

Article

Parents as Nomads: Journeys, In-Betweenness and Identity

Miriam Twomey 

Trinity College Dublin, The University of Dublin, D02 PN40 Dublin, Ireland; twomeym6@tcd.ie

Abstract: When considering the parent voice as an individual subjective reality, it is observed as unique to the parent and not shared by others. This research sought to explore if parent voices could constitute intersubjective realities; inviting narratives from parents and professionals that may reveal a shared existence. The first theme explored the journeys of the parent as a nomad in their search for services to support their children. The second theme describes the position of the parent during the period of their child's assessment, diagnosis and intervention, as that of 'in-betweenness'. The third theme describes parents' experiences as those of journeys, during which their identities change. Qualitative, in-depth, longitudinal case studies were undertaken with parents of young children with ASD and professionals over eighteen months. Semi-structured interviews (n=83) were conducted. Autoethnography was critical as a methodological tenet in defense of a position that states that research is an extension of our lives. The findings of this research show evidence of parental isolation and marginalization when procuring services for their children or when children failed to experience inclusion. This research suggests that nomads navigate (difficult) ways of forming new multiple selves and identities.

Keywords: Early Childhood Intervention; children's assessment; education; inclusion; parents' journeys; in-betweenness and identity



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1. Introduction

Ireland reflects international trends witnessing significant developments relating to educational provision for children with disabilities at early childhood, primary and post-primary education levels. While education is considered an inalienable human right, children with disabilities may not be able to realize this right in the absence of health-related, therapeutic support and Early Intervention. Early Intervention therefore can be considered a necessary precursor to children's participation in inclusive education. Irish policy relating to children with disabilities is education and health focused. While the Education for Persons with Special Educational Needs (EPSEN) Act, (2004) [1] is child focused, it is not rights based, insofar as it does not recognize the right of children with disabilities to therapy or supports to enhance their participation [2]. The Disability Act, enacted in 2005, did [3] not make specific provision for children and thus the only legislative instrument of importance in this area focuses on the rights of disabled children to and in education. In 2007 the Disability Act had commenced with the under 5 age group; however, sections 3–13 of the EPSEN Act, concerned with assessment and furtherance of a child's education plan, has not commenced. This was of critical importance as the EPSEN Act and the Disability Act were designed to work in concert with each other. The pausing of the EPSEN Act has had detrimental effects [4]. Children with disabilities have rights that the Government has an obligation to uphold and enforce, however, there is no comprehensive statutory framework to ensure that children with disabilities have the right to access and enjoy a full range of health, social and educational services, in line with Articles 3 and 23 of the CRC and the Convention on the Rights of Persons with Disabilities (Articles 3 and 7).

This paper will outline current issues relating to context and policy of Early Intervention in Ireland. It will explore themes in the literature relative to the challenges encountered

by parents when advocating for their children and engaging with incoherent services. The paper will present findings from a research project eliciting authentic parental and professional voices to describe issues relating to the challenges young children with autism and their parents experience in Early Intervention and early education settings.

1.1. Current Issues

Early Intervention services for young children with additional needs in Ireland are fragmented. This fragmentation is mirrored in an underdeveloped pre-school sector. The Department of Health, and the Department of Children, Equality, Disability, Integration and Youth are currently responsible for a significant proportion of existing provision, while the Department of Education and Science also plays a role in the establishment of special classes and units [5]. Difficulties are posed by the fact that work relating to provision is contracted out by the Health Service Executive (HSE) to voluntary bodies. Occasionally the HSE provides services directly. Services vary dramatically from one geographical region to another, even within (former) Health Board areas. Noted concerns include the implementation and pausing of the Education of Persons with Special Needs (EPSEN) Act [1]. While the EPSEN Act focuses on addressing children's needs within the education system, the Disability Act [3] published in 2005 does not address the specific needs of children, therefore legislation fails to ensure that children with disabilities have rights to a range of required health services. The Disability Act proposed a statutory right for children to an independent assessment of needs (AON). This should take place within a specified time period, resulting in a service statement outlining the services required for the child. Critiques of this process are ongoing and children remain on lengthy waiting lists. While some of these issues have been attributed to the pandemic, the operation of the Act was ineffectual in the period prior to the pandemic, resulting in inadequate services and few resources available. At the time of writing this paper, contemporary services remain underresourced.

The HSE initiated a program in 2010 on Progressing Disability Services for Children and Young People (PDSCYP), supported by a National Coordinating Group with representation from the then Department of Health, and Department of Education and Skills. The overall vision was to provide one clear pathway to services for all children with disabilities, according to need, with the health and education sectors collaborating to support children to achieve their full potential. This program was launched in 2011; its aims were to deliver disability services in line with a primary care model, where disability services would be geographically based and where health and education sectors would work in partnership. Despite this development, children with additional needs are subject to lengthy waiting lists for supports such as speech and language therapy and occupational therapy. More recent work on a reconfiguration of the PDSCYP supports implementation of proximal, collaborative family-centered services providing appropriate and timely service in the child's community. Notwithstanding these developments, the current situation comprises long waiting lists and more recently the Ombudsman for Children presented the conundrum: "If children have not been assessed, how will they receive the services they need?" [6]. What is notable here is that not only are children waiting to be assessed, but a further lengthy wait for intervention will ensue after assessment.

