negotiate Their Pathways to College Identities", *Learning, Culture and Social Interaction*, 3(2), 170–6, doi:10.1016/j.lcsi.2013.12.005.

Corker, M., and Davis, J. M. (2000) 'Disabled children—invisible under the law', in: Cooper, J., and Vernon, S. (Eds) *Disability and the Law*, London, Jessica Kingsley.

Coru.ie, Accessed at <https://www.coru.ie/health-and-social-care-professionals/education/criteria-and-standards-of-proficiency/>, on 28/10/2020.

CORU (2011) *Social Work Registration Board: Code of Professional Conduct and Ethics for Social Workers*. Dublin, CORU. Available at: [http://www.coru.ie/uploads/documents/typeset\\_Social\\_Worker\\_Code\\_Feb\\_2010.pdf](http://www.coru.ie/uploads/documents/typeset_Social_Worker_Code_Feb_2010.pdf), Accessed on 13/08/2017.

Crenshaw, K. (1991) 'Mapping the margins: Intersectionality, identity politics, and violence against women of color', *Stanford Law Review*, 43(6), 1241–1299.

Crenshaw, K. (1989) "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics", *University of Chicago Legal Forum* 1989, 139–167.

Creswell, J. W. (2009) *Research design: Qualitative, quantitative, and mixed method approaches*, Thousand Oaks, CA, Sage Publications, Inc.

Creswell, J. W. (2007) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, Thousand Oaks, London, Sage.

Cross, T., Bazron, B., Dennis, K. and Isaacs, M. (1989) *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, Vol. 1, Washington DC, Georgetown University Child Development Center.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in The Research Process*, London, Sage.

Crow, L. (1996) 'Including all of our lives: renewing the social model of disability', in: Barnes, C. and Mercer, G. (Eds) *Exploring the Divide: illness and disability*, Leeds, Disability Press, pp. 91–102.

CSO (Central Statistics office) (2017) Accessed at: [https://www.cso.ie/en/csolatestnews/pressreleases/2017pressreleases/presstatementcensus2016resultsprofile9-healthdisabilityandcarers/#:~:text=There%20were%2083%2C754%20carers%20\(42.9,of%20total%20care%20hours%20provided,](https://www.cso.ie/en/csolatestnews/pressreleases/2017pressreleases/presstatementcensus2016resultsprofile9-healthdisabilityandcarers/#:~:text=There%20were%2083%2C754%20carers%20(42.9,of%20total%20care%20hours%20provided,) on 05/08/20.

CSO (Central Statistics Office) (2016) *Profile 9: Health, Disability and Carers*, Dublin, Stationery Office.

CSO (2012) Accessed at: <https://www.cso.ie/en/csolatestnews/pressreleases/2012pressreleases/pressreleasecensus2011profile8ourbillofhealth/>, on 05/08/20.

Currie, D. (2005) *Developing and Applying Study Skills*, CIPD.

Curry, P., Gilligan, R., and McGrath, J. (2010) *Where to from Here? Inter-ethnic Relations among Children in Ireland*, Dublin, Liffey Press in association with the Children's Research Centre, Trinity College Dublin.

Dale, N. (1996) *Working with Families of Children with Special Needs: partnership and practice*, London, Routledge.

Daliken, C. (2022) *Child Protection Social Workers and Asylum-Seeking Families in Ireland: Issues of Culture, Race, Power Relations, and Mistrust*, UK, Peter Lang.

Daliken, C. (2021) 'Child-rearing practices: cross cultural perspectives of African asylum-seeking families and child protection social workers in Ireland', *European Journal of Social Work*, 24(1), 8-20, DOI: 10.1080/13691457.2019.1585333.

Daneco, E.R. (1997) 'Parental Beliefs on Childhood Disability: insights on culture, child development and intervention', *International Journal of Disability, Development and Education*, 44 (1), 41-52.

Danso, R. (2016) 'Cultural competence and cultural humility: A critical reflection on key cultural diversity concepts', *Journal of Social Work*, Accessed at <https://doi.org/10.1177/1468017316654341>, on 26/10/17.

Darawsheh, W., Chard, G., and Eklund, M. (2015) 'The Challenge of Cultural Competency in the Multicultural 21<sup>st</sup> Century: A Conceptual Model to Guide Occupational Therapy Practice', *The Open Journal of Occupational Therapy*, 3(2), Article 5, Available at: <https://doi.org/10.15453/2168-6408.1147>.

Dare, A. and O'Donovan, M. (2002) *Good Practice In Caring for Young Children with Special Needs*, 2<sup>nd</sup> ed., United Kingdom, Nelson Thornes Ltd.

Darling, R. B. (1979) *Families against society: A study of reactions to children with birth defects*, London, Sage.

- Daudji, A., Eby, S., Foo, T., Ladak, F., Sinclair, C., Landry, M. D., Moody, K., and Gibson, B. E. (2011) 'Perceptions of disability among south Asian immigrant mothers of children with disabilities in Canada: implications for rehabilitation service delivery', *Disability and Rehabilitation*, 33(6), 511-521.
- David, E. J. R., and Derthick, A. O. (2014) 'What is internalized oppression, and so what?', In David, E. J. R. (Ed.) *Internalized oppression: The psychology of marginalized groups*, Springer Publishing Company, pp. 1–30.
- Davidson, M. (2016) 'Crippling Consensus: Disability Studies at the Intersection', *American History*, 28(2) 433-453.
- Davies, M. B. (2007) *Doing a successful research project: using qualitative or quantitative methods*, Basingstoke, Palgrave Macmillan.
- DCYA/Department for Children and Youth Affairs (2016) *Diversity, Equality and Inclusion Charter and Guidelines for Early Childhood Education and Care*, Dublin, Government Publications.
- Department of Children and Youth Affairs (2012) *Statement of Strategy 2011-2014*, Dublin.
- De Wispelaere, J. & Walsh, J. (2007) 'Disability rights in Ireland: chronicle of missed opportunity', *Irish Political Studies*, 22(4), 517-543.
- Dean, R. G. (2001) 'The myth of cross-cultural competence', *Families in Society: The Journal of Contemporary Human Services*, 82(6), 623-630.
- Deegan, G. (2011) 'Concern over speech therapy', *Irish Times*, February 8th, 2011.
- Dei, G. J. S. (2000) 'Rethinking the Role of Indigenous Knowledges in Academy', *International Journal of Inclusive Education*, 4(2), 111-132.
- Denscombe, M. (2007) *The good Research Guide for Small Scale Social Research Projects*, 3<sup>rd</sup> ed., England, Open University Press.

Department of Health Australia (2009) *Because Mental Health Matters - Victoria Mental Health Reform Strategy 2009-2019*, Victoria, Department of Health. Available at: [http://www.health.vic.gov.au/mentalhealth/reform/documents/mhs\\_web\\_summary.pdf](http://www.health.vic.gov.au/mentalhealth/reform/documents/mhs_web_summary.pdf), Accessed on 14/09/14.

Department of Health and Children, Dublin, <http://tinyurl.com/6lvbtg2>, Accessed on 27/01/12.

Department of Health (1991) *The Children Act 1989 Guidance and Regulations*, Vols 1–9, London, HMSO.

Department of Health (1966) *Circular 27/66, District Nursing Service*, Dublin, Stationary Office.

Department of Justice, Equality and Law Reform (2005) *Planning for Diversity: The National Action Plan Against Racism 2005-2008*, Department of Justice, Equality and Law Reform, Dublin.

DES/Department of Education and Skills (2016) *Survey of Early Years Practitioners: Consultation for the Review of Education and Training Programmes in Early Years*, Dublin, Department of Education and Skills.

Devery, H. (2018) “*You have to fight for everything*”: *An exploration of the experiences of parents accessing early intervention.*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <http://www.ucc.ie/en/scishop/completed/> , Accessed on 18/05/20.

Dhamoon, R. K. (2011) ‘Considerations on mainstreaming intersectionality’, *Political Research Quarterly*, 64, 230–243, doi:10.1177/1065912910379227.

Doka, J. K., and Martin, T. I. (2020) *Grieving Beyond Gender: Understanding the Ways Men and Women Mourn*, revised edition, series in death, dying and bereavement, New York, Routledge, Taylor and Francis group.

Drevdahl, D, Canales, M. K., Dorcy, K. S. (2008) 'Of goldfish tanks and moonlight tricks. Can cultural competency ameliorate health disparities?' *Advances in Nursing Science*, 31 (1), 13-27.

Driscoll, D. L. (2011) *Introduction to Primary Research: Observations, Surveys, and Interviews*, San Francisco, Parlor Press.

Dumas, A. D. (2012) *Process, power, and possibilities: An exploration of experienced white social workers' cultural competence in clinical practice* (Doctoral dissertation), Available from ProQuest Dissertations and Theses database, (UMI No. 3496020).

Duncan, P. (2014) 'More than 32,000 children await speech services', *Irish Times*, 31st March 2014.

Dunn, A. M. (2002) 'Culture competence and the primary care provider', *Journal of Pediatric Health Care*, 16, 105–111.

Duong, K. (2012) 'What does queer theory teach us about intersectionality?', *Politics and Gender*, 8, 370–386, doi:10.1017/ S1743923X12000360.

Duong, K. (2012) 'What does queer theory teach us about intersectionality?', *Politics and Gender*, 8, 370–386, doi:10.1017/ S1743923X12000360.

Dyche, L. and Zayas, L. H. (2001) 'Cross Cultural Empathy And Training The Contemporary Psychotherapist', *Clinical Social Work Journal*, 29, 245-258.

Egner, J. (2017) 'Crip Theory And Medical Sociology', In Green, S. and Barnartt, S. N. (eds) *Sociology Looking At Disability: What Did We Know And When Did We Know It?*, UK, Emerald Group Publishing Limited, pp. 159-192.

Ellis, K. (2019) *Disability and Digital Television Cultures: Representation, Access and Reception*, New York, Routledge.

Emerson, E., and Hatton, C. (2007) 'The Socio-Economic Circumstances of Children at Risk of Disability in Britain', *Disability and Society*, 22, 563–580, Doi:10.1080/09687590701560154.

Emerson, E., Robertson, J. and Wood, J. (2004) 'Levels of Psychological Distress Experienced by Family Carers of Children and Adolescents in an Urban Conurbation', *Journal of Applied Research in Intellectual Disabilities*, 17, 77–84, Doi:10.1111/j.1360-2322.2004.00183.x.

Emery, R. and Wiseman, R. L. (1987) 'An intercultural understanding of able-bodied and disabled persons communication', *International Journal of Intercultural Relations*, 11, 7-27.

Employment Equality Acts, 1998 and 2004, [www.equality.ie](http://www.equality.ie) , <https://www.ihrec.ie/>, Accessed on 14/06/21.

Equal Status Acts, 2000 and 2004, [www.equality.ie](http://www.equality.ie) , <https://www.ihrec.ie/>, Accessed on 14/06/21.

Eskay, M. (2009) *Cultural Perceptions of Special Education Administrators in Nigeria*, Koln: Germany, Lambert Academic Publishing.

Evans, C. (2018) 'Analysing Semi-Structured Interviews Using Thematic Analysis: Exploring Voluntary Civic Participation Among Adults', *SAGE Research Methods Datasets*, SAGE Publications, Ltd. <http://dx.doi.org/10.4135/9781526439284>.

Fedor, C-G. (2014) 'Stereotypes and Prejudice in the Perception of the "Other"', *Procedia - Social and Behavioral Sciences*, 149, 321 – 326.

Fellin, M., King, G., Esses, V., Lindsay, s. and Klassen, A. (2013) : Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability, *International Journal of Migration, Health And Social Care*, 3, 135-145.

Ferrie, J., and Watson, N. (2015) 'The psycho-social impact of impairment: the case of motor neurone disease', In Shakespeare, T. (ed.) *Disability Research Today*, Routledge, Oxon, pp. 43-59, ISBN 9780415748445.

Figueiredo, C. C., and Gil, D. (2013) 'Assessment of the degree of involvement in family therapy for children with hearing impairment', *Audiology—Communication Research*, **18**(4), 303–307.

Finkelstein, V. (1980) *Attitudes and Disabled People*, New York, World Rehabilitation Fund.

Fisher-Borne, M., Cain, J.M., and Martin, S. L. (2015) 'From Mastery to Accountability: Cultural Humility as an Alternative to Cultural Competence', *Social Work Education: The International Journal*, 34(2), 165-181, Accessed at <http://dx.doi.org/10.1080/02615479.2014.977244>, on 15/11/17.

Fisher, B. C. and Anushko, E. A. (2008) 'Research Ethics in Social Science', in Alasuutari, P., Bickman, L., Brannen, J. (eds) (2008) *The SAGE Handbook of Social Research Methods*, London, Sage.

Fitzgerald, E., and Campinha-Bacote, J., (2019) 'An Intersectionality Approach to the Process of Cultural Competemility – Part II', *OJIN: The Online Journal of Issues in Nursing*, 24(2).

Florian, V. (1987) 'Family supports in Israel', in Lipsky, D. K. (Ed.), *Familv supports for families with a disabled member*, New York, World Rehabilitation Fund.

Flynn, S. (2021) 'Convergent Identities, Compounded Risk: Intersectionality and Parenting Capacity Assessment for Disabled Children', *Child and Youth Services Review*, 129, (106185).