There is a failure at policy level, therefore, to acknowledge that Early Intervention for children with disabilities is foundational to meeting their health and their education requirements (Article 23 [7]).

Recently the detrimental effects of the pandemic have exacerbated these needs [8]. While telehealth has had some positive outcomes regarding increased accessibility and the ability to see children in their natural environment, Rosenbaum et al. [9] caution that childhood rehabilitation in the digital space should not simply go back to normal or its existence pre-pandemic; rather, it should expand the range, nature and location of services for children with neurodevelopmental disorders and their families. While some children clearly benefitted from virtual support, children with autism and their parents

lacked socialization as a key factor during public health restrictions enforced during the pandemic [10]. Healthcare providers and institutions were challenged in providing services for children with autism and their families. King et al. [11] emphasize parent engagement and that service providers can encourage their collaboration in planning, fostering a sense of partnership and conveying a sense of hope. Camden and Silva [12] note caution relating to professional expectations that do not translate well virtually; issues arise relating to the timing and pacing of interventions online and the determination of which goals of telehealth are effective for whom and under what circumstances.

Internationally, family-centered approaches to Early Intervention are well established [13]. Family-centered approaches emphasize the importance of relationships with families but also the need to empower the family. However, Twomey and Shevlin [14] noted the challenges and complexities associated with children's and families' needs. The authors acknowledged the inner journeys of parents who experienced uncertainty while awaiting their children's assessment and diagnosis. Their study witnessed parents emerging as pathfinders through a morass of incoherent policy, seeking and finding new paths through State initiatives. While legislation is ineffectual, parents have to act as duty bearers; they have to bear duties and obligations to respect, protect and fulfill children's rights. Parents' roles and identities therefore endow them with a duty to enable their children as rights holders to participate in educational and society. While O'Connor, Carpenter and Barry's [15] research proposes that parents develop "confident championing" as a way of adjusting when a child has a disability, they also note the fulfillment and sense of purpose that parents achieve. However, less attention is dedicated to supporting these parents' during these processes [14,16].

Despite advances in research into effective approaches for children with autism, little is known about parents' understandings and interpretations of experiences surrounding their children's assessment and diagnosis. When considering the parent voice as an individual subjective reality, it is usually observed as unique to the parent and not shared by others. This research sought to explore if the parent voice could constitute an element of a shared intersubjective reality; inviting narratives from parents and professionals that may reveal a collective existence.

Research denoting the life of the parent is presented utilizing the metaphor of the nomad (Greek: νομάς, nomas, plural νομάδες, nomads) adopting three themes.

The first theme describes the parent as nomad; a dynamic and evolving character who travels from place to place with an awareness of tracks, plants and nourishment, finding themselves in different lands (clinics, classrooms and schoolyards).

The second theme describes the position of the parent during the period of their child's assessment, diagnosis and intervention as that of 'in-betweenness' which signifies that the parent is neither here nor there. In-betweenness can pertain to the emergence of new voices symbolizing positionality that resists binaries where new understandings occur. According to Deleuze and Guattari [17], "the life of the nomad is the intermezzo", (p. 380) allowing us to think that though an in-between space is characterized by movement and change, it may also achieve significance.

The third theme describes parents' experiences as those of journeys, during which their identities change. Flows, energies and movement defy the subject becoming a fixed identity [17]. Early Intervention and early education experiences are examined as a locus of identity formation for the parent.

1.2. Nomadic Journeys

Historically regarded as a central focus in anthropology, an interest in nomadic people, or nomadism, was founded on ideas of mobility and movement frequently relating to colonialism [18]. The nomad as a metaphor in philosophy and education presents an ontology of becoming and development, not heroism. It is apt to symbolize the parent in Early Intervention and early education in that it challenges existing State-like structures. Deleuze and Guattari's [17] philosophy of difference and becoming is often utilized to

conceptualize State policy and incoherent State systems where difference is acknowledged as embracing transformation. The metaphor of the nomad has become celebrated in Europe and has become associated with interpretations of the 'other' [18]. In this research, the nomad epitomizes the parent who, while being part of the State, exists and moves outside of it. The nomad challenges the order of things and movement, therefore his/her modus operandi is to enculturate him/herself, but also to move past State or policy strictures. At the time of children's assessment and diagnosis, parents' requirements include services but also information and knowledge about their child's disability. Deleuze and Guattari [17] used the concept of the rhizome to exemplify nomadic movements across space extending in different directions rather than following one path; multiplying and creating new lines of thinking. The 'rhizome' as a non-hierarchical symbol conceptualizes learning where "the rhizome has no beginning and no end, it is always in the middle, or between things, interbeing, intermezzo . . ." [17] (p. 25). The concept of the rhizome in education challenges linear thought. Learning is generally constructed hierarchically as arborescent or tree-like. The rhizome is suitable to a broader conceptualization of Early Intervention which combines health and education philosophies and practices. For the parent and the child with autism, the rhizome provides conceptualizations of learning comprising mutually dependent roots and shoots, that are dynamic and flexible, encompassing complexity and heterogeneity [19]. Pursuing the metaphor of the nomad, and faced with institutional and provisional barriers, the parent as nomad travels from place to place in search of food, nourishment and sustenance. The nomad in this research signifies the parent and their quest to procure services, resources and educational provision for their child.

1.3. *In-Betweenness*

In-betweenness draws on anthropology to describe a liminal, interstitial, or transitory space that occurs during rites of passage or transitional experiences [20,21] (p. 3). It challenges binaries and "shines a light on transitional spaces where a multiplicity of roles is negotiated and assimilated" [21] (p. 3). The theme of in-betweenness signifies that the parent is neither here nor there. "The life of the nomad is the intermezzo" [17] (p. 380) allows us to think that an in-between space is characterized by transversal movement. Transversal movement, a concept developed by Deleuze and Guattari to describe movement along different axes and intersections, extends both vertically and horizontally, moving across space, aligning with the needs of the individual parent, but also emphasizing a collective approach. Transversal movement allows us to open up previously closed avenues of movement and perception to produce new groups or collectives. Movement aptly denotes perception, and due to movement, we may lose sight of the river when we focus on its banks [22]. To refocus on the river, we need to become aware of our changing relationship with objects caused by transversal movement and shift our perspective to longitudinal issues and trajectories. This research suggests that the in-between space that parents inhabit becomes increasingly transversal and constitutes their very flows, energies and movement, defying them from becoming a fixed identity [17]. In-between space therefore may serve as an actual strength. In Deleuzo-Guattarian terms it describes where "things pick up speed" [17] (p. 25). To extend the water metaphor, the position of in-betweenness may be like a stream without a beginning or end. In-betweenness can also describe the potential for ambivalence, losing and finding oneself and the elusiveness of the role of the parent when faced with a medicalized or pathologised approach to their child's diagnosis. Increasingly, there is more emphasis on the integration of the parental experience of parenting a child with a disability. This research takes on board this in-betweenness and seeks to examine it interpretively by incorporating the lived experience of the parent and the challenges associated with procuring services.

1.4. *Identities*

The third theme, also linked to the central metaphor of the nomad, describes parents' experiences as those of journeys, during which their identities change. This research sought

to understand how parents' evolving identities were impacted during the trajectory of their child's assessment, diagnosis and Early Intervention and education experiences. Education is explored as a locus of identity formation for the parent where parents may develop new social competence and belonging. Twomey and Shevlin [2] suggest that we need to understand the nature of the parents' inner journeys through their child's assessment and diagnosis, where systems and services can empower or disempower them. If a child fails to experience inclusion or is unable to remain within a mainstream (pre)school setting, this can have a negative effect on parents' identities [23]. Territories of failure are described by Julie Allan [24] as the frustration, guilt and exhaustion experienced by those attempting and failing to be included. Hodge and Runswick-Cole [25] identify further issues when they consider how medical and professional discourses are more highly valued than those of parents, in school settings. Sustaining the metaphor of the nomad, this research suggests that considering these challenges, parents navigate (difficult) ways of forming new multiple selves and so they are opening up new life worlds. In terms of identity, Braidotti [26] (p. 35) describes the function of the nomadic subject as that of a relay team:

“S/he connects, circulates, moves on; s/he does not form identifications but keeps on coming back at regular intervals. [. . .] Identity is retrospective; representing it entails that we can draw accurate maps, indeed, but only of where we have already been and consequently no longer are. Nomadic cartographies need to be redrafted constantly.”

Braidotti claims that the point is not to know who we are but, rather, what we want to become [27]. McLaughlin and Goodley [28] suggest that parents of disabled children are nomads but are also settlers with their children in their research, recounting the impact of diagnosis on parents.

1.5. Contextual Frame

Intersubjectivity is a concept relative to parent and professional interactions. It was first a concept developed by Husserl (1859–1938) to explain the conscious and unconscious interchange of thoughts and ideas between two persons or subjects, which could be facilitated by empathy [3]. Its usage in social science may suggest cognitive agreement between different groups, or simultaneous relationships from diverging positions. Cooper-White [29] explains that in order to understand intersubjectivity, it is first useful to understand the concept of subjectivity, which is the perception or appearance of reality from one's own point of view. However, our perceptions may be limited or biased by our world views or by our own limitations. For the purposes of this paper, intersubjectivity will be interpreted as the possible convergence of two worldviews; put simply, a coming together, which may ultimately contribute to socially constructed worlds where reality is created by participations through their shared social interactions. The self is considered a fluid, movable entity subject to influence outside the self, whereas intersubjectivity is created through reciprocal social interaction and is influenced by the dynamics of multiple selves [29].

A disjuncture or rupture in parent professional interactions therefore may become the parent's point of departure. Broomhead [7] refers to a clash of two worlds in her exploration of differing values between parents and professionals. The events of flow and rupture in a destabilizing world with no sense of continuity beckon the need for intersubjectivity in Early Intervention so that professionals can see themselves in the parents' situation and where it becomes a shared experience or worlds. The usefulness of thinking that embraces intersubjectivity could be a nexus point between professional and parent in the problematic field of Early Intervention and education.