Flynn, S. (2020) 'Convergent spaces: Intersectional analysis of ethnic minority status and childhood disability in Irish safeguarding work', *Child & Family Social Work*, 25, 648–656, <https://doi.org/10.1111/cfs.12739>.

Fombonne, E. (2009) "Epidemiology of Pervasive Developmental Disorders", *Pediatric Research*, 65 (6), 591–598, doi:10.1203/PDR.0b013e31819e7203.

Foran, S. and Sweeney, J. (2010) 'Accessing specialist early intervention for preschool children', *Learning Disability Practice*, 13 (2), 30-35.

Fraser, N., and Honneth, A. (2003) *Redistribution or Recognition? A Political Philosophical Exchange*, London, Verso.

French, S. (1993) 'Disability, impairment or something in between?', in: Swain, J., Finkelstein, V., French, S., and Oliver, M. (Eds) *Disabling Barriers—Enabling Environments*, London, Sage.

Furness, S. (2005) 'Shifting sands: developing cultural competence', *Practice*, 17 (4), 247–256.

- Garneau, A. B., and Pepin, J. (2015) 'Cultural Competence: A Constructivist Definition', *Journal of Transcultural Nursing*, 26(1), 9-15.
- Galanti, G.A. (1991) *Caring for Patients from Different Cultures*, University of Pennsylvania Press.
- Gallegos, J., Tindall, C., and Gallegos, S. (2008) 'The need for advancement in the conceptualization of cultural competence', *Advances in Social Work*, 9(1), 51-62.
- Garcia Coll, C., and Magnuson, K. (2000) 'Cultural differences as sources of developmental vulnerabilities and resources', In Shonkoff, J. P., and Meisels, S. J. (Eds), *Handbook of Early Childhood Intervention* (2<sup>nd</sup> ed.), New York, Cambridge University Press, pp. 94-114.
- García, S. B., and Ortiz, A. A. (2013) 'Intersectionality as a framework for transformative research in special education', *Multiple Voices for Ethnically Diverse Exceptional Learners*, 13(2), 32-47.
- Gardiner, E., and French, C. (2011) 'The Relevance of Cultural Sensitivity in Early intervention', *Exceptionality Education International*, 21(3), 34-39.
- Garneau, A. B., and Pepin, J. (2015) 'Cultural Competence: A Constructivist Definition', *Journal of Transcultural Nursing*, 26(1), 9-15.
- Garran, A. M., and Rozas, L. W. (2013) 'Cultural Competence Revisited' *Journal of Ethnic and Cultural Diversity in Social Work*, 22, 97-111. doi:10.1080/15313204.2013.785337.
- Geertz, C. (1973) *The Interpretation of Cultures*, New York, Basic Books.
- Gerrish, K. (1997) 'Preparation of nurses to meet the needs of an ethnically diverse society: educational implications', *Nurs Educ Today*, 17(5), 359-65.
- Ghaddar, S., Ronnau, J., Saladin, S., and Martínez, G. (2013) 'Innovative approaches to promote a culturally competent, diverse health care workforce in an institution serving Hispanic students', *Academic Medicine: Journal of the Association of American Medical Colleges*, 88(12), 1870-1876, <http://dx.doi.org/10.1097/ACM.0000000000000007>.
- Gillborn, D. (2015) "Intersectionality, Critical Race Theory, and the Primacy of Racism: Race, Class, Gender, and Disability in Education", *Qualitative Inquiry*, 21 (3), 277-287, Doi:10.1177/1077800414557827.

Gilligan, R., and Curry, P. (2010) *In Front Line of Integration: Young people managing migration to Ireland*. Dublin: Children Research Centre Trinity College.

Gilson, S. F. and Depoy, E. (2000) 'Multiculturalism and Disability: A critical perspective', *Disability and Society*, 15(2), 207-218.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, Englewood Cliffs, NJ: Prentice-Hall.

Goldberg, D. T. (1993) *Racist Culture*, Cambridge, Blackwell Press.

Goode, T. D., Dunne, M. C. and Bronheim, S. M. (2006) 'The evidence base for cultural and linguistic competency in health care', *The Commonwealth Fund*, available online at [www.cmwf.org](http://www.cmwf.org), retrieved on 3/07/2009).

Goodley, D., Hughes, B., and Davis, L. (2012) 'Introducing Disability And Social Theory' In Goodley, D., Hughes, B., and Davis, L.(eds) *Disability And Social Theory: New Developments And Directions*, London, Palgrave Macmillan, pp. 1-16.

Gov.Uk, 'Discrimination: your rights', Accessed at <https://www.gov.uk/discrimination-your-rights>, on 13/10/22.

Gray, D. P., and Thomas, D. J. (2006) 'Critical Reflections on Culture in Nursing', *Journal of Cultural Diversity*, 13(2), 76-82.

Gray, D. E. (2009) *Doing Research in the Real World*, London, Sage.

Gray, D. (2004) *Doing Research in the Real World*, London, Sage.

Gray, D. E. (1993) 'Perceptions of Stigma: The Parents of Autistic Children', *Sociology of Health and Illness*, 15 (1), 102–120, Doi:10.1111/1467-9566.ep11343802.

Gross, G. D. (2000) 'Gatekeeping for cultural competence: Ready or not? Some post and modernist doubts', *Journal of Baccalaureate Social Work*, 5(2), 47–66.

Green, S. E. (2007) "'We're Tired, Not Sad": Benefits and Burdens of Mothering a Child with a Disability', *Social Science and Medicine*, 64 (1), 150–163, Doi:10.1016/j.socscimed.2006.08.025.

Green, S., Davis, C., Karshmer, E., Marsh, P., and Straight, B. (2005), "'Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of

Individuals with Disabilities and their Families’, *Sociological Inquiry*, 75 (2), 197–215, Doi:10.1111/j.1475-682X.2005.00119.x.

Green, S. (2003) “‘What do you mean ‘what’s wrong with her?’’: stigma and the lives of families of children with disabilities’, *Soc Sci Med*, 57, 1361–1375.

Gregory, D., Harrowing, J., Lee, B., Doolittle, L., and O’Sullivan, P. S. (2010) ‘Pedagogy as influencing nursing students’ essentialized understanding of culture’, *International Journal of Nursing Education Scholarship*, 7(1), 30. doi:10.2202/1548-923X.2025.

Grix, J. (2004) *The Foundations of Research*, Hampshire, Palgrave MacMillan.

Groce, N. (2005) ‘Immigrants, Disability and rehabilitation’, In Stone, J. H. (2005) *Culture and Disability: Providing Culturally Competent Services*, London, Sage, Multicultural Aspects of Counselling Series 21, pp. 1-14.

Gross, G. D. (2000) ‘Gatekeeping for cultural competence: Ready or not? Some post and modernist doubts’, *Journal of Baccalaureate Social Work*, 5(2), 47–66.

Guba, E. G., and Lincoln, Y. S. (1994) ‘Competing Paradigms In Qualitative Research’, In Denzin, N. K., and Lincoln, Y. S. (Eds.) *Handbook Of Qualitative Research*, Thousand Oaks, CA: Sage, pp. 105-117.

Günther, T., and Hautvast, S. (2010) ‘Addition of contingency management to increase home practice in young children with a speech sound disorder’, *International Journal of Language and Communication Disorders*, 45(3), 345–353.

Guralnick, M. J. (2011) ‘Why early intervention works: A systems perspective’, *Infants and Young Children*, 24, 6-28. Retrieved from <http://dx.doi.org/10.1097/fYC.Ob013e3182002cfe>.

Guralnick, M.J. (2001) ‘A Developmental Systems’ model for Early Intervention’, *Infants and Young Children*, 14, 1-18.

Halpin, A. (2022) ‘The annual crisis: school places for children with special needs’, *RTE*, August 22<sup>nd</sup> 2022, Accessed at: <https://www.rte.ie/brainstorm/2022/0819/1316675-ireland-education-school-places-special-needs/>, on 15/10/22.

Haltiwanger, E. (2010 August) 'Client empowerment through cultural sensitivity', *OT Practice*, 15,7–11.

Hammell, K. R. W. (2013) 'Occupation, well-being, and culture: Theory and cultural humility', *Canadian Journal of Occupational Therapy*, 80, 224–234. doi:10.1177/0008417413500465.

Hancock, A. (2007) 'When multiplication doesn't equal quick addition: Examining intersectionality as a research paradigm', *Perspectives on Politics*, 5(1), 63–79.

Hankivsky, O., and Cormier, R. (2011) 'Intersectionality and public policy: Some lessons from existing models', *Political Research Quarterly*, 64, 217–229, doi:10.1177/1065912910376385.

Hanvey, L. (2002) 'Children with Disabilities and Their Families in Canada. A Discussion Paper. Commissioned by the National Children's Alliance for the First Roundtable of Children with Disabilities', Accessed at <http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf>, on 30/11/13.

Harrison, G., and Turner, R. (2011) 'Being a 'Culturally Competent' Social Worker: Making Sense of a Murky Concept in Practice', *British Journal of Social Work*, 41(2), 333-350.

Harry, B. (2008) 'Collaboration with culturally and linguistically diverse families: Ideal versus reality', *Exceptional Children*, 74(3), 372-388.

Harry, B., and Kalyanpur, M. (1994) 'Cultural underpinnings of special education: Implications for professional interactions with culturally diverse families', *Disability and Society*, 9 (2), 145-165.

Hart, C. (1998) *Doing a literature review: Releasing the social science research imagination*, London, Sage Publications.

Harvey, B. (2007) *Evolution of Health Services and Health Policy in Ireland*, Dublin, Combat Poverty Agency.

Hauskov-Graungaard, A., Andersen, S., and Skov, L. (2011) "When Resources Get Sparse: A Longitudinal Qualitative Study of Emotions, Coping and Resource-creation When Parenting as Young Child with Severe Disabilities", *Health*, 15 (2), 115–136.

Hausmann, L. R. M., Hannon, M. J., Kresevic, D. M., Hanusa, B. H., Kwoh, C. K., and Ibrahim, S. A. (2011) 'Impact of perceived discrimination in healthcare on patient-provider communication', *Medical Care*, 49, 626–633.

Health Information and Quality Authority (HIQA) (2012) *National Standards for the Protection and Welfare of Children, for Health Service Executive Children and Family Services*, Dublin, Health Information and Quality Authority, Social Services Inspectorate HSE, 2007 (SSI).

Health Service Executive (HSE) (2021) National policy for Children's Disability Network Teams on family engagement and attendance, Accessed at: <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/>, on 11/09/2022.

Health Service Executive (HSE) (2020), New accredited Intercultural Awareness ELearning Programme now available, Accessed at: <https://www.hse.ie/eng/about/who/primarycare/socialinclusion/about-social-inclusion/news/new-accredited-intercultural-awareness-elearning-programme-now-available.html>, on 16/10/22.

Health Service Executive (HSE) (2021) Progressing Disability Services for Children and Young People Programme (PDS), Accessed at: <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/introduction/>, on 11/09/22.

Health Service Executive (HSE) (2019) Second National Intercultural Health Strategy 2018-2023, Health Service Executive (HSE), available at <https://www.lenus.ie/bitstream/handle/10147/624029/intercultural-health-strategy-2018-2023.pdf?sequence=1&disAllowed=y>, Accessed on 20/02/2020.

Health Service Executive (HSE) (2016) *Intercultural Awareness and Practice in Health and Social Care* (Participants Guidebook), Waterford: HSE Community Healthcare Organisation Area 5 Social Inclusion.

Health Service Executive (HSE) (2013) *Progressing Disability Services*, available at: <http://www.hse.ie/progressingdisabilityservices/>, Accessed on 01/9/19.

Health Service Executive (2011) *Child Protection and Welfare Practice Handbook*, Naas, Oakhouse, Accessed at [https://www.tusla.ie/uploads/content/CF\\_WelfarePracticehandbook.pdf](https://www.tusla.ie/uploads/content/CF_WelfarePracticehandbook.pdf), on 14/10/22.

Health Service Executive (2010b) *National Service Plan*, Dublin: Stationary Office.

Health Service Executive (HSE) (2009) *Health services intercultural guide: responding to the needs of diverse religious communities and cultures in healthcare settings*, Health Service Executive, Dublin.

Health Service Executive (HSE) (2008) *National Intercultural Health Strategy 2007-2012*, Dublin, HSE.

Health Service Executive (HSE) (2005), *Learning, Training and Development Needs of Health Services Staff in Delivering Services to Members of Ethnic Minority Communities*, Dublin, HSE, Available at: <https://lenus.ie/handle/10147/45179>.

Healy, B. (2015) *Helping Parents Deal with the Fact That Their Child Has a Disability*, available at: <http://www.ldonline.org/article/5937/>, Accessed on 23/03/15.

Heer, K., Rose, J., and Larkin, M. (2016) 'The Challenges of Providing Culturally Competent Care Within a Disability Focused Team: A Phenomenological Exploration of Staff Experiences', *Journal of Transcultural Nursing*, 27(2), 109–116.

Heer, K., Larkin, M., Burchess, I., and Rose, J. (2012) 'The cultural context of care-giving: Qualitative accounts from South Asian parents who care for a child with intellectual disabilities' *Advances in Mental Health and Intellectual Disabilities*, 6, 179-191, doi:10.1108/20441281211236580.