2. Materials and Methods

This research sought to explore the narratives of parents of children with autism for insight into disability. Kelly's [30] concept of disability as a materially and socially constructed phenomenon is relevant. Drawing from a narrative approach, in-depth interviews with parents were employed to explore the ambiguities of parenthood and childhood

impairment as experienced by an intimate other [30]. The objective of interviewing was to explore parents' experiences and challenges when procuring services for their child. Areas focused on in interviews included: the period before assessment, the assessment and diagnostic processes and the supports received by parents and children in Early Intervention and early education settings. Parents' perspectives were also elicited in relation to their own roles, the challenges they faced as parents of a disabled child and their needs in terms of their children's education. Questions posed to professionals sought their views on policy and provision, their experience as professionals providing services to children with autism and their families and the challenges faced when dealing with inadequate and deficient systems and resources.

Tracing the journeys of parents of children with disabilities suggested a need for an epistemological reformation and parity of subject and other. The author's positionality as parent and academic was embodied in a living autoethnographical approach. Living autoethnography provides a window through which the internal world of the parent can be interpreted and understood [31]. As parent, I was well positioned to conduct this research, which involved focusing on intimate details of first-hand accounts as well as relying on (auto) biographical accounts examining how human subjects constitute themselves through narrative [32,33]. Searching for new ways of knowing, I had an awareness of parenting adaptations, contradictions and resources created and used to meet the challenges of disability parenting. The existence of heterogeneity in how disability research is viewed makes triangulation necessary; there was a need for many perspectives beyond my own.

Through qualitative, longitudinal, in-depth case studies, parents and professionals participated in semi-structured interviews ($n = 83$) over an eighteen-month period in the Republic of Ireland. Parents and professionals were interviewed to gain their perspectives of assessment, diagnosis and early education experiences. I was aware of the danger of preparation for a stylized interview response, in that these narratives become organized and ordered, obscuring lived experiences, and are not congruent with the normal experiences of parenthood.

Observations of intervention and education encounters were also undertaken. Observations focused on the inclusion of children with autism in preschool, Early Intervention and early primary school settings. Children's ability to engage and participate in classroom activities and their interaction with peers were prioritized. However, this paper will focus on the qualitative interviews undertaken with parents and professionals.

A major point of difference in this research was the presence of the parent voice. Accessing parents of children undergoing assessment and diagnosis can present significant ethical and methodological challenges for researchers. Providing information and negotiating consent presented the need for reassurance regarding confidentiality and anonymity. Participants were recruited primarily through purposive sampling based on the researcher's practitioner knowledge in the area of Early Intervention, as well as the parents' willingness to become involved in the research.

After the research procedures were explained to the parents, parents were reassured that their names would be anonymized and any distinguishing features would be dealt with confidentially. Anonymization in the form of removing names and any other characteristic features was explained. Pseudonyms were assigned to each parent. The researcher was sensitive to the fact that parents had recently experienced significant challenges during assessment and diagnostic processes. The researcher was also aware that some of their children were experiencing difficulties in their educational settings. Designing the research process sensitively was of the utmost importance.

While the parent voice was a key focus of this research, professionals were also included. Professional multi-disciplinary teams associated with each child in the research representing urban and rural parts of Ireland were interviewed. These teams included psychologists, speech and language therapists, occupational therapists, play therapists, and physiotherapists.

The research was analyzed interpretively, incorporating the data and participants' interpretations of the data [34]. Member checking was adopted with parents and professionals following interviews. The researcher wished to overcome any potential bias associated with the autoethnographic stance. Tiered layers of open, axial and selective coding of data were undertaken. In relation to the parent interviews, codes were also derived from critical events in the child's and parents' lives. Analysis of these narratives involved researcher sensitivity and scrutiny acknowledging the complexity of the relationship and responses of the researcher. Narrative approaches can involve a distance between the researcher and those being researched. In this sense, autoethnography reduced the interpretation gap and brought valuable epistemic reflexivity between the researcher, participants' stories and the text [35].

3. Results

The findings will be presented according to the themes arising: parents' experiences as nomadic journeys, parent positioning and in-betweenness and parents' changing identities.

3.1. Parents Experiences as Nomadic Journeys

Parents frequently referred to difficulty accessing services and the lack of availability of services. One parent, Helen (chairperson of the local autism support group) was adamant that "there was no help forthcoming from the government". While for some parents, services were haphazard, other parents received no service. Describing the early days after her son's diagnosis, Kate explained that "we were left high and dry. We've never had speech therapy, we've never really had occupational therapy, and we've never seen a physio". This quest for services precipitated the nomadic experience. Helen who occupied the position of chairperson of the local autism support group and is mother to four children identified with additional needs, described her perceptions of access to support and services: "Luckily for parents receiving support, they've been in it—the [EI] system." Otherwise, she explained, they didn't know "where to go and who to talk to. If you were living in an area where you didn't know anybody, you would be lost, completely lost". This epitomized the inadequacy of planning in Early Intervention. Another parent mentioned the lack of continuity, referring to the "stop, start aspect of assessment . . ." Parents described long and enduring battles in the procurement of assessments, diagnoses and services. Parents frequently personified themselves as warriors, crusaders and pathfinders in their procurement of support and resources. Parent voice provided a glimpse of the lived experience of the parent of a child with additional needs. While parents were intrinsically motivated to advocate for their young children in the quest for services, they were also exhausted. One father (Dave, Adam's father) described his situation: "I gave up work to look after my son . . . it's like constantly having to travel; being so incredibly tired; not enough time in the day . . ."