Heffer, G. (Thu, Jan 5, 2017) 'Britain facing 'crisis' over integration of immigrants as MPs demand action after Brexit', Accessed at <https://www.express.co.uk/news/politics/750610/immigration-social-integration-crisis-Chuka-Umunna-Holly-Lynch-Labour-Brexit-control>, on 10/02/18.

Hendriks, A., De Moor, J., Savelberg, M., and Oud, J. (2001) 'The rehabilitation process of children with motor disabilities in the Dutch therapeutic toddler class: main phases and parent involvement', *International Journal of Rehabilitation Research*, 24(2), 115–122.

Hendrikson, S., Baldwin, J., Allred, K., (2000) 'Factors Perceived by Mothers as Preventing Families from Obtaining Early Intervention Services for their Children with Special Needs', *Children's Health Care*, 29 (1), 1-17.

Hernandez, P., and McDowell, T. (2010) Intersectionality, power, and relational safety in context: Key concepts in clinical supervision, *Training and Education in Professional Psychology*, 4(1), 29-35, <http://dx.doi.org/10.1037/a0017064>

Hibel, J., and Jasper, A. D. (2012) 'Delayed special education placement for learning disabilities among children of immigrants', *Social Forces*, 91(2), 503-530.

Hibel, J., and Jasper, A. D. (2012) 'Immigrant Children's Delayed Special Education Placement for Learning Disabilities: Examining the Influence of Language Minority Status and ESL Participation', *Social Forces*, DOI: 10.2307/23361099.

Hickey, C. (2018) 'Research Ethics in Social Research: Teaching Council Webinar', Centre for Effective Services.

Hilgenberg, C., Schlickau, J. (2002) 'Building transcultural knowledge through intercollegative collaboration', *J Transcult Nurs*, 13(3), 241–7.

Hock, R., Yingling, M. E., and Kinsman, A. (2015) 'A parent-informed framework of treatment engagement in group-based interventions', *Journal of Child and Family Studies*, 24(11), 3372–3382.

Hodge, N., and Runswick-Cole, K. (2008) 'Problematising parent–professional partnerships in education', *Disability and Society*, 23(6), 637-647, DOI: 10.1080/09687590802328543.

Hodge, N. (2006) *Disabling families: How parents experience the process of diagnosing autism spectrum disorders*, Ed.D. dissertation, Sheffield Hallam University.

Hodge, N. (2005) 'Reflections on diagnosing autism spectrum disorders', *Disability and Society*, 20 (3), 345–9.

Holland, K., and Blood, R. W. (2008) 'Carers' Perspectives on Caring: A Qualitative Analysis of Open-Ended Responses to the Carer Health and Wellbeing Index Survey 2007', Deakin, ACT, Carers Australia.

Holmes, A. G. D. (2020) 'Researcher Positionality – A Consideration of Its Influence and Place in Qualitative Research – A New Researcher Guide', *Shanlax International Journal of Education*, 8 (4), 1-10. DOI: <https://doi.org/10.34293/education.v8i4.3232>.

Home, A. (2002) 'Challenging Hidden Oppression: Mothers Caring for Children with Disabilities', *Critical Social Work*, 3(1), (n.p.), Accessed at: <http://www1.uwindsor.ca/criticalsocialwork/challenging-hidden-oppression-mothers-caring-for-children-withdisabilities>, on 07/09/2013..

Honey-Arcement, R. R. (2016) 'Immigrant parents of children with disabilities and their perceptions of their access to services and the quality of services received', MA (Master of Arts) thesis, University of Iowa, <http://ir.uiowa.edu/etd/3103>.

hooks, b. (2015) *Ain't I a Woman: Black Women and Feminism*, New York, Routledge.

Hope, T., and Oppenheimer, C. (1997) 'Ethics and the Psychiatry of Old Age', in Jacoby, R., and Oppenheimer, C. (eds) *Psychiatry in the Elderly*, Oxford, Oxford University Press, pp. 709-735.

Horevitz, E., Lawson, J., and Chow, J. C. (2013) 'Examining Cultural Competence in Health Care: Implications for Social Workers', *Health and Social Work*, 38(3): 135-145.

Hough, J. (2010) '23,000 on waiting list for speech therapy', *Irish Examiner*, May 3rd, 2010.

Houses of the Oireachtas (2017) Joint Committee on Children and Youth Affairs: Report on the Working Conditions of the Early Years Education and Care Sector 2017, Accessed at: [https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint\\_committee\\_on\\_children\\_and\\_youth\\_affairs/reports/2017/2017-07-26\\_report-on-the-working-conditions-of-the-early-years-education-and-care-sector-2017\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_children_and_youth_affairs/reports/2017/2017-07-26_report-on-the-working-conditions-of-the-early-years-education-and-care-sector-2017_en.pdf), on 29/08/20.

HSE's Primary Care, Disability, Child and Adolescent Health Joint Working Protocol (2017) Accessed at: <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/>, on 11/09/22.

Humphrey, G. M., and Zimpfer, D. G. (2008) *Counselling for Grief and Bereavement*, 2nd ed., London, Sage.

Hurdle, D. E. (2002) 'Native Hawaiian Traditional Healing: Culturally Interventions for Social Work Practice', *Social Work*, 47(2), 183-192.

Hyman, H. (1972) *Secondary Analysis of Sample Data*, New York, John Wiley, in Rady, M. (2010) 'Secondary Data Analysis Studies', in Thyer, B. (ed) *The Handbook of Social Work Research Methods*, 2nd ed., London, Sage, pp. 163-182.

IASLT (Irish Association of Speech and Language Therapists) (2017) 'Supporting Children with Developmental Language Disorder in Ireland', IASLT Position Paper and Guidance Document, Accessed at <https://www.iaslt.ie/documents/public-information/Childhood%20Speech%20and%20Language/DLD%20Position%20Paper%20FINAL%2023MAY2017.pdf>, on 29/10/20.

IASW (Irish Association of Social Workers) (2007) *IASW Code of Ethics*, Available at: <https://www.iasw.ie/attachments/8b37e75a-26f6-4d94-9313-f61a86785414.PDF>, Accessed on 13/08/17.

Ibrahim, F. A. (1991) 'Contribution of cultural worldview to generic counseling and development', *Journal of Counseling and Development*, 70, 13–19.

Immigrant Council of Ireland (ICI) (2016) 'Code of Ethics for An Garda Síochána', Submission to The Policing Authority, Dublin.

Inglis, T. (2008) *Global Ireland, Same Difference*, New York, Taylor and Francis.

Inglis, T. (1998) *Moral Monopoly: The Rise and Fall of the Catholic Church in Modern Ireland*, Dublin, University College Dublin.

Ingstad, B. (1988) 'Coping behaviour of disabled persons and their families: Cross cultural perspectives from Norway and Botswana', *International journal of Rehabilitation Research*, 11, 351-359.

International Federation of Social Workers (IFSW) (2014) Global definition of social work, retrieved 20/12/2016, from <http://ifsw.org/policies/definition-of-social-work/>.

Irish Human Rights Commission (IHRIC) (2010) *Submission to the UN CERD Committee on the Examination of Ireland's Combined Third and Fourth Periodic Reports*, Irish Human Rights Commission, Dublin.

Iwama, M. (2007) 'Culture and occupational therapy: Meeting the challenge of relevance in a global world', *Occupational Therapy International*, 14, 183–187.

Jarrett, C. F., Mayes, R., Llewellyn, G. (2014) 'The impact of disablism on the psycho-emotional well-being of families with a child with impairment', *Scandinavian Journal of Disability Research*, 16(3), 195–210, <http://dx.doi.org/10.1080/15017419.2013.865671>.

Jayaweera, H., and Quigley, M.A. (2010) 'Health status, health behaviour and healthcare use among migrants in the UK: evidence from mothers in the Millennium Cohort Study', *Social Science and Medicine*, 71 (5), 1002–1010.

Jegatheesan, B. (2010) 'Cross-cultural issues in parent-professional interactions: A Qualitative study of perceptions of Asian American families of children with developmental disabilities', *Research and Practice for Persons with Severe Disabilities*, 34, 123-136.

Jennings, S., Khanlou, N., and Su, C. (2014) 'Public health policy and social support for immigrant mothers raising disabled children in Canada', *Disability and Society*, 29 (10), 1645-1657, DOI: 10.1080/09687599.2014.966804.

Jewell, P. and Blackmore, P. (2004) *From Strength to Strength: A Manual for Professionals Who Facilitate Diverse Parent Groups*, Australian Council for Educational Research, Acer Press.

Jezewski, M. A. (1995) "Evolution of a Grounded Theory: Conflict Resolution through Culture Brokering", *Advances in Nursing Science*, 17(3), 14–30, doi:10.1097/00012272- 199503000-00004.

Jezewski, M. A., and Sotnik, P. (2001) *The Rehabilitation Service Provider as Culture Broker: Providing Culturally Competent Services to Foreign Born Persons*, Buffalo, NY, Center for International Rehabilitation Research Information and Exchange.

Jiménez-Castellanos, O., and García, E. (2017) 'Intersection of language, class, ethnicity, and policy: Toward disrupting inequality for English language learners', *Review of Research in Education*, 41(1), 428–452.

Johnson, Y. M. and Munch, S. (2009) 'Fundamental contradictions in cultural competence', *Social Work*, 54(3), 220-231.

Joppke, C. (2007) 'Beyond National Models: Civic Integration Policies for Immigrants in Western Europe', *West European Politics*, 30(1), 1-22.

Joseph, Y (May 5, 2017) 'In Their Own Words: Marine Le Pen and Emmanuel Macron, Accessed at <https://www.nytimes.com/2017/05/05/world/europe/emmanuel-macron-marine-le-pen-quotes.html>, on 20/05/18.

Joyce, C. (2010) *European Migration Network Annual Policy Report on Migration and Asylum 2009*, Ireland, The Economic and Social Research Institute and European Migration Network, Dublin. <http://tinyurl.com/7lhdfgr>, Accessed on 27/01/12.

Kediye, F., Valeo, A., and Berman, R. C. (2009) 'Somali-Canadian Mothers' Experiences in parenting a child with Autism Spectrum Disorder', *Journal for The Association of Research on Mothering*, 11 (1), 211-223.

Kelley, S. D., and Lambert, S. S. (1992) 'Family support in rehabilitation: A review of research 1980- 1990', *Rehabilitation Counselling Bulletin*, 36, 98-119.

Khanlou, N., Haque, N., Mustafal, N., Vazquez, L. Mantini, A. and Weiss, J. (2017) 'Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada', *International Journal of Mental Health Addiction*, 15, 239–25.

Khanlou, N., Mustafal, N., Vazquez1, L., Haque, N. and Yoshida, K. (2015) 'Stressors and Barriers to Services for Immigrant Fathers Raising Children with Developmental Disabilities', *International Journal of Mental Health Addiction*, 13, 659–674.

Khanlou N., Haque N., Sheehan S., and Jones, G. (2015) “It is an issue of not knowing where to go”: service providers’ perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities, *Journal of Immigr Minor Health*, 17(6), 1840–7.

Kiernan, C. (1999) ‘Participation in research by people with learning disability: origins and issues’, *British Journal of Learning Disabilities*, 27, 43–47.

King, G. A., Esses, V. M. and Solomon, N. (2013) ‘Immigrant And Refugee Families Raising Children With Disabling Conditions: A Review Of The International Literature On Service Access, Service Utilisation And Service Care Experiences’, In Grigorenko, E. L (ed) *U.S Immigration and Education: Cultural And Policy Issues Across The Lifespan*, New York, Springer, 179-206.

King, G., Lindsay, S., Klassen, A., Esses, V. and Mesterman, R. (2011) ‘Barriers to health service utilization by immigrant families raising a disabled child: Unmet needs and the role of discrimination’, Report prepared for Citizenship and Immigration Canada, <https://www.amssa.org/wp-content/uploads/2016/01/families-with-disabled-child-final-report1.pdf>.

Kingston, A. K. (2007) *Mothering Special Needs: A Different Maternal Journey*, London and Philadelphia, Jessica Kingsley Publishers.

Kingsley, K., and Mailloux, Z. (2013) ‘Evidence for the Effectiveness of Different Service Delivery Models in Early Intervention Services’, *The American Journal of Occupational Therapy*, 67 (4), 431-436.

Klawetter, S. (2016) *MSW students’ experiences and understanding of social location: The development of a positionality measure*, Paper presented at the Society for Social Work and Research 20<sup>th</sup> Annual Conference - Grand Challenges for Social Work: Setting a Research Agenda for the Future, Abstract retrieved from <https://sswr.confex.com/sswr/2016/webprogram/Paper25933.html>.

Kleinman, A. and Benson, P. (2006) ‘Anthropology in the clinic: The problem of cultural competence and how to fix it’, *PLoS Medicine*, 3(10), pp. 1673 – 6.

Koegel, R. L., Schreibman, L., O'Neill, R. E. and Burke, J. C. (1983) 'The personality and family characteristics of parents of autistic children', *Journal of Consulting and Clinical Psychology*, 51,683-692.

Kohli, H. K., Huber, R. and Faul, A. C. (2010) 'Historical and Theoretical Development of Culturally Competent Social Work Practice', *Journal of Teaching in Social Work*, 30(3), 252-271, DOI: 10.1080/08841233.2010.499091.

Kumaş-Tan, Z., Beagan, B., Loppie, C., MacLeod, A., and Frank, B. (2007) 'Measures of cultural competence: Examining hidden assumptions', *Academic Medicine*, 82(6), 548-557.

Ladson-Billings, G., and Tate, W. F. (1995) 'Toward a critical race theory of education', *Teachers College Record*, 97, 47-68.

Laird, S. E. (2008) *Anti-Oppressive Social Work: A Guide for Developing Cultural Competence*, London, SAGE.

Landsman, G. (2005) "Mothers and Models of Disability", *Journal of Medical Humanities*, 26, 121–141, doi:10.1007/s10912-005-2914-2.

Lappegard, T. (2014) 'Changing European Families', In Treas, J., Scott, J., and Richards, M. (eds) (2014) *The Wiley Blackwell Companion to the Sociology of Families*, UK, John Wiley and Sons Ltd, pp. 20-42.

Larkin, H. and Moore, T. (2005) 'More than my child's disability...' SCOPE, available online at: <http://hdl.handle.net/10536/DRO/DU:30010364>, Accessed on 01/06/17.

Lay, K., and McGuire, L. (2010) 'Building a lens for critical reflection and reflexivity in social work education', *Social Work Education: The International Journal*, 29(5), 539–550.

Lazarevic, V. (2017) "Effects of Cultural Brokering on Individual Wellbeing and Family Dynamics among Immigrant Youth", *Journal of Adolescence*, 55, 77–87, doi:10.1016/j.adolescence.2016.12.010.

Leahy-Warren, D., McCarthy, G. and Corcoran, P. (2011) "Postnatal Depression in First Time Mothers: Prevalence and Relationships between Functional and Structural Social Support at 6 and 12 Weeks Post Partum", *Archives in Psychiatric Nursing*, 25 (3), 174–184.

LeCompte, M. D., Preissle, J., and Tesch, R. (1993) *Ethnography and Qualitative Design in Educational Research*, 2nd edition, Chicago, Academic Press.

Lee, R. and Zhu, Y. (2020) ‘Diagnosis as a sociocultural practice: critical personal narratives of Asian immigrant mothers with Autism-Spectrum Disorder children in Canada’, *Disability and Society*, DOI: 10.1080/09687599.2020.1804326.

Lehane, M. (2022) ‘Lack of school places for children with special needs raised in Dáil’, *RTE*, June 23<sup>rd</sup> 2022, Accessed at: <https://www.rte.ie/news/ireland/2022/0623/1306479-special-needs-school-places/>, on 15/10/22.

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., Suárez-Orozco, C. (2018) ‘Journal Article Reporting Standards for Qualitative Primary, Qualitative Meta-Analytic, and Mixed Methods Research in Psychology: The APA Publications and Communications Board Task Force Report’, *American Psychological Association*, 73 (1), 26-46, <http://dx.doi.org/10.1037/amp0000151>, Accessed on 04/04/22.

Liasidou, A. (2013) ‘Intersectional understandings of disability and implications for a social justice reform agenda in education policy and practice’, *Disability and Society*, 28 (3), 299-312, DOI: 10.1080/09687599.2012.710012.

Lindsay, S., Tétreault, S., Desmarais, C., King, G. A., and Piérart, G. (2014b) ‘Social workers as “cultural brokers” in providing culturally sensitive care to immigrant families raising a child with a physical disability’, *Health and Social Work*, 39(2), 10–20.

Lindsay, S., Tétreault, S., Desmarais, C., King, G. A., and Piérart, G. (2014a.) “Social Workers as “Cultural Brokers” in Providing Culturally Sensitive Care to Immigrant Families Raising a Child with a Physical Disability”, *Health and Social Work*, 39(2), E10–E20, doi:10.1093/hsw/hlu009.

Lindsay, S., Tétrault, S., Desmaris, C., King, G. and Piérart, G (2014) ‘Social Workers as “Cultural Brokers” in Providing Culturally Sensitive Care to Immigrant Families Raising a Child with a Physical Disability’, *Health and Social Work*, 39 (2), e10-e20.

Lindsay, S., King, G., Klassen, A. F., Esses, V., and Stachel, M. (2012) ‘Working with immigrant families raising a child with a disability: challenges and recommendations for

healthcare and community service providers’, *Disability and Rehabilitation*, Early Online, 1-11.

Lo, M. C. M. (2010) ‘Cultural brokerage: Creating linkages between voices of lifeworld and medicine in crosscultural clinical settings’, *Health*, 14, 484–504.

Lo, M. C. M., Stacey, C. L. (2008) ‘Beyond Cultural Competency: Bourdieu, Patients and Clinical Encounters’, *Sociology of Health and Illness*, 30(5), 741–755.

Logan, S. (2012) ‘Cultural Competence and Ethnic Sensitive Practice’, *Oxford Bibliographies Online, Social Work*.

Lonergan, K. R. (2009) ‘Ireland, Immigration and social change in contemporary society: An assessment of the process of integration and the ‘recognition’ of ethnic minorities’, *Critical Social Thinking: Policy and Practice*, Vol. 1, Dept. of Applied Social Studies, University College Cork, 333-344.

Luft, R. E., and Ward, J. (2009) ‘Toward an intersectionality just out of reach: Confronting challenges to intersectional practice’, In Demos, V., and Segal, M. T. (Eds.), *Perceiving gender locally, globally, and intersectionally*, Bingley, UK: Emerald Group, pp. 9–37, doi:10.1108/S1529-2126(2009)0000013005.

Lum, D. (2011) *Culturally competent practice: A framework for understanding diverse groups and justice issues*, 4th ed., Belmont, CA, Brooks/Cole.

Lund, D. E., and Lee, L. (2015) ‘Fostering cultural humility among pre-service teachers: Connecting with children and youth of immigrant families through service-learning’, *Canadian Journal of Education*, 38, 1–30, Retrieved from <http://www.cje-rce.ca/index.php/cje-rce/article/view/1744/1756>, on 12/04/2019.

Maatta, T. (2017) ‘Broadening Social work’s framework on place and belonging: An investigation into Identity Processes Intersected by Experiences of Migration’, *British Journal of Social Work*, 0, 1-17.

Mac Éinrí, P. (2007) ‘Integration models and choices’, In Fanning, B. (ed.) *Immigration and Social Change in the Republic of Ireland*, Manchester, Manchester University Press.

Mackey, S., and Goddard, L. D. (2006) ‘The Experience of Health and Wellness in Mothers of Young Children with Intellectual Disabilities’, *Journal of Intellectual Disabilities*, 10, 305-315.

Magnusson, D.M., and Mistry K. B. (2017) 'Racial and ethnic disparities in unmet need for pediatric therapy services: the role of family-centred care, *Acad Pediatr*, 17(1), 27–33.

Maloni, P.K., Despres, E.R., Habbous, J., Primmer, A.R., Slatten, J.B., Gibson, B.E., Landry, M.D. (2010) 'Perceptions of disability among mothers of children with disabilities (CWD) in Bangladesh: implications for rehabilitation service delivery', *Disabil Rehabil*, 32, 845–854.

Mancoske, R. J., Lewis, M. L., Bowers-Stephens, C., and Ford, A. (2012) 'Cultural competence and children's mental health service outcomes', *Journal of Ethnic and Cultural Diversity in Social Work*, 21(3), 195-211.

Mandell, D., & Novak, M. (2005) 'The role of culture in families' treatment decisions for children with autism spectrum disorders', *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110-115.

Marshall, J., Adelman, A., Kesten, S., Natale, R., Elbaum, B. (2017) 'Parents' Experiences Navigating Intervention Systems for Young Children with Mild Language Delays', *Journal of Early Intervention*, 39 (3), 180-198.

May Institute (2010) 'Developmental disabilities QandA', Accessed at [https://www.mayinstitute.org/pdfs/developmental\\_disabilities\\_fact\\_sheet.pdf](https://www.mayinstitute.org/pdfs/developmental_disabilities_fact_sheet.pdf), on 20/02/22.

McCall, L. (2005) 'The complexity of intersectionality', *Signs*, 30, 1771–1800, doi:10.1086/426800.

McCallion, P., and Janicki, M. (1997) 'Exploring the impact of culture and acculturation on older families caregiving for persons with developmental disabilities' *Family Relations*, 46, 347–357.

McGinnity, F., Enright, S., Quinn, E., Maître, B., Privalko, I., Darmody, M., Polakowski, M. (2020) 'MONITORING REPORT ON INTEGRATION', Funded by the Department of Children, Equality, Disability, Integration and Youth in line with the Migrant Integration Strategy 2017-2020.

McGinnity, F., Privalko, I., Fahey, E., Enright, S., and O'Brien, D. (2020) 'Origin and Integration: a study of migrants in the 2016 Irish Census', ESRI (Economic and Social Research Institute), Dublin, Accessed at <https://www.esri.ie/sites/default/files/media/file-uploads/2020->

[06/SLIDES\\_Origin%20and%20integration%20A%20study%20of%20migrants%20in%20the%202016%20Irish%20Census\\_MCGINNITY.pdf](#), on 13/09/22.

McGregor, C., Dalikeni, C., Devaney, C., Moran, L., Garrity, S. (2019) 'Practice guidance for culturally sensitive practice in working with children and families who are asylum seekers: learning from an early years study in Ireland, *Child Care in Practice*, 1-14, doi: 10.1080/13575279.2018.1555137.

McInerney, S. (June 13, 2009) 'Pay foreigners to leave, says TD', *The Sunday Times*, Accessed at: <https://www.thetimes.co.uk/article/pay-foreigners-to-leave-says-td-0gxzh77dz5m>, on 28/10/18.

McKeever, P., and Miller, K.-L. (2004) 'Mothering Children Who Have Disabilities: A Bourdieusian Interpretation of Maternal Practices', *Social Science and Medicine*, 59 (6), 1177–1191, doi:10.1016/j.socscimed.2003.12.023.

McKeown, K. (2001) *fathers and families: research and reflection on key questions*, Kieran McKeown Limited, Social & Economic Research Consultants, Dublin.

McPhatter, A. (1997) 'Cultural competence in child welfare: What is it? How do we achieve it? What happens without it?', *Child Welfare*, 76, 255–278.

Mehrotra, G. (2010) 'Toward a continuum of intersectionality theorizing for feminist social work scholarship', *Affilia*, 25, 417–430, doi:10.1177/0886109910384190.

Meichenbaum, D., and Fitzpatrick, D. (1993) 'A constructivist narrative perspective on stress and coping: Stress inoculation applications', In L. Goldberger, and S. Breznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects* (2nd ed.), New York, The Free Press, pp. 706–723.

Merton, R. K. (1972) 'Insiders and Outsiders: A Chapter in the Sociology of Knowledge', *American Journal of Sociology*, 78 (1), 9-47.

Michaelsen, J. J., Krasnik, A., Nielsen, A. S., Norredam, M., Torres, A.M. (2004) 'Health professionals' knowledge, attitudes, and experiences in relation to immigrant patients: a questionnaire study at a Danish hospital', *Scand J Public Health*, 32(4), 287–95.

Middleton, L. (1999) *Disabled Children: challenging social exclusion*, Oxford, Blackwell.

Miehls, D., and Moffat, K. (2000) 'Constructing social work identity based on the reflexive self', *British Journal of Social Work*, 30, 339–348.

Migrant Rights Centre Ireland (2010) 'Racism and Migrant Workers In Ireland', Policy paper, Migrant Rights Centre Ireland, [www.mrci.ie](http://www.mrci.ie).

Miles, M.B. and Huberman, A. M. (1984) *Qualitative Data Analysis: A Sourcebook of New Methods*, Thousand Oaks, CA, Sage publications.

Minda, G. (1995) *Postmodern legal movements. Law and jurisprudence at century's end* New York, University Press.

Minervino, S. and Martin, M. C. (2007) 'Cultural Competence and Cultural Mediation: Diversity Strategies and Practices in Health Care', *The Irish Migration, Race and Social Transformation Review*, 2(1), 190-198, <http://www.translocations.ie>.

Miodrag, N., and Hodapp, R. M. (2010) 'Chronic stress and health among parents of children with intellectual and developmental disabilities', *Current Opinions in Psychiatry*, 23, 407-411.

Mitchell, A. M., Gale, D.D, Matzo, M. L., McDonald, M. C., Gadmer, N. (2002) 'Critique of transcultural practices in end-of-life clinical nursing practice', *Nurs Forum*, 37(4), 24-31.

MMHA (Multicultural Mental Health Australia, National Ethnic Disability Alliance, and Australian Mental Health Consumer Network) (2004) 'Reality check: Culturally diverse mental health consumers speak out', Parramatta, National Ethnic Disability Alliance.

Mohammad, R. (2001) 'Insiders and/or Outsiders: Positionality, Theory and Praxis', In Melanie, L. and Dwyre, C. (eds) (2001) *Qualitative Methods for Geographers: Issues and Debates*, Oxford University Press, pp. 101-117.

Moloney, C., de Bhailís, C., Kennan, D., Kealy, C., Quinlivan, S., Flynn, E., and Phiri, J. (2021) *Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland*, Centre for Disability Law and Policy, NUI Galway, Research commissioned by the Ombudsman for Children's Office, Dublin 1.

Moncho, C. (2013) 'Cultural humility, Part I-What is 'Cultural humility'?', *The social work practitioner*, Accessed at <https://thesocialworkpractitioner.com/2013/08/19/cultural-humility-part-i-what-is-cultural-humility/>, on 27/10/17.