Parents felt that while they were procuring and waiting for services, the process of assessment was a minefield with little guidance or support:

"Very little contact with any member of the team since the last assessment period . . . There's no sense of what will happen next. He's got a diagnosis of mild autism, but what will happen next?" (Becky, Jack's mum)

Professional voices shed some light on provision of services for children being assessed or already in receipt of a diagnosis. They identified policy as ineffective and assessment focused.

"Right now, with regard to the purpose of the services we provide, physio, OT, speech and language, psychology, we all provide what we can within the resources that we have, and my particular role as an occupational therapist would be to provide . . . generally is . . . talking to the parents around their anxieties, so there's no point in me doing an assessment and finding ten things wrong . . ." (occupational therapist, EI Team)

One psychologist expressed his dissatisfaction with policy lead processes that were not family-centered: "There's no holistic view of an IEP, families' priorities, or the families' needs, which are, in Early Intervention, paramount!" (lead psychologist, EI Team).

Professionals also disparaged an overreliance on the 2005 Disability Act:

“It has put a lot of emphasis on assessment and has pulled intervention out of it. Professionals would have been doing a lot more intervention-based work in the early days based on the child’s needs. The Act is a deficit model really, and intervention is based on that”
(home visiting educational therapist, EI Team)

Professionals in one of the HSE regions referred to isolatory, domain-specific practices involved in unidisciplinary professional approaches to assessment. Teams in this region showed dedicated efforts to reduce the number of clinic attendances for parents during their child’s assessment period. Dave, (Adam’s father) described the impact of unidisciplinary clinical assessment:

“Having visited umpteen professionals; I quit my job so as to provide a parental presence in my son’s newly pathologised life”. Another parent agreed that the number of professional visits were overwhelming in describing her overwhelming journey: *“You had speech therapy, occupational therapy, physiotherapy, psychology. We were on a never-ending treadmill.”* (Jack’s mum)

Commenting on the challenges, Cathy mentioned that “the low points were many. Every time we took a step forward, we took ten or twenty back. So many times, I thought am I ever, ever, going to get off this? We thought that this would never stop . . . ”

One father in the early parent focus group described his early experience: *“We were literally, as a family, at breaking point.”*

Amy and her husband referred to the need for information and parent training on their journey. They felt that professional input was scarce and inadequate at the time of their child’s assessment. Increasingly their son’s behaviour become more challenging: *“A lot of the behaviours came from frustration.”* Jenny also had difficulties with her son’s behaviours: *“Yeah, you see the whole thing is—with Daniel particularly—is you couldn’t see the child for all the behaviours and all the layers that they had.”*

In the absence of professional information, researching on the internet was the predominant mode of inquiry during the assessment and diagnostic periods. Non-specific and indiscriminate information was generalized and not always relevant to parents’ children: *“You pick up so much information and in some cases it’s too much information, you know, you have to sort of—in the initial stage you go on the internet and then you steer yourself away from it because you just get blown away with too much information”* (Jenny, Daniel’s mum). Amy and Kate reported how their own research added to their fears and that they sought guidance and support from their general practitioner who was not familiar with “the ‘A’ word.” While they were procuring services and advocating for their children, these parents wanted to know: *“What is autism?”*

3.2. Parents Positioning and In-Betweenness

Rob, Simon’s father, described his liminal position when his child started having difficulties at his local preschool. Simon was also experiencing behaviour and communication issues at home: *“We were at the end of our tether, we didn’t know where to go, what to do and thank God we found this place here.”* Describing her son’s negative experience at his local preschool, Jenny explained her in-between position: the ‘wait and see’ approach being adopted:

“And this sort of carried on, it was all very informal with the preschool, no formal meeting . . . you know, ‘He’ll catch up’ . . . and the same thing with the G.P., and I wasn’t happy with that . . . ” (Jenny, Simon’s mum)

Jenny and Rob shared a similar experience describing their liminal spaces of assessment:

“And, as I say, they assessed him and they said, ‘Yeah, nothing really to worry about but we’ll see him again in six months.’ So, they saw him again in six months and that’s when they did proper assessment.” (Jenny)

One parent in the focus groups was told that the professional was not available from one discipline and that her son instead would be provided with therapy from a different

discipline when this had not been prioritized. This was incongruent with information she had read about autism and addressing a child's individual developmental needs. It also resonated with critiques of the Disability Act in relation to the ineffectiveness of policy's emphasis on the practicability and availability of resources. It was only if resources were available and practicable that children would receive them.

With regard to assessment, a National Educational Psychological Service (NEPS) psychologist who previously worked as a diagnostic Early Intervention professional explained her thoughts:

"I'm not sure how effective assessment is. Assessment may not always be the best starting point. It shouldn't be the focus. You're starting off with a label and then the label will attract . . . if you start labeling children, you put them into a cycle of resource teaching . . . a stuck cycle. It should be a continuum—in and out—where you might need extra help and then back in the mainstream classroom; the child is stuck in a cycle of extra support. Descending circles as opposed to a continuum."

This research confirmed that children were waiting on assessment processes; waiting to become labeled in order to receive intervention. Parents meanwhile felt that assessment itself was an in-between space. Waiting lists lacked any embodiment of the interstitial stage where something might occur between the present and the future.