Moriarty, H. J., Deatrick, J. A., Mahon, M. M., Feetham, S. L., Carroll, R. M., and Shepard, M.P. (1999) 'Issues To Consider When Choosing And Using Large National Databases For Research On Families', *Western Journal of Nursing Research*, 21, 143-153.

Morris, J. (1991) *Pride Against Prejudice: transforming attitudes to disability*, London, Women's Press.

Moses, K. (1988) *Lost Dreams and Growth: Parents' Concerns [A video recording]*, Evanston, IL, Resource Network, Inc.

Munroe, K., Hammond, L. and Cole, S. (2016) 'The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis', *Disability and Society*, 31(6), 798-819, DOI: 10.1080/09687599.2016.1200015.

Murphy, R. (1990) *The body silent*, New York, Norton Press.

Murray, P. (2000) 'Disabled children, parents and professionals: Partnership on whose terms?', *Disability and Society*, 15 (4), 683–98.

Muntinga, M., Krajenbrink, V., Peerdeman, S., Croiset, G. and Verdonk, P. (2016) 'Toward diversity-responsive medical education: Taking an intersectionality-based approach to a curriculum evaluation', *Advances in Health Science Education*, 21(3), 541–559, doi: 10.1007/s10459-015-9650-9.

Naaeke, A., Kurylo, A., Grabowski, M., Linton, D., and Radford, M. L. (2012) 'Insider and Outsider Perspective in Ethnographic Research', *Proceedings of the New York State Communication Association*, 2010(9), Available at: <https://docs.rwu.edu/nyscaproceedings/vol2010/iss1/9>.

Nadan, Y. (2014) 'Rethinking 'cultural competence' in international social work', *International Social Work*, 60(1), DOI: 10.1177/0020872814539986.

Nakano Glenn, E. (1999) 'The social construction and institutionalization of gender and race: An integrative framework', In Feree, M. M., Lorber, J. and Hess, B. B. (Eds.) *Revisioning gender*, Thousand Oaks, CA: Sage, pp. 3–43.

Narayanasamy, A. (1999a) 'Transcultural mental health nursing 1: Benefits and limitations', *Br J Nurs*, 8(10), 664–8.

Narayanasamy, A. (1999b) 'Transcultural mental health nursing 2: Race, ethnicity and culture', *Br J Nurs*, 8(11), 741–4.

Narayanasamy, A., White, E. (2005) 'A review of transcultural nursing', *Nurs Educ Today*, 25(2), 102–11.

Nash, J. C. (2008) 'Re-thinking intersectionality', *Feminist Review*, 89(1), 1–15, <https://doi.org/10.1057/fr.2008.4>.

National Association of Social Workers (NASW, 2015) 'Standards and indicators for cultural competence in social work practice', Washington, DC. Retrieved from <http://www.socialworkers.org/practice/standards/PRA-BRO-253150-CC-Standards.pdf>, on 11/05/2017.

National Center for Cultural Competence (2011) "Promising Practice: Cultural Brokers Help Families and Providers Bridge the Cultural Divide", Accessed at [https://nccc.georgetown.edu/documents/NCCC\\_PP\\_Cultural%20Brokers.pdf](https://nccc.georgetown.edu/documents/NCCC_PP_Cultural%20Brokers.pdf), on 22/11/19.

National Center for Cultural Competence (2004) *Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programs*, Washington D.C., Georgetown University Center for Child and Human Development, Georgetown University Medical Center.

National Consultative Committee on Racism and Interculturalism and Irish Health Services Management Institute (2002) *Cultural diversity in the Irish Health Care Sector: Towards the Development of Policy and Practice Guidelines for Organisations in the Health Sector*, National Consultative Committee on Racism and Interculturalism; Irish Health Services Management Institute, Dublin.

National Disability Authority (NDA) (2017), National Survey of Public Attitudes to Disability in Ireland, Behaviour and Attitudes and the National Disability Authority.

NDA (2019) National Disability Authority 2000-2020: Twenty Years of Disability Policy Development in Ireland, Accessed at: <https://nda.ie/publications/20-years-of-disability-policy>, on 14/11/22.

National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (2007) 'Informing Families of their child's disability: National Best Practice Guidelines', Oranmore, Co. Galway, Accessed at [http://www.informingfamilies.ie/\\_fileupload/Informing\\_Families\\_Guidelines.pdf](http://www.informingfamilies.ie/_fileupload/Informing_Families_Guidelines.pdf), on 30/07/20.

National Health and Medical Research Council (NHMRC) (2006) *Cultural Competency in Health: A Guide for Policy, Partnerships and Participation*, Canberra, Commonwealth of Australia.

Neely-Barnes, S., Graff, C., Roberts, R., Hall, H., and Hankins, J. (2010) “‘It’s Our Job’: Qualitative Study of Family Responses to Ableism”, *Intellectual and Developmental Disabilities*, 48, 245–258, Doi:10.1352/1934-9556-48.4.245.

Neuman, W. L. (2006) *Basic of social research: Quantitative and qualitative approaches*, 2nd ed., Boston, Allyn and Bacon.

Newman, D.M. and Grauerholz, L. (2002) *Sociology of families*, 2<sup>nd</sup> ed., USA, Pine Forge Press.

Ngadaonye, D. A. (2012) ‘Migrants’ Integration Experience In Ireland’, Submitted in partial fulfillment of the requirements of the Bachelor of Arts degree (Social Science Specialization) at DBS School of Arts, Dublin.

Njala, J.C. (2011) African Parenting: The Sane Way to Raise Children, Accessed at <https://www.incultureparent.com/african-parenting-the-sane-way-to-raise-children/>, on 13/12/20.

Ní Chonail, B. (2009) ‘Perceptions of Migrants and their Impact on the Blanchardstown area: Local Views’, A report funded by the Irish Research Council in Humanities and Social Science.

Norbury, C. F., and Sparks, A. (2013) ‘Difference or Disorder? Cultural Issues in Understanding Neurodevelopmental Disorders’, *Developmental Psychology*, 49 (1), 45–58, doi:10.1037/a0027446.

O'Brien, C. (2022) ‘Special needs children bussed out of their communities due to shortage of school places: Oireachtas committee hears of long waiting lists for access to vital supports such as speech and language or occupational therapy’, *Irish Times*, October 4<sup>th</sup> 2022, Accessed at: <https://www.irishtimes.com/ireland/education/2022/10/04/special-needs-children-bussed-out-of-their-communities-due-to-shortage-of-school-places/>, on 15/10/22.

O'Brien, C. (2022) Up to 80 children with special needs in Dublin without school places: Taoiseach apologises to family without appropriate education for seven years, *Irish Times*, May 18<sup>th</sup> 2022, Accessed at: <https://www.irishtimes.com/news/education/up-to-80-children-with-special-needs-in-dublin-without-school-places-1.4882174>, on 15/10/22.

O'Brien, C. (2014) 'Thousands of children with disabilities waiting years for supports', *Irish Times*, February 7th, 2014.

O'Connor, A. and Ciribuco, A. (2017) 'Language and Migration in Ireland', Immigrant Council of Ireland (ICI), Dublin.

O'Donnell, P., Tierney, E., O'Carroll, A., Nurse, D., and MacFarlane, A. (2016) 'Exploring Levers and Barriers to Accessing Primary Care for Marginalised Groups and Identifying Their Priorities for Primary Care Provision: A Participatory Learning and Action Research Study', *International Journal for Equity in Health*, 15 (197), 1- 16.

OECD (2018a) 'Settling In 2018: Indicators of Immigrant Integration, Paris', OECD Publishing, doi.org/10.1787/9789264307216-en

Office of Minority Health (2001) 'National Standards for Culturally and Linguistically Appropriate Services in Health Care: Final Report, US Department of Health and Human Services', Washington, DC, available online at <https://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf>, Accessed on 10/07/17.

O'Hagan, K. (2001) *Cultural competence in the Caring Professions*, London, Jessica Kingsley Publishers.

OHCHR (Office of the High Commissioner for Human Rights) 1996-2023, 'International standards governing migration policy: OHCHR and migration', accessed at: <https://www.ohchr.org/en/migration/international-standards-governing-migration-policy> , on 09/06/23.

Okitikpi, T. and Aymer, C (2010) *Key Concepts in Anti-Discriminatory Practice*, London, Sage.

Oliver, M. (2004) 'The Social Model in Action: if I had a hammer', In Barnes, C. and Mercer, G. (eds) (2004) *Implementing the Social Model of Disability: Theory and Research*, Leeds, The Disability Press, pp. 18-31.

Oliver, M. (1990) *The Politics of Disablement*, Basingstoke, Macmillan.

Oliver, M. (2009) *Understanding Disability: from theory to practice*, 2<sup>nd</sup> ed., Basingstoke, Macmillan.

Oliver, M., and Campbell, J. (2013) *Disability Politics: Understanding Our Past, Changing Our Future*, London and New York, Routledge.

Oliver, M. and Sapey, B. (1999) *Social Work with Disabled People*, 2nd ed., London, Macmillan.

Ombudsman for Children's Office (2020) *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs*, Dublin.

Onwuegbu, O. L. (1977) *The Nigerian Culture: Its Perceptions And Treatment Of Learners With Disabilities*, Oyo, Nigeria, Federal Advanced Teachers College.

O'Reilly, H. N. (2020) 'Intersectionality and Cultural Competence: A Quick Introduction', Accessed at: <https://www.health.mil/Military-Health-Topics/Centers-of-Excellence/Psychological-Health-Center-of-Excellence/Clinicians-Corner-Blog/Intersectionality-and-Cultural-Competence-A-Quick-Introduction>, on 14/10/22.

Ortega, R. M., and Faller, K. C. (2011) 'Training child welfare workers from an intersectional cultural humility perspective: A paradigm shift', *Child Welfare*, 90, 27–49. Retrieved from [http://www.academia.edu/14128356/Cultural\\_Humility\\_for\\_Child\\_Welfare\\_Professionals\\_A\\_Paradigm\\_Shift](http://www.academia.edu/14128356/Cultural_Humility_for_Child_Welfare_Professionals_A_Paradigm_Shift) on 24/12/2018.

Pacheco, E. R., Plaza, S. H., Fernandez-Ramirez, B. and Andre's, P. C. (2003) 'The implications of immigration for the training of social work professionals in Spain', *British Journal of Social Work*, 33 (1), 49–65.

Padgett, D. K. (2008) *Qualitative Methods in Social work Research*, 2<sup>nd</sup> ed., California, Sage.

Paquette, D. (2004) 'Theorizing the Father/Child Relationship: Mechanisms and Development Outcomes', *Human Development*, 47 (193–219), doi:10.1159/000078723.

Pang, Y., Dinora, P. and Yarbrough, D. (2020) 'The gap between theory and practice: using cultural brokering to serve culturally diverse families of children with disabilities', *Disability and Society*, 35 (3), 366–388, DOI: 10.1080/09687599.2019.1647147.

Paradies, Y. (2006) 'A systematic review of empirical research on self-reported racism and health', *International Journal of Epidemiology*, 35, 888 –901.

Parrott, L. (2009) 'Constructive Marginality: Conflicts and Dilemmas in Cultural Competence and Anti-Oppressive Practice', *Social Work Education*, 28(6), 617 –30.

Patton, M.Q. (1990) *Qualitative Evaluation and Research Methods*, 2nd ed., Newbury Park CA, Sage Publications.

Payne, G., and Payne, J. (2004) *Key concepts in social research*, London, Sage.

Pease, B. (2010) *Undoing privilege: Unearned advantage in a divided world*, London, UK, Zed Books.

Pelchat, D., Lefebvre, H., and Levert, M. J. (2007) "Gender Differences and Similarities in the Experience of Parenting a Child with a Health Problem: Current State of Knowledge", *Journal of Child Health*, 11(2), 112–131,

Petriwskyj, A., Adkins, B. and Franz, J. (2017) 'Parent, carer, person: future plans and the identities of parent carers for people with disabilities', *Disability and Society*, 32 (1), 93-109, DOI: 10.1080/09687599.2016.1269640.

Pfeiffer, D. (1993) 'Overview of the disability movement: History, legislative record and political implications', *Policy Studies Journal*, 21(4), 724-734.

Pierce, M. (2003) 'Minority Ethnic People with Disabilities in Ireland: Situation, Identity and Experience', Department of Social Policy and Social Work, University College Dublin in conjunction with the Institute for the Study of Social Change, *Equality Research Series*, the Equality Authority.

Pinderhughes, E. (1989) *Understanding race, ethnicity, and power: The key to efficacy*, New York, Free Press.

Pon, G. (2009) 'Cultural Competency as New Racism: An Ontology of Forgetting', *Journal of Progressive Human Services*, 20(1), pp. 59 – 71.

Ponde, M. P., and Rousseau, C. (2013) 'Immigrant Children with Autism-Spectrum-Disorder: The Relationship between the Perspective of the Professionals and the Parents' Point of View', *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 22 (2), 131–138.

Pooremamali, P., Östman, M., Persson, D., and Eklund, M. (2011) 'An occupational therapy approach to the support of a young immigrant female's mental health: A story of bicultural personal growth', *International Journal of Qualitative Studies on Health and Well-being*, 6(3). <http://dx.doi.org/10.3402/qhw.v6i3.7084>.

- Powell, D. (2016) 'Social determinants of health: Cultural competence is not enough', *Creative Nursing*, 22(1), 5-10, doi:10.1891/1078-4535.22.1.5.
- Prasad, S., Nair, P., Gadhvi, K., Barai, I., Danish, H. & Philip, A. (2016) 'Cultural humility: Treating the patient, not the illness', *Med Educ Online*, 21, doi:10.3402/meo.v21.30908.
- Prins, B. (2006) 'Narrative accounts of origins: A blind spot in the intersectional approach?', *European Journal of Women's Studies*, 13, 277–290, doi:10.1177/1350506806065757.
- Puckett, T. (2020) 'The importance of Developing Cultural Competence', in Puckett, T., and Lind, N. S. (eds) *Cultural Competence In Higher Education*, UK, Emerald Publishing LTD, pp. 7-22.
- Punch K. F. (2005) *Introduction to Social Research: Quantitative and Qualitative Approaches*, 2nd ed., Thousand Oak, California: Sage.
- Quin, S. and Redmond, B. (2003) *Disability and Social Policy in Ireland*, UCD Press.
- Qureshi, A. and Collazos, F. (2005) 'Cultural competence in the mental health treatment of immigrant and ethnic minority clients', *Diversity in Health and Social Care*, 2, 307–17.
- Qureshi, B. (2004) 'Transcultural health care: What a rehabilitation professional needs to know', *International Journal of Therapy and Rehabilitation*, 11, 198.
- Rady, M. (2010) 'Secondary Data Analysis Studies', in Thyer, B. (ed) *The Handbook of Social Work Research Methods*, 2nd ed., London, Sage.
- Ralaheen Ltd (1999) *Working Paper on Information Provision at Local Level: Developing an Integrated Approach*, Dublin, National Social Service Board.
- Ravindran, N, and Myers, B. J. (2012) 'Cultural Influences on Perception of Health, Illness, and Disability: A Review and Focus on Autism', *Journal of Child Family Studies*, 21(2), 311-9.
- Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', *Disability and Society*, 17(5), 493-508.
- Reid, C. (2004) "Advancing Women's Social Justice Agenda's: A Feminist Action Research Framework", *International Journal of Qualitative Methods*, 3 (3), 1–22.

- Rhodes, C. and Scheeres, H. (2004) 'Developing people in organizations: working (on) identity', *Studies in Continuing Education*, 26 (2), 175-193.
- Rief, S.F. (2005) *How to Teach Children with ADD/ADHD: Practical Techniques, Strategies and Interventions*, 2<sup>nd</sup> Ed., San Francisco, Jossey-Bass.
- Ripat, J., and Woodgate, R. (2011) 'The intersection of culture, disability and assistive technology', *Disability and Rehabilitation: Assistive Technology*, 6, 87–96.
- Ritchie, J. and Lewis J. (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, London, Sage.
- Ritche, J., Lewis, J. and Elam, G. (2003) 'Designing and Selecting Samples', In Ritchie, J. and Lewis J.(eds) (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, London, Sage, pp. 77-108.
- Roberts, D., and Jesudason, S. (2013) 'Movement intersectionality: The case of race, gender, disability, and genetic technologies', *Du Bois Review*, 10(2), 313-328, <https://doi.org/10.1017/S1742058X13000210>.
- Robertson, M. A., and Sgoutas, A. (2012) 'Thinking beyond the category of sexual identity: At the intersection of sexuality and humantrafficking policy', *Politics and Gender*, 8, 421–429, doi:10.1017/ S1743923X12000414.
- Robinson, M. A., Cross-Denny, B., Lee, K. K., Rozas, L. M. W., and Yamada, A. M. (2016) 'Teaching Note—Teaching Intersectionality: Transforming Cultural Competence Content in Social Work Education', *Journal of Social Work Education*, 52 (4), 509-517, DOI: 10.1080/10437797.2016.1198297.
- Robson, C. (2002) *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, 2<sup>nd</sup> ed., Oxford, Blackwell Publishers Ltd.
- Rorie, J. L., Paine, L. L., and Barger, M. K. (1996) 'Primary Care for Women: Cultural Competence in Primary Care Services', *Journal of Nurse-Midwifery*, 41 (2), 92-100.
- Roos, S. (2013) *Chronic Sorrow: a Living Loss*, New York, Routledge.

Ross, L. (2010) 'Notes from the field: Learning cultural humility through critical incidents and central challenges in community-based participatory research', *Journal of Community Practice*, 18, 315–335. doi:10.1080/10705422.2010.490161.

Royal College of Physicians of Ireland (2016) 'Migrant Health- The Health of Asylum Seekers, Refugees and Relocated Individuals: A Position Paper from the Faculty of Public Health Medicine', Dublin, Accessed at <https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2016/06/Migrant-Health-16062016.pdf>, on 29/07/20.

Runswick-Cole, K. (2007) 'Parents as advocates: The experiences of parents who register an appeal with the Special Educational Needs and Disability Tribunal (SENDisT)', Ph.D. dissertation, University of Sheffield.

Ryan, S., and Runswick-Cole, K. (2008) 'Repositioning Mothers: Mothers, Disabled Children and Disability Studies', *Disability and Society*, 23 (3), 199–210.

Sakamoto, I. (2007) 'An Anti-Oppressive Approach to Cultural Competence', *Canadian Social Work Review*, 24(1):105–118.

Sandhu, P., Ibrahim, J., Chinn, D. (2107) 'I wanted to come Here because of my child': stories of migration told by Turkish-speaking families who have a Son or daughter with intellectual disabilities', *J Appl Res Intellect Disabil*, 30(2), 371–82.

Sanghera, G. S., and Bjorkert, T. S. (2008) 'Methodological Dilemmas: Gatekeepers and Positionality in Bradford', *Ethnic and Racial Studies*, 31 (3), 543-562.

Schultz, D. (2004) 'Cultural Competence in Psychosocial and Psychiatric Care: A Critical Perspective with Reference to Research and Clinical Experiences in California, US and in Germany', *Social Work in Health Care*, 39 (3-4), 231-247.

Schuman, A. (2000) 'Parental and Institutional Decision Making About Children's Healthy Development: Conflicts and Interests Across Cultures', *Journal of Immigrant Health*, 2(1), 43–51.

Scorgie, K., Wilgosh, L., and Sobsey, D. (2004) 'The experience of transformation in parents of children with disabilities: Theoretical considerations', *Developmental Disabilities Bulletin*, 32, 84–110.

Scott, E. (2010) "I Feel as If I Am the One Who is Disabled: The Emotional Impact of Changed Employment Trajectories of Mothers Caring for Children with Disabilities", *Gender and Society*, 24 (5), 672–696.

Second National Intercultural Health Strategy (2018-2023), HSE, Accessed at: <https://www.hse.ie/eng/about/who/primarycare/socialinclusion/intercultural-health/intercultural-health-strategy.pdf>, on 22/02/20.

Sensoy, Ö., and DiAngelo, R. (2012) *Is everyone really equal? An introduction to key concepts in social justice education*, New York, NY, Teachers College Press.

Shakespeare, T (2006) 'The Social Model of Disability', In Davis, L.J. (ed) *The Disability Studies Reader*, 2<sup>nd</sup> ed., New York, Routledge, pp. 197-204.

Shakespeare, T., Barnes, C., Priestley, M., Cunninghambirley, S., Davis, J., and Watson, N. (1999) *Life as a Disabled Child: A qualitative study of young peoples experiences and perspectives*, Leeds, Disability Research Unit, University of Leeds.

Shakespeare, T. (1993) 'Disabled People's Self-organisation: a new social movement?', *Disability, Handicap and Society*, 8, 249-264.

Shearn, J., and Todd, S. (2000) 'Maternal Employment and Family Responsibilities: The Perspectives of Mothers of Children with Intellectual Disabilities', *Journal of Applied Research in Intellectual Disabilities*, 13 (3), 109–131, Doi:10.1046/j.1468-3148.2000.00021.x.

Sheldon, B. and MacDonald, G. (2009) *A Textbook of Social Work*, New York, Routledge.

Shields, S. A. (2012) 'Waking up to privilege: Intersectionality and opportunity', In Flores-Niemann, Y., Harris, A., González, C. and Gutiérrez y Muhs, G. (Eds.) *Presumed incompetent: The intersections of race and class for women in academia*, Logan, Utah State University Press, pp. 29–39.

Sherry, M. (2017) *A Sociology of Impairment*, Interdisciplinary Disability Studies, Routledge.

Shields, S. A. (2008) 'Gender: An Intersectionality Perspective', *Sex Roles*, 59, 301–311, DOI 10.1007/s11199-008-9501-8.

Siebers, T. (2001) 'Disability in Theory: From Social Constructionism to the New Realism of the Body', *American Literature History*, 13(4), 737-754.

Simon, J., Kiss, N., Łaszewska, A. and Mayer, S. (2015) 'Public health aspects of migrant health: a review of the evidence on health status for labour migrants in the European Region', Copenhagen, WHO Regional Office for Europe.

Simon, M. (2001) 'Beyond broken promises: Reflections on eliminating barriers to the success of minority youth with disabilities', *Journal of the Association for Persons with Severe Handicaps*, 26(3), 200-203.

Simon, C. and Mosavel, M. (2008) 'Key Conceptual Issues in the Forging of "Culturally Competent" Community Health Initiatives: A South African example', *Cambridge Quarterly of Healthcare Ethics*, 17, 195– 205.

Singer, G. H. S. (2006) "Meta-Analysis of Comparative Studies of Depression in Mothers of Children with and without Developmental Disabilities", *American Journal on Mental Retardation*, 111 (3), 155–169.

Skrinda, M. M. (2008) "'You Have to Have Tough Skin": The Impact of Social Exclusion on Immigrant Mothers of Children with Disabilities', Unpublished doctoral dissertation, Toronto, Ryerson University.

Slade, G. (2014) *Diverse Perspectives: 'The Challenges for Families affected by Autism from Black, Asian and Minority Ethnic Communities'*. The National Autistic Society, available online at: <file:///C:/Users/helen/Desktop/research%20ideas/MigrantsandAutism/NAS-Diverse-perspectivesreport.pdf>, Accessed on 01/06/17.

Smith, T., Gartin, B.G., Murdick, N., and Hilton, A. (2006) *Families And Children With Special Needs*, New Jersey, Pearson.

Soldatic, K., Meekosha, H., and Somers, K. (2012) 'Finding Ernesto: Temporary Labour Migration and Disabled Children's Health', *International Journal of Population Research*, 2012 696753, 9, doi:10.1155/2012/696753.

Soldatic, K., and Fiske, L. (2009) 'Bodies 'Locked Up': Intersections of Disability and Race in Australian Immigration', *Disability & Society*, 24 (3), 289–301.

Sousa, P., and Almeida, J. L. (2016) 'Culturally Sensitive Social Work: Promoting Cultural Competence', *European Journal of Social Work*, 19, 3-4, 537-555, DOI: 10.1080/13691457.2015.1126559.

Spencer, C. (2014) 'How Transformational is Irish Healthcare Education?: Exploring the Role of Intercultural Competence Learning for Practising Health Professionals', *Irish Journal of Academic Practice*, 3(1), Article 2, doi:10.21427/D7P99X Available at: <https://arrow.tudublin.ie/ijap/vol3/iss1/2>.

Spencer, S. (2003) *The politics of migration. Managing opportunity, conflict and change*, Oxford, Blackwell.

Spiegle, J. A. and Van Den Pol, R. A. (1993) *Making Changes: family voices on living with disabilities* (Cambridge, Brookline Books).

Stout, A. and Schwartz, A. (2014) 'It'll Grow Organically and Naturally: The Reciprocal Relationship Between Student Groups And Disability Studies on College Campus', *Disability Studies Quarterly*, 34(2), retrieved from doi:10.1080/dsq.v34.2.

Suarez-Balcazar, Y., and Rodakowski, J. (2007, September) 'Becoming a culturally competent occupational therapy practitioner', *OT Practice*, pp. 14–17, in Beagan, B. L. (2015) 'Approaches to culture and diversity: A critical synthesis of occupational therapy literature', *Canadian Journal of Occupational Therapy*, 82(5), 272-282, DOI: 10.1177/0008417414567530, p. 274.

Sue, D. W., and Sue, D. (1990) *Counseling the culturally different: Theory and practice*, 2nd ed., New York, John Wiley and Sons.

Sutton, J. and Austin, Z. (2015) 'Qualitative Research: Data Collection, Analysis, and Management', *Canadian Journal of Hospital Pharmacy*, 68 (3), 226–231.

Swift, A., Iriarte, E. D., Curry, P., McConkey, R., Gilligan, R., and Antunes, M (2020) ‘How Disability and Other Socio-Economic Factors Matter to Children’s Socio-Emotional Outcomes: Results from a Longitudinal Study Conducted in Ireland’, *Child Indicators Research*, 14, 391–409 (2021).

Tan, L. J. and Tan, K. K. H. (2018) Paediatric Tracheal Stenosis- A 10-Year Experience from a Tertiary Paediatric Otolaryngology Unit, Department of Otolaryngology, KK Women’s and Children’s Hospital, 100 Bukit Timah Road, Singapore.

Tang, L. C. (2008) *Psychological Well-being in Parents of Children with Pervasive Developmental Disorders and Attention-deficit*, Michigan State University.

Tate, W. F. (1997) ‘Critical race theory and education: History, theory, and implications’, In Apple, M. W. (Ed.) *Review of research in education*, Vol. 22, Washington DC, American Educational Research Association, pp. 195-247.