Stephen (EI Team psychologist) identified a dilemma. His question relating to accessibility represented the views of many professionals interviewed:

"Why can't we treat all children the same? In relation to autism, the assessment of need (AON) is a problem. It's an assessment only. Because of the stipulations of the AON, the team do the assessment and see what will happen later."

Support received from private therapists proved invaluable to parents. When children's names were placed on lengthy public waiting lists, parents procured assessment and intervention from private therapists. Cathy mentioned the strategies that she learned to deal with her son's tantrums. She recounted how the therapist gave her strategies firstly to calm his sensory system and then help him to communicate. Cathy mentioned that in her case, de-escalation was key. Her therapist was Floortime-trained. The strategies were developmental in nature and suited Cathy and Alex in the home environment. Emphasizing the developmental nature of her son's needs Cathy underlined the need for ongoing guidance regarding intervention. Alex's needs were neither static nor consistent and varied in different environments. "His needs change and just when I think I have a handle on them . . . they change again."

In the absence of a counselling or coaching service, parents articulated how their psychological and emotional needs were not addressed. They had developed a peer-to-peer counselling and mentoring service. Some parents were attending peer counselling during the research. A dichotomy of needs was apparent; on the one hand parents' needs for psycho-emotional support were evident, and on the other parents did not wish to endanger their child's access to services by prioritizing their own needs. All parents affirmed that they did not receive counselling from State services at any time during their journeys. Parents as sentient beings continuously occupied liminal physical and emotional spaces.

While stage-based or grief theories were not referred to in this research, parents were asked about their experiences and if their journeys had changed over time. Kate, whose son was progressing well in mainstream primary school, offered information on the stages that emerged in her journey. This awareness of stages was retrospective:

"I think there're probably three stages; there was the stage prior to his assessment where we were literally at our wits end because we were struggling to cope with this child, we didn't know what was wrong . . . That middle period is like the information overload. Where you've got all of this information coming at you, yes there's a huge relief that it's been diagnosed but then you've got speech therapists coming at you, one-way, occupational therapists coming another way,

and school visits . . . And now we're in the stage where it's just become a part of life and everything is a lot calmer—it's the calm, sort of, after the storm".

3.3. Parents' Changing Identities

In this research parents felt that their identities were put on hold; with the potential of becoming pathologised. Parents initially assumed a passive role, waiting for information and services that did not materialize. This research situated the professional voice as representative of policy and provision; what parents considered a proxy for the State. Parents themselves felt that they were policing the professionals through their reactions and transgressions towards inadequate services. Parents' experienced levels of 'loss' of their former identity as parent and professional, but in some cases parents flourished in their advocacy for their child. A number of parents had worked professionally and gave up their roles to support their children. In some instances, parents felt that there were disadvantages both personally and professionally to embarking on these new journeys.

Adam's father initially was hesitant to become involved in the research. Redolent of the nomad, he explained that his experience of assessment involved "travelling for yet another appointment" and that travel for interviewing would be a deterrent to his involvement.

John, an E.I. team occupational therapist, also referred to the role of parent as advocate, where the parent assumes responsibility to procure resources. His opinion on this role was that it detached the parent from the child further, especially within an impoverished health system: "I feel that it is . . . spending time advocating to get other people to come in and make contact . . . to try and fix something that's broken?"

Parents were in inequitable positions. A central theme underpinning accounts of professional involvement was the perception that parents were forced into unsolicited relationships with professionals, which did not bear the hallmarks of typical relationships. Parents felt that these relationships exerted an imbalance of power and were based on assumptions that professionals were the gatekeepers of knowledge and more importantly, services.

When asked for her opinion on what presented as the greatest need for parents, support, training, or counselling, a female senior EI occupational therapist reiterated "empowerment". When asked what constitutes empowerment, a play therapist supporting parents in the home responded, "giving parents confidence and skills, and making them well-informed. Resourcing and access." Empowerment and capacity building in families are key principles of family-centered approaches to EI.

Regarding identities, professionals saw their role as critical in the support around individual children's transition to (pre)school. Embodying a collaborative, synergistic approach, one team leader emphasized that: "Teachers aren't trained therapists. In reality the curriculum should aim to deliver therapeutic goals" (Paul, senior EI psychologist). These professionals emphasized the centrality of relationships and inclusion of parents in their children's services.

In terms of how EI could support parental identities, Paul emphasized the importance of "family-centeredness and inclusive education. Therapists are no longer the 'treaters' of the child. The consultancy role of EI professionals will make sure that" Explaining this further, Paul suggested that the philosophy underpinning the direct or consultative approach to intervention aligned with his beliefs. "My particular feeling with regard to children is the fact that you are really facilitating an environment whereby you don't have a whole lot of professionals coming in and out short-time." Direct input from team members or a consultative model mediated through education staff in schools, was agreed by the majority of the professionals to benefit the child, parent and teachers. When asked what family-centered intervention looks like, John, an educational play therapist supporting families in the home, asserted that:

"It's about getting to know you . . . A relationship might have developed with a team member, where there is cognizance of stages of parents' responses and engagement around the time of a diagnosis. This is the difficult part of this job; it's like losing a child. This

loss might affect parents; therefore, relationships are key . . . without the trust piece with the service provider, the child may not have their needs met."