Terry, G., Hayfield, N., Clarke, V., and Braun, V. (2017) ‘Thematic Analysis’ in Willig, C. and Rogers W. S. (Eds) *The SAGE Handbook of Qualitative Research in Psychology*, 2<sup>nd</sup> ed., London, Sage, pp. 17-37.

Tervalon, M., and Murray-Garcia, J. (1998) ‘Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education’, *Journal of Health Care for the Poor and Underserved*, 9(2), 117-25.

Thackrah, R. D., and Thompson, S. C. (2013) ‘Refining the Concept of Cultural Competence: Building on Decades of Progress’, *The Medical Journal of Australia*, 199(1), 35-38.

The Associated Press (Jan. 23, 2017), ‘Dutch Race Heats Up’, Accessed at <https://www.usnews.com/news/world/articles/2017-01-23/fight-for-the-right-dutch-pm-says-integrate-or-leave>, on 20/10/18.

The Irish Human Rights and Equality Commission Act (2014), Accessed at <https://www.ihrec.ie/documents/ihrec-act-2014/>, on 16/11/22.

Therbon, G. (2014) ‘Family Systems of the World: Are They Converging?’, In Treas, J., Scott, J., and Richards, M. (eds) (2014) *The Wiley Blackwell Companion to the Sociology of Families*, UK, John Wiley and Sons Ltd, pp. 3-19.

Thomas, C. (2004) ‘Rescuing a Social Relational Understanding of Disability’, *Scandinavian Journal of Disability Research*, 6 (1), 22–36, Doi:10.1080/15017410409512637.

Thomas, D. R. (2003) *A General Inductive Approach for Qualitative Data Analysis*, New Zealand, School of Population Health University of Auckland.

Thomas, C. (1999a) *Female Forms: Experiencing and Understanding Disability*, Buckingham, Open University Press.

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*, Buckingham, Open University Press.

Thomas, T. N. (1995) ‘Accultural stress in the adjustment of immigrant families’, *Journal of Social Distress and the Homeless*, 4(2), 131 – 142.

Thompson, N. (2021) *Anti-Discriminatory Practice: Equality, Diversity and Social Justice*, 7<sup>th</sup> ed., London, Red Globe Press.

Todd, S., and Jones, S. (2003) ‘‘Mum’s the word!’: Maternal accounts of dealings with the professional world’, *Journal of Applied Research in Intellectual Disabilities*, 16, 229–44.

Todd, S., and Shearn, J. (1996a) ‘Struggles with Time: The Careers of Parents with Adult Sons and Daughters with Learning Disabilities’, *Disability and Society*, 11 (3), 379–402.

Treas, J., Scott, J., and Richards, M. (eds) (2014) *The Wiley Blackwell Companion to the Sociology of Families*, UK, John Wiley and Sons Ltd.

Turnbull, A. P., Patterson, J. M., Behr, S. K., Murphy, D. L., Marquis, J. G. and Blue-Banning, M.J. (eds) (1993) *Cognitive Coping, Families, and Disability*, Baltimore, Paul H. Brookes.

Tylor, E. B. (1958) *Origins of Culture*, Vol. I, In Moore J. D. (2012), *Visions Of Culture: An Introduction to Anthropological Theories and Theorists*, 4th ed., Maryland, AltaMira Press, P.5.

UNCRPD (2006) Convention on the Rights of Persons with Disabilities: Human rights and fundamental freedoms | Persons with disabilities, A/RES/61/106, Annex I.

UN High Commissioner for Refugees (UNHCR), *UNHCR Global Trends 2010*, June 2011, Accessed at: <https://www.refworld.org/docid/4e01b00e2.html>, on 8,6/2023.

UNICEF (2012) *The state of the world's children 2013: Children with disabilities*, New York, UNICEF.

United Nations, Department of Economic and Social Affairs, Population Division (2017) 'International Migration Policies: Data Booklet', ST/ESA/ SER.A/395.

University College Cork (UCC) (2017) Code of Research Conduct Version 2.1, available online at: <https://www.ucc.ie/en/media/research/researchatucc/policiesdocuments/UCCCodeofResearchConductV2-111thApril2017.pdf>, Accessed on 20/02/18.

Urban, M., Robson, S., Scacchi, V. (2017) 'Review of Occupational Role Profiles in Ireland in Early Childhood Education and Care', London, University of Roehampton, Early Childhood Research Centre (ECRC).

Urdang, E. (2008) *Human Behaviour in the Social Environment: Interweaving the Inner and Outer worlds*, 2<sup>nd</sup> ed., New York, Routledge.

Urquia, M. L., Glazier, R. H., Blondel, B., Zeitlin, J., Gissler, M., Macfarlane, A., Ng, E., Heaman, M., Stray-Pedersen, B. and Gagnon, A. J. (2010) "International Migration and Adverse Birth Outcomes: Role of Ethnicity, Region of Origin and Destination", *Journal of Epidemiology and Community Health*, 64 (3), 243–251.

Vega, W. A. (2005) 'Higher Stakes Ahead for Cultural Competence' *Gen Hosp Psychiatry*, 27, 446-450.

Wade, G. H. (1998) 'A concept analysis of personal transformation', *Journal of Advanced Nursing*, 28, 713–719.

Warner, D. F., and Brown, T. H. (2011) 'Understanding how race/ethnicity and gender define age-trajectories of disability: An intersectionality approach', *Social Science and Medicine*, 72, 1236–1248, doi:10.1016/j. socscimed.2011.02.034.

Warner, L. R., and Shields, S. A. (2013), 'The Intersections of Sexuality, Gender, and Race: Identity', *Sex Roles*, 68, 803–810, DOI 10.1007/s11199-013-0281-4.

Watt, P. (2008) 'Building Integrated Neighbourhoods', Dublin, National Consultative Committee on Racism and Interculturalism (NCCRI).

Weiss, M. S. (1994) “Marginality, Cultural Brokerage, and School Aides: A Success Story in Education”, *Anthropology and Education Quarterly*, 25(3), 336–46, doi:10.1525/aeq.1994.25.3.04x0148r.

Wellington, J. (2015) *Educational Research: Contemporary Issues and Practical Approaches*, 2<sup>nd</sup> Ed., London, Bloomsbury Publishing.

Welterlin, A., and LaRue, R. H. (2007) ‘Serving the needs of immigrant families of children with autism, *Disability and Society*, 22(7), 747-760.

Wenger, A. F. Z. (1995) “Cultural Context, Health and Health Care Decision Making”, *Journal of Transcultural Nursing*, 7(1), 3–14, doi:10.1177/104365969500700102, In Pang, Y., Dinora, P. and Yarbrough, D. (2020) ‘The gap between theory and practice: using cultural brokering to serve culturally diverse families of children with disabilities’, *Disability and Society*, 35 (3), 366-388, DOI: 10.1080/09687599.2019.1647147.

Wijekoon, S., Rudman, D. L., Hand, C. and Polgar, J. (2021) ‘Late-life immigrants’ place integration through occupation’, *Journal of Occupational Science*, DOI: 10.1080/14427591.2021.1960589.

Wilgosh, L., and Scorgie, K. (2006) ‘Theoretical Model for Conceptualizing Cross-Cultural Applications and Intervention Strategies for Parents of Children With Disabilities’, *Journal of Policy and Practice in Intellectual Disabilities*, 3 (4), 211–218.

Williams, C. C. (2006) ‘The Epistemology of Cultural competence’, *Families in Society*, 87(2), 209-220.

Williams, C. C. (2002) ‘Evaluation of an Educational Intervention to Increase Cultural Competence in Social Workers’, Unpublished Doctoral Dissertation, University of Toronto, Toronto.

Williams, C., and Graham, M. (2010) ‘Travelling hopefully: Race/ethnic relations and social work: A transnational dialogue’ *European Journal of Social Work*, 13(2), 155–161.

Williams, C. C. (2006) ‘The Epistemology of Cultural competence’, *Families in Society*, 87(2), 209-220.

Williams, C. C. (2003) 'Seeking Cultural Competence: What Is It, How Do You Develop It and How Do You Know When You've Got It?', In Shera, W. (ed.) *Emerging Perspectives on Anti-oppressive Practice*, Toronto, Canadian Scholar's Press, pp. 265-278.

Williams, C. C. (2002) 'Evaluation of an Educational Intervention to Increase Cultural Competence in Social Workers', Unpublished Doctoral Dissertation, University of Toronto, Toronto.

Woodcock, J., and Tregaskis, C. (2006) 'Social work communication skills with parents of disabled children: A combined social model and social work analysis' *The British Journal of Social Work*, Advance Access (published electronically).

Woodgate, R. (2008) 'Living In A World Of Our Own: The Experience Of Parents Who Have A Child With Autism', *Qualitative Health Research*, 18, 1075-10.

World Federation of Occupational Therapists (2010) 'Position statement: Diversity and culture', Retrieved from <http://www.wfot.org/ResourceCentre.aspx#>, in Beagan, B. L. (2015) 'Approaches to culture and diversity: A critical synthesis of occupational therapy literature', *Canadian Journal of Occupational Therapy*, 82(5), 272-282, DOI: 10.1177/0008417414567530, p. 274.

World Health Organization (WHO) (2011) *World report on disability*, Geneva, Switzerland, World Health Organization.

World Health Organization (WHO) (2002) *Towards a common language for functioning, disability and health*, Geneva, Switzerland, World Health Organization.

World Health Organisation (WHO) (2001) *International Classification of Functioning, Disability And Health*, Geneva, WHO.

Yan, M., and Yuk-Lin, R. (2005) 'Rethinking self-awareness in cultural competence: Toward a dialogic self in cross-cultural social work', *Families in Society*, 86, 181–188.

Yancu, C., and Farmer, D. (2017) 'Product or process: Cultural competence or cultural humility?', *Palliative Medicine and Hospice Care Open Journal*, 3(1), e1-e4, doi:10.17140/PMHCOJ-3-e005.

Yantzi, N. M., and M. W. Rosenberg (2008) “The Contested Meanings of Home for Women Caring for Children with Long-Term Care Needs in Ontario, Canada”, *Gender, Place, and Culture*, 15 (3), 301–315.

Young, S., Shakespeare-Finch, J., and Obst, P. (2020) ‘Raising a child with a disability: a one-year qualitative investigation of parent distress and personal growth’, *Disability and Society*, 35 (4), 629-653, DOI: 10.1080/09687599.2019.1649637, <https://doi.org/10.1080/09687599.2019.1649637>.

## Appendix 1 – Poster



**Are you an African parent of a child with a disability (aged 0 to 6years)?**

**Do you avail of Early Intervention Services?**

**Have you been denied access to Early Intervention Services?**

**Have you chosen not to use Early Intervention Services?**

**Would you like to share your experiences in confidence?**

**If you answered yes to any of the above questions, this research is for you.**

My name is Asong Jingwa. I am a PhD Social Work student at University College Cork (UCC). I am carrying out research on the experiences of African immigrant parents of children with disabilities in relation to Irish Early Intervention Services. It is hoped that this research will increase our understanding of how African immigrant parents of children with disabilities view, approach and engage with Irish Early Intervention Services and what can be done to improve their experiences.

As part of this research, I would like to conduct interviews with African parents who have children with disabilities. Participation will be voluntary. You will not be identifiable in any reports of the research. These interviews will provide parents with an opportunity to think about and share their experiences of Early Intervention Services.

**Please, if you are an African parent of a child with a disability (aged between 0 to 6years) and are interested in sharing your experiences, kindly contact me on 087... or at [112221030@umail.ucc.ie](mailto:112221030@umail.ucc.ie).**



I look forward to hearing from you.

Yours sincerely,  
Asong

## Appendix 2

### **Letter of Invitation to Participate in PhD of Social Work Research**



**Title:** *Culture and Ethnicity: Critical Factors in Irish Early Intervention Services*

**Date:**

Dear Parent/Healthcare Professional,

Cultural diversity is a reality in Ireland and is becoming more visible with the passing of each year. However, no known research has been conducted in relation to African immigrant parents of children with disabilities' experiences of Irish Early Intervention Services, which is a very important and critical domain.

I am currently undertaking a PhD of Social Work course in University College Cork (UCC) and I wish to conduct research in this area. It is hoped that this research will increase our understanding of how African immigrant parents of children with disabilities view, approach and engage with Irish Early Intervention Services and what can be done to increase their level of engagement with services and level of advocacy for their children. It is also hoped that this research will increase our understanding of how healthcare professionals on Early Intervention teams work with African immigrant parents and their children with disabilities, what informs their practice and their recommendations for better practice.

The overall aim of this research is to obtain a better picture of African immigrant parental involvement with Irish Early Intervention Services and what could be done to enhance this interaction to ensure better outcomes for the child with a disability. By partaking in this research, you will be helping to build upon our understanding of this crucial period in the lives of African immigrant parents and their children with disabilities.

I would be very grateful if you would consider taking part in this research. I understand that this will require you taking time off your very busy schedule and sincerely thank you in anticipation of your help and cooperation.

The decision to participate in this research is solely yours. All information provided will be treated in very strict confidence and all materials relating to this research will be processed only by myself and discussed with my supervisors, Dr Eleanor Bantry-White and Dr Claire Edwards, School of Applied Social Studies, UCC.

Data obtained through interviews will be held in locked cabinets in my supervisor's office and on password protected audio files. The data will be destroyed ten years after the successful

completion of my research, in line with the UCC Code of Research Conduct. Data generated from the interviews will be anonymised in order to protect participant identity.

Please, find attached Information Sheet and Consent Form. Kindly indicate your willingness to participate and how I can contact you on the Consent Form. My phone number is: 087....

Thank you in advance for considering my request.

Kind regards,

---

Ndemazia Asongleack Jingwa  
PhD Social Work Student  
University College Cork.

## **Appendix 3**

### **Information Sheet for Parents**



**Title:** *Culture and Ethnicity: Critical Factors in Irish Early Intervention Services*

#### **The Researcher and Supervisors**

My Name is Ndemazia Asonglefack Jingwa and I am currently enrolled in the second year of the PhD Social Work in University College Cork (UCC). I am equally a Professionally Qualified Social Worker.

My supervisors are Dr Eleanor Bantry-White and Dr Claire Edwards, School of Applied Social Studies, UCC.

#### **The Nature and Purpose of the Research**

I am carrying out research as part of a PhD Social Work. The research is concerned with African immigrant parents of children with disabilities' experiences of Irish Early Intervention Services. The aim of the research is to explore the following:

- 1) How immigrant parents of children with disabilities construct and understand disability.
- 2) How immigrant parents of children with disabilities perceive and experience Irish Early Intervention Services in terms of access and utilisation.
- 3) Challenges and barriers in developing Early Intervention Services which are accessible and responsive to immigrant parents of children with disabilities.
- 4) Measures that can be taken to improve the level of access and utilisation of Irish Early Intervention Services by immigrant families of children with disabilities.
- 5) The usefulness of the concept of cultural competence in facilitating our understanding of how Early Intervention Services and professionals respond to immigrant parents of children with disabilities.

#### **What Will the Research Involve?**

This research will involve the use of semi structured qualitative interviews. 10 multidisciplinary healthcare professionals who have worked in Early Intervention Services for at least one year will be interviewed. In addition, 10 African parents of children with disabilities with at least one to ten consecutive years' residence in Ireland, who avail of Early Intervention Services, will be interviewed. Each interview will last between 60 to 90 minutes. Contact between the researcher and the participant will take place at a suitable venue to

facilitate the participant. The interviews will be recorded on a digital voice recorder and transcribed by the researcher. Audio recordings will be destroyed once transcribed in order to ensure confidentiality.

### **Why Have You Been Asked to Take Part?**

You have been asked because you are an African immigrant parent of a child with a disability and thus suitable to provide data for this research.

### **Do You Have to Take Part?**

No. Participation is voluntary. If you agree to take part, your written consent will be sought prior to the commencement of the interview. You will get to keep the information sheet and a copy of the consent form. You will be advised that you have the right to turn off the audio tape at any time during the interview and are entitled to refuse to answer any question(s) posed. You will also be advised that you can withdraw permission to use the data within two weeks of the interview, and ask to have the data destroyed.

### **Will Your Participation in The Research Be Kept Confidential?**

Yes. I will ensure that no clues to your identity appear in the dissertation. Any extracts from what you say that are quoted in the dissertation will be entirely anonymous.

### **What Will Happen to The Information Which You Give?**

All information gathered will remain confidential and will not be released to any third party, including participant organisations. For the duration of the research, the data will only be available to me, my research supervisors and external examiners. It will be securely stored in a locked cabinet in my supervisor's office, password protected audio files and an encrypted laptop. On completion of the project, data will be retained for minimum of a further ten years, as per the UCC Code of Research Conduct, and then destroyed.

You will be given the opportunity to review a transcript of the audio taped interview.

### **What Will Happen to The Results?**

The results will be presented in the dissertation. They will be seen by my supervisors and the external examiner. The dissertation may be read by future students on the course. The research may be published in a research journal and shared through presentations in organisations/seminars.

### **Are There Any Benefits Associated with Participation?**

The interview will give you the opportunity to discuss your experiences of accessing and utilising Irish Early Intervention Services. It will also give you an opportunity to reflect on and propose what you think could be done to address any challenges that Early Intervention Services may present to you and your family.

### **What Are the Possible Disadvantages of Taking Part?**

Talking about your experience in relation to your child with a disability can be a very sensitive issue and may cause some distress for you.

### **What If There Is a Problem?**

Should any problem arise for you during the interview, you may terminate the interview at any point. However, at the end of the interview, I will discuss with you how you found the experience and how you are feeling. I will also provide you with a list of local and national support agencies that you can contact if in need of support.

### **Who Has Reviewed This Research?**

The Social Research Ethics Committee (SREC) UCC has reviewed and approved the research.

### **Any Further Queries?**

If you need any further information, you can contact me on 087... or by email at: 112221030@umail.ucc.ie.

My supervisors can be contacted as follows:

Dr Eleanor Bantry-White may be contacted at: E.BantryWhite@ucc.ie

Dr Claire Edwards may be contacted at: Claire.Edwards@ucc.ie

If you agree to take part in the research, please sign the Consent Form overleaf.

## Appendix 4

### **Information Sheet for Professionals**



**Title:** *Culture and Ethnicity: Critical Factors in Irish Early Intervention Services*

#### **The Researcher and Supervisors**

My Name is Ndemazia Asongleack Jingwa and I am currently enrolled in the second year of the PhD Social Work in University College Cork (UCC). I am equally a Professionally Qualified Social Worker.

My supervisors are Dr Eleanor Bantry-White and Dr Claire Edwards, School of Applied Social Studies, UCC.

#### **The Nature and Purpose of the Research**

I am carrying out research as part of a PhD Social Work. The research is concerned with African immigrant parents of children with disabilities' experiences of Irish Early Intervention Services. The aim of the research is to explore the following:

- 1) How immigrant parents of children with disabilities construct and understand disability.
- 2) How immigrant parents of children with disabilities perceive and experience Irish Early Intervention Services in terms of access and utilisation.
- 3) Challenges and barriers in developing Early Intervention Services which are accessible and responsive to immigrant parents of children with disabilities.
- 4) Measures that can be taken to improve the level of access and utilisation of Irish Early Intervention Services by immigrant families of children with disabilities.
- 5) The usefulness of the concept of cultural competence in facilitating our understanding of how Early Intervention Services and professionals respond to immigrant parents of children with disabilities.

#### **What Will the Research Involve?**

This research will involve the use of semi structured qualitative interviews. 10 multidisciplinary healthcare professionals who have worked in Early Intervention Services for at least one year will be interviewed. In addition, 10 African parents of children with disabilities with at least one to ten consecutive years' residence in Ireland, who avail of Early Intervention Services, will be interviewed. Each interview will last between 60 to 90 minutes. Contact between the researcher and the participant will take place at a suitable venue to facilitate the participant. The interviews will be recorded on a digital voice recorder and

transcribed by the researcher. Audio recordings will be destroyed once transcribed in order to ensure confidentiality.

**Why Have You Been Asked to Take Part?**

You have been asked because you are a healthcare professional working with immigrant parents of children with disabilities and thus suitable to provide data for this research.

**Do You Have to Take Part?**

No. Participation is voluntary. If you agree to take part, your written consent will be sought prior to the commencement of the interview. You will get to keep the information sheet and a copy of the consent form. You will be advised that you have the right to turn off the audio tape at any time during the interview and are entitled to refuse to answer any question(s) posed. You will also be advised that you can withdraw permission to use the data within two weeks of the interview, and ask to have the data destroyed.

**Will Your Participation in The Research Be Kept Confidential?**

Yes. I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous. Your organization will not be identified by name in the thesis.

**What Will Happen to The Information Which You Give?**

The data will be kept confidential from third parties, including your superiors. For the duration of the research, the data will only be available to me, my research supervisors and examiners. It will be securely stored in a locked cabinet in my supervisor's office, password protected audio files and an encrypted laptop. On completion of the project, data will be retained for minimum of a further ten years, as per the UCC Code of Research Conduct, and then destroyed.

You will be given the opportunity to review a transcript of the audio taped interview.

**What Will Happen to The Results?**

The results will be presented in the thesis. They will be seen by my supervisors and examiners. The thesis will be a publicly available document and may thus be read by anyone. The research may be published in journals and presented at conferences.

**Are There Any Benefits Associated with Participation?**

The interview will give you the opportunity to discuss your experiences of working with immigrant parents of children with disabilities and a forum to reflect on what you think could be done to address any challenges that may present themselves in this role. The information obtained will be of interest to you and other healthcare providers in relation to how healthcare

professionals engage with immigrant families of children with disabilities and how this is viewed by the parents receiving the services.

**What Are the Possible Disadvantages of Taking Part?**

Reflecting on and talking about your practice experience may be unsettling.

**What If There Is a Problem?**

Should any problem arise for you during the interview, you may terminate the interview at any point. However, at the end of the interview, I will discuss with you how you found the experience and how you are feeling. I will also give you a list of local and national support agencies that you can contact if in need of support.

**Who Has Reviewed This Research?**

The Social Research Ethics Committee (SREC) UCC has reviewed and approved the research.

**Any Further Queries?**

If you need any further information about the study, you can contact me on 087... or by email at: 112221030@umail.ucc.ie.

My supervisors can be contacted as follows:

Dr Eleanor Bantry-White may be contacted at: E.BantryWhite@ucc.ie

Dr Claire Edwards may be contacted at: Claire.Edwards@ucc.ie

If you agree to take part in this research, please sign the Consent Form overleaf.

## Appendix 5

### Consent Form



**Title:** *Culture and Ethnicity: Critical Factors in Irish Early Intervention Services*

I, \_\_\_\_\_, agree to participate in the above research being conducted by Ndemazia Asonglefack Jingwa.

- The purpose and nature of the research has been explained to me in writing and verbally.
- I am participating voluntarily (It is my choice).
- I understand that I will be asked to take part in a semi-structured interview, which will be audio-recorded.
- I give permission for my interview with Ndemazia Asonglefack Jingwa to be audio-recorded.
- I understand that I can decline answering any of the questions posed and can withdraw from the research, without repercussions, at any time, whether before it starts or while I am participating.
- I understand that I will be given an opportunity to review a transcript of the audio taped interview.
- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
- I understand that anonymity will be ensured in the write-up by disguising my identity.
- I understand that anonymised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below (Please tick one box):

I agree to quotation/publication of extracts from my interview

☐

I do not agree to quotation/publication of extracts from my interview

☐

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

PRINT NAME: \_\_\_\_\_

## **Appendix 6**

### **Interview Topic Guide for Parents and Professionals**



**Title:** *Culture and Ethnicity: Critical Factors in Irish Early Intervention Services*

### **Topic Guide for Parents**

#### **1. Introduction**

*Explain about the project. Obtain information on country of origin, length of stay in Ireland, age of the child with a disability, nature of first contact with Early Intervention Services, other children / family members.*

What is your country of origin?

How long have you lived in Ireland?

How old is your child with a disability?

Do you have other children?

How and when did you first come in contact with Early Intervention Services?

#### **2. Parental Perceptions of Disability**

What does it mean to have a child with a disability in your country of origin?

Personally, how do you view your child's disability?

How does your experience in your country of origin in relation to disability affect your experience in Ireland?

What is your perception of attitudes towards disability in Ireland? How do these differ from your country of origin?

### **3. Parental Experiences of Early Intervention Services**

How did you first hear about Early Intervention Services? Where did you obtain your information?

Did you require any supports to enable you to access them e.g interpreters? If so, how did you experience accessing these supports?

What is your understanding of the role of Early Intervention Services? Does this reflect your values/expectations?

What has facilitated your access and utilisation of Early Intervention Services?

What, if any, challenges have you experienced in accessing these services?

To what extent do you feel that Early Intervention Services are sensitive to the cultural needs of your child?

How far do you think your opinion is valued by service providers in relation to caring for your child with a disability?

### **4. Recommendations**

What do you think could make Early Intervention Services more accessible and more helpful?

## **Topic Guide for Professionals**

### **1. Introduction**

*Explain about the research. Gain information on the role of the individual and the organisation they work for.*

What is your job title?

How long have you been in this role?

How do you view your role as a disability healthcare professional?

What are your main responsibilities?

What populations do you serve? Does this include African immigrant families of children with disabilities?

What do you think are some of the challenges for immigrant families of children with disabilities in terms of accessing services, utilising services and perceptions of disability?

How do you think the needs of these families are understood or recognised by the State?

## **2. Perceptions of Culturally Competent Practice**

How would you describe your experience of working with African immigrant families?

Are you familiar with culturally competent practice? If yes, how would you define it and what does it mean for you?

How did you learn about cultural competence? Was it through formal education or practice experience?

Can you describe a fairly typical example of your own experience on how culturally competent practice influences your day-to-day practice?

- What skills do you use in providing culturally competent care to immigrant parents of children with disabilities?
- What skills do you use to ensure better engagement from immigrant parents of children with disabilities?

## **3. Evaluation of Culturally Competent Practice**

How do you evaluate or assess your own abilities to be culturally competent?

What efforts do you make at developing your cultural competence?

Can you recall an experience in which you struggled in the provision of culturally sensitive service?

Can you provide an example of cultural sensitivity in your practice?

Do you feel that culturally competent practice is being implemented in working with immigrant families of children with disabilities in Ireland?

- If so, can you elaborate on this and if not how and why?

What recommendations for the improvement of culturally competent practice do you have, based on your experience?

Would you like to further comment or add anything?

Do you have any questions for me?