Intersubjectivity was considered a cross-cutting theme in this research. John succinctly acknowledged this when he highlighted the need for relationships with parents and the possible benefits accrued to those relationships.

"The other thing I find is trying to have a relationship where if parents have a particular concern they can ring up and have a conversation with you. I find that sometimes because you are an outlet for that stress, they don't actually end up contacting you that much because what happens is they know they can if they want to." (John, educational play therapist)

Meghan, a senior speech and language therapist, emphasized the importance of the role of the parent and that the parent–professional relationship starts at the time of assessment:

"From the play-based team assessment, involve the parent in the play, look at the dynamics in a number of settings, not just in preschool or clinic but also the home environment. We skill-share, work on a goal together, including the SLT and the OT who will also work on this. We goal-set together, the parent decides what the goals are. Family-centered team based goals are established for the child. They can be time saving or time intense . . . in a smooth, more coordinated way, the family is the main liaison between the professionals."

In a number of parent narratives, there was very little evidence of parent representation in the goal setting or formal decision-making during assessment and diagnosis processes. A tokenistic presence may have been evident; in many cases parents reported that they were not involved.

In one of the five Early Intervention teams interviewed, close alliances and consultation between therapists, educators, parents and professionals demonstrated evidence of effective team philosophies and processes, but these were the exception. However, parental, peer alliances supported parents through the in-betweenness of assessment when they felt at sea, waiting for elusive supports; advocating, lobbying, struggling.

4. Discussion

Themes arising from analysis of the findings are described using the metaphor of the nomad. Parents' journeys comprised uncertainty, vulnerability and need. However, they also provided evidence of inner resourcefulness, and potential for insightful support. The themes arising in the findings will be discussed in relation to the conceptual frame.

4.1. Nomadism

Similar to nomads in anthropology, nomads are key figures of mobility but are also metaphors for ways of being outside the confines of territory or State strictures. This paper proposes the use of the concept of the 'nomad' as a central tenet which draws threads from multiple literature sources, paradigms and ideologies. A central metaphor of the nomad therefore provides validity and relevance to triangulated accounts but also a conceptualization which integrates the State and the individual.

This research is congruent with that of Engebrigsten [18], who refers to the use of the nomad to describe social organization and power relations, as well as a form of contrast between the individual and the State. Engebrigsten [18] notes that the nomad portrays European perspectives on the 'other' but that this nomenclature may also serve parent identity construction as 'other-becoming' in order to displace binaries. Nomadism usefully identifies boundaries between sedentarism and movement, which is apt for the parents in this research who through their movement constantly searched, strived and tried to locate and procure services and resources, all the while being the constant in their children's lives. This research also identifies the nomad as a fitting term when used to describe the life world of the parents who do not fit the trope of being settled, or settling (for less), rather settled like McLaughlin and Goodley's [28] parents, with their disabled children.

Deleuze and Guattari's [17] postmodern embodiment of the nomad is also congruent with the parents in this research, who through their journeying have become stateless, where their identities are unformed or continuously reforming. As the philosophers of difference suggest, parents acknowledge and embrace their difference in their quest. This adoption of difference becomes transformative. An openness to difference therefore positions the nomad in a state of becoming, or as a war machine against the State. While State policies are inadequate, parents seek something beyond these limitations and locate new resources and provisions; defying State-like restrictions or hierarchical learning concepts.

4.2. *In-Betweenness*

Through their vicarious experiences—acting or doing for another—parents occupied liminal positions and in-between spaces. What reinforced their liminality was their perception of hegemony, where potential dominance by the State or professional discourse dominated or silenced them [25]. Similar to Twomey and Shevlin's [14] findings, parents occupied different positions and were on different journeys. Journeys both inner and external were epitomized by in-betweenness.

Tensions with the 'would-be collaborators' existed at various levels of different and incoherent educational and health systems. Evidence of inconsistent service provision at a national level was apparent in the narratives of Early Intervention professional teams. These narratives manifested incoherency of practices of education and care.

Parents wandering on uncharted nomadic journeys lacked certainty and appropriate support. They existed liminally outside of the organizational State but with a sense of autonomy and a direction of their own [21]. While many professionals in this research were family-centered, EI systems were ad hoc and inconsistent, where children's assessment and diagnosis were prioritized over intervention. The concept developed by O'Connor, Carpenter and Barry [15] of "confident championing" was evident in many cases, but this was an individual endeavour on the part of the resilient parent. Occasional evidence of Deleuze and Guattari's [17] becoming was evidenced when parents felt a sense of achievement in procuring services for their children or when they developed competence in terms of peer-to-peer support.

Many parents revealed an ability to survive and flourish; looking for what more is there and what more can be created similar to the theory of Braidotti [27]. However, their perceptions and understandings of service provision and access to practical resources to support their children were ambiguous, reflecting a sense of disconnection and in-betweenness. Twomey and Shevlin [14] have acknowledged parents' role as pathfinders and creators as resonant of journeys that are emotional, physical and intellectual. The majority of parents in this research expressed the need for a strong State support system where resources were accessible and available to support their children's communicative, behavioural and developmental needs as well as the possibility of their inclusion in mainstream (pre)school. This study highlighted the importance of positive collaborative relationships between parents and professionals and the need for support and guidance during nomadic journeys of uncertainty and in-betweenness. Intersubjectivity was a key subtheme; parents' needs and desires did not differ greatly from the desires and wishes of the professionals. Unwitting consensus revealed a collective view centered on the child but also on the family. This highlights the need to forefront family-centered practices in Early Intervention and early education.

4.3. *Identities*

This research proposes that parents were (re)forming identities in their quests for their children's services. EI practices were fluid and dynamic, reflecting the individual needs of the child and family in one setting. Evidence in this setting subscribed to family-centered approaches proposed by Dunst and Espe-Scherwindt [13]. In contrast, when parents perceived power imbalances or that professional discourses were prioritized [25], they felt disempowered. What was of particular interest were the processes of engagement

and interaction during parental identity development, in what appeared as the vague, unwitting constructions of intersubjectivity. Occasionally the individual quest of the parent became the collective goal agreed upon by both parent and professional [13]. This research investigated the changing identities of the parent, where identities varied across contexts (clinics, classrooms and school years). Identity was negotiated and shaped by statutory inadequacy but also by intersubjective encounters; with core revelations that identity is not fixed and is subject to multiplicitous representations. Interpretation of the data evidenced that parents, like their children, valued belonging and inclusion. Children whose disabilities occasionally remained invisible and unvoiced, mirrored their parents' early inarticulate state when they felt pathologised and their trajectories medicalized.

Following austerity, the pandemic and its strictures have negatively affected the life course of the child with autism and their parents and have entrenched a deficit orientation resonant of the charity model. While an increased number of EI classes and inclusive environments have been provided, inclusion of children with more complex needs is not always evident.

5. Conclusions

Concluding Thoughts

This paper provides a discussion of parental experiences during their journeys when seeking to advocate for their children. The research highlights the challenges parents experience as they navigate and engage with incoherent services. The nomad as metaphor provides a central tenet to draw together different conceptualizing of parents on uncharted journeys. Nomadic journeying occupying in-between and liminal spaces sometimes revealed that, in the absence of a coherent or structured pathway towards resources and services, the journey becomes the identity. Journeying allowed parents to deal with fragmented and inadequate supports, displacing the hegemony of the State, by creating something new for and by themselves. Parents as nomads engaged in rhizomatic thinking; the learning captured on their journeys was transformative. Rhizomatic thinking and learning allowed parents to send out shoots and roots, through transversal movement, into their communities. Parents as nomads engaged in multiplicitous, transversal activities creating arable points of nourishment in what were formerly karst and desert-like lands.

In order to improve EI services, in-between time/space could be used optimally to implement family-centered practices. This in-between time/space—the period of waiting (for their child's assessment and diagnosis)—could provide opportunities for the engagement and participation of the parent. Without this engagement, parents experienced ambiguity and uncertainty; interpreting the professional role as a proxy for the State. In a sense, the professionals personified what parents were resisting, when in fact they were only the purveyors of policy and provision services, if available. In the absence of appropriate State resources and supports, rhizomatic thinking by the professionals could have transformed the parent experience, if intersubjectivity was prioritized and in-betweenness evolved into something more manifest and real. Therefore, temporal and tangible support and resources must be provided at the appropriate time.

It is also worth noting that services are not always concrete and tangible; the offer and reassurance of a phone call by a professional was comfort in itself for a vulnerable parent. Some professionals viewed relationships as key. This could be a starting point for intersubjectivity or the development of shared worlds.

This research proposes that both parents and EI professionals embodied the nomad. Parents wandered from home, to clinic and schoolyard, seeking support and help. Professionals purposefully strayed outside of State-defined processes and limitations in seeking to help families who were struggling. When parents and professionals engaged optimally, children's and families' needs were addressed. Parent professional intersubjectivity was sometimes apparent in this research, however, it occurred less by design and more so by happenstance.

This research proposes that parent professional intersubjectivity should be integral to future planning, research and practice. While parents' perceptions and understandings of EI philosophy and practice were negative and deficit orientated, parent professional intersubjectivity could have displaced uncertainty and liminality. Impoverished State provision and denial of access to resources did not dampen the human condition in this research, rather it precipitated nomadic journeys and states of in-betweenness, where parents' transversal movements reinforced their ability to reimagine EI services. This research had limitations that were for the most part due to the geographical features of the sample. It would be highly advantageous if the sample were more representative of the country as a whole. Data were representative of a sample group based on convenience sampling and accessibility to the researcher. A second limitation was the presence of insider research. In order to address this unduly criticized approach, the positioning of the insider was made explicit at the outcome.

In terms of improving practice, pedagogical innovation should be prioritized. A synergistic approach to interdisciplinary and transdisciplinary learning has to be adopted in the education and training of Early Intervention professionals. All professionals supporting children with additional needs or disabilities should share knowledge and move past their discipline-specific boundaries.

On this continuous process of journeying in the face of inadequate policies, practice and services, parent voice illuminates the complex navigation required. This research recommends therefore that increased parental involvement occupy a centerpiece in the future planning of Early Intervention philosophies, provision and services in an effort to improve the human condition for all.

